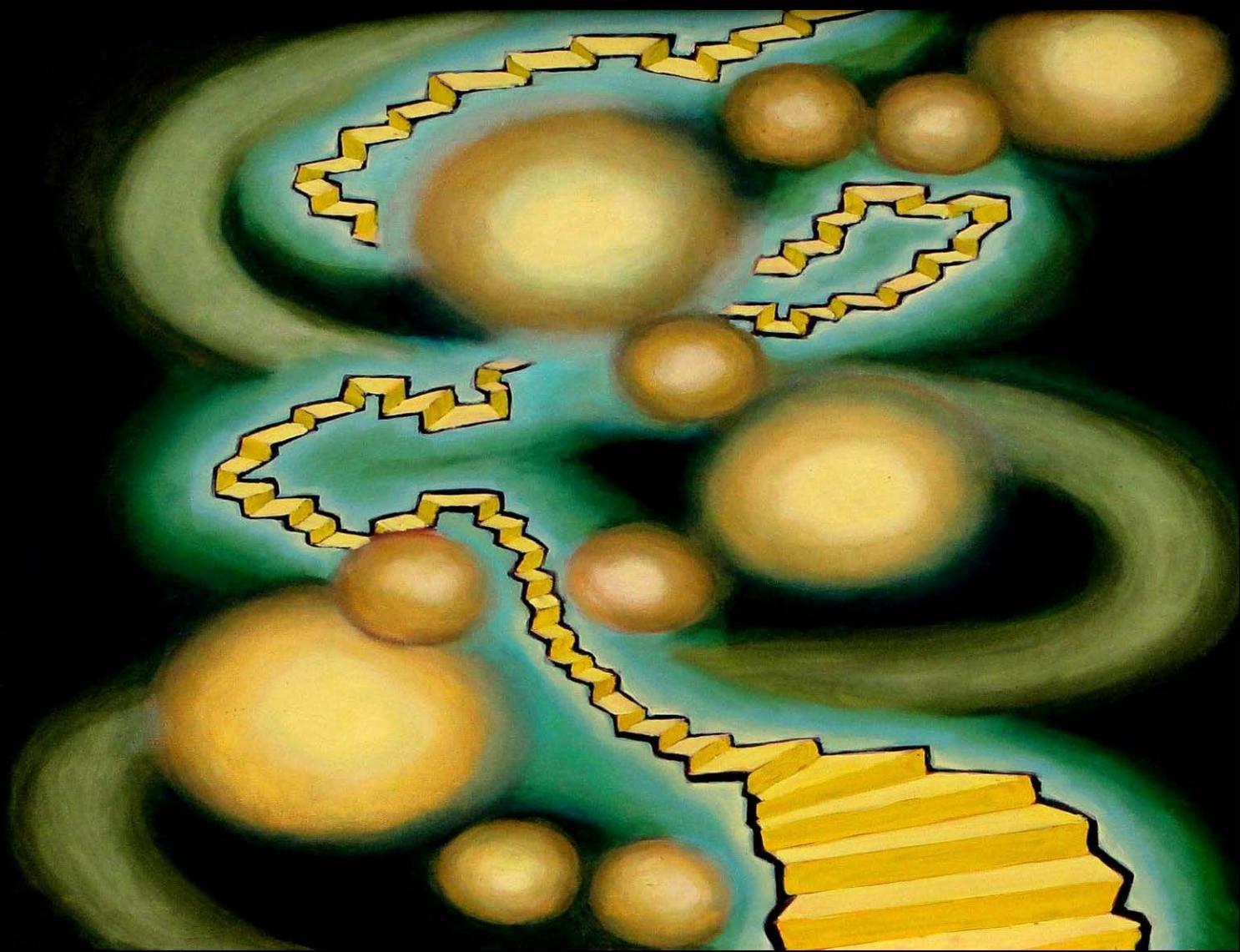


*Real-life Solutions to
Living with a
Mental Illness*



Dr Karola Mostafanejad

Real-life solutions to living with a mental illness

By Dr Karola Mostafanejad

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The front cover is based on a painting by the author's late father, Helmut Witt.

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This book is dedicated to the people who shared their real-life solutions on what it is like to live with a mental illness due to their insight and wisdom.

Feedback from the people interviewed for this book:

"At last someone is actually tackling the whole of life and the real issues behind mental illness."

"Fantastic - I have never seen anything like it."

"That is why I am talking to you because I am hoping that some of these things I say will make a difference."

"I don't care for me but I know that ... that information [in this book] is going to be valuable because it will save lives ultimately."

"[This book will help people with a mental illness because] if somebody had been able to come along to me 20 odd years ago with what I know now, I know I would have listened to them because they were people like me."

"[This book will be] of benefit to the broader community. There is no doubt about that."

"[This book contains information that] would be good for the professionals in the front line. If they can pick it up."

"It is about where I have come from, where I am and where I am going."

"It fits me to a 'T'."

"101% accurate."

"I was almost overwhelmed."

"It is causing me considerable pain and anguish to go through this but it is very enlightening and good."

"It has been a hard challenge to read it."

"Like a guidebook – brilliant!"

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What this book is about

People living with a mental illness are desperate to improve their situation. This book offers not a pill, not another medicine, but a better way for those who have endured conventional 'treatment' and have found it wanting. This book suggests a way forward for society, for health professionals, families and, most of all, for individuals who struggle with mental health on a daily basis. All the material is based on what people with a mental illness told me. They explain what their life in Western society is about and how they deal with the immense difficulties they face. This is their account. What they say challenges the current viewpoint of mental health. Nevertheless, the people with a mental illness speaking in this book ask you to take on board what they are saying because they are desperate, and desperate for a better society.

Sensing the desperation of people with a mental illness and wanting to get to the bottom of it to try and make sense of what is happening, I decided to ask them directly. Although a qualified and experienced mental health nurse, amongst other qualifications, I had to admit to myself that I did not know anything about how people with a mental illness lead their lives and what real-life solutions they had found. I therefore embarked on a comprehensive study to find out. The participants who came forward to take part left me in no doubt what was important for them, what solutions they had found and how society could be made a better place.

It is important to look for real-life solutions for living with a mental illness because 450 million people worldwide have a mental disorder¹ and in Australia, where this study was conducted, mental disorders are identified as the third largest reason for a disability, after heart disease and cancer². Thirteen percent of the population have had suicidal thoughts, with 3.2% attempting suicide³. In total numbers, at least 800000 people die by suicide every year worldwide with an estimated additional 20 times as many making attempts⁴. These statistics highlight the enormous personal and financial costs associated with living with a mental illness.

However, these numbers do not give an adequate enough account of the social, economic and political context people with a mental illness find themselves in. They are confronted with a hostile social environment in the way they are viewed and treated by society. In fact, for people with a mental illness, stigma has become the greatest barrier to living a normal life in the community⁵. As a consequence of the hostile social environment many people with a mental illness remain marginalised. They experience disadvantages with regards to employment, housing, health care and access to support services. These disadvantages often lead to poverty, lack of opportunity and, in some cases, homelessness.

Despite the fact that most people with a mental illness now live in the community, they largely remained hidden⁶ and silent for fear of experiencing discrimination⁷. Until recently, those who spoke out against their treatment and against community attitudes were often regarded with condescension because "what the mad said was no better than meaningless babble"⁸. According to Porter⁸, history has been written in the main from the perspective of the establishment, such as health professionals or family members. This book aims to redress this imbalance and report on the experience of people with a mental illness from their perspective.

Although some autobiographical writings have been released recently in both book form⁹⁻¹⁴ and in professional journals on specific aspects of living with a mental illness¹⁵⁻²⁶, no

authoritative and comprehensive account documenting the collective experience of many people of what it is like to live with a mental illness and what to do about it has been published.

By taking into account the whole picture of what it is like to live with a mental illness and what to do about it, I decided to use the grounded theory method to handle the collection and analysis of the interviews (see the appendix for details of this method). The aim of the grounded theory method is to develop a theory that encompasses the experience of study participants from their perspective. No other book published to date has attempted and accomplished this in the mental health field.

All the people who came forward to take part in this study, from now on referred to as participants, identified that they had been diagnosed with major depression, bipolar disorder or schizophrenia. These three diagnoses were chosen because they represent the greatest personal and social costs attributed to mental disorders. It was postulated that the real-life solutions participants found in these most difficult circumstances would also be helpful to other people, even those without a mental illness. None of the participants in this study were in an episode of illness whilst being interviewed. The typical length of having lived with their mental illness was 20 to 40 years, with up to 60 years in some instances. Many participants had used mental health services for up to 40 years with both treatment in the community and extended time in mental hospitals including in locked wards. They were highly educated about their mental disorder and very knowledgeable about a large variety of treatment options, including medications. One fifth was degree qualified, some of them as health professionals, adding to their knowledge and experience of mental disorders.

However, participants' desperation became evident when they reported on how they were treated by society and how they were, by and large, not helped by mental health services. Nearly two-thirds told of how they had been abused in their childhood and/or adolescence; most of this abuse was severe. Over 80% had been thinking about suicide with just over a third reporting attempts. Yet some participants had decided to use their extensive experience and insight of what it was like to be a person with a mental illness and had become mental health advocates. These participants had been or are currently members of government advisory groups, had made submissions towards improving governmental mental health plans, lobbied politicians and health care managers, featured in newspaper articles furthering the cause of people with a mental illness, were leading members of support groups, and had given guest lectures at universities on their experience. (More information about the participants is given in the appendix).

How participants had reached the real-life solutions to living with a mental illness through their long experiences, and the insight and wisdom they had developed, is mapped out in four chapters. In order to identify participants' real-life solutions we first have to find out what problems are supposed to be solved. Participants explained that what needed to be solved was that life was a struggle for them. In turn, life as a struggle could only be understood if certain experiences that brought it on, or the causative factors, were made clear first. Chapter 1 therefore covers the experiences that brought on life as a struggle. It is the foundation for the rest of the theory and is called *the experience of disempowerment*. (The main themes identified in this book are highlighted in italics for easy identification.) The experiences recounted here were disempowering for participants because they were beyond their influence to control. They emphasised that the importance of being disempowered by the signs and symptoms of their mental disorder was dwarfed by the importance of being disempowered by how other people viewed them. Participants explained that they were not believed what they said, even when it had nothing to do with signs and symptoms. People

also devalued and dehumanised them. This attitude then laid the basis for society's reaction in not wanting to help and justified mistreating people with a mental illness. It also fostered an atmosphere of letting perpetrators get away with their abuse and mistreatment.

Identifying disempowerment, especially in the relationship with other people, as the central concept around which the lives of people with a mental illness revolves, differs from established understanding. Moreover, *the experience of disempowerment* was identified as the cause or reason that brought on the main concern of participants, namely that their life was a struggle. In conventional mental health care, no causes or reasons for what is happening to people with a mental illness are acknowledged. The accounts in chapter 1 necessarily contain the negative experiences participants were exposed to. Many of them were shocking and confronting.

Chapter 2 details the impact of *the experience of disempowerment* on participants. This impact brought on *life is a struggle*. *Life is a struggle* left participants without power to take charge of their personal and social life. They struggled primarily with existential matters questioning who they were as a person and what their place was in society. The struggle with identifying any intrinsic value in oneself was pivotal. Again, social aspects predominated, the struggle with having a mental disorder relegated to a minor position. Secondly, participants also struggled with the mundane, such as trying to survive through daily life. The emphasis in this chapter on the struggle with existential matters that participants were subjected to, particularly with their value as a person, again differs from established mental health care that seeks to identify and treat signs and symptoms only.

Chapter 3 explains what participants did to resolve *life is a struggle*. This contains the real-life solutions they had devised in order to tackle *life is a struggle* in their personal lives. They resolved it by *transforming themselves*. Participants *transformed themselves* from being someone who had no power in dealing with *life is a struggle* to someone who had gained sufficient power to make major decisions and influence important aspects of their life. During this long and arduous journey, or process, participants initially decided that they did not want to deal with anything. This helped them to survive. When that was no longer feasible, they tried to get on top of their mental disorder. However, both turned out to be futile in resolving *life is a struggle*. Instead they left participants in despair. Only by being forced to now confront their hopeless situation, participants encountered a turning point where they recognised that they had to address the pivotal aspect of *life is a struggle* first, namely their value as a person. They termed this wanting to get better as a person, where they took a much broader view beyond the mental disorder. They found that they had gained some power for the first time. This power enabled them to tackle each aspect of *life is a struggle*. They developed a new, positive identity. They learnt new strategies, including some that addressed what to do when signs and symptoms occurred, and took action that was effective, especially in their interaction with other people. *Life is a struggle* was resolved when participants reported that they could live in peace. This newly discovered process took participants many years or even decades to figure out because, as they explained, there was no precedence. However, participants found that their ability to gain power through *transforming oneself*, though essential, remained fragile because *the experience of disempowerment* that had brought on *life is a struggle* in the first place was still present. Most importantly, this needed to be changed also.

Chapter 4 contains participants' real-life solutions to what society needs to do in order to counter or even prevent the experience of disempowerment from occurring. In the absence of a medical cure the only avenue open to making a lasting difference to the lives of people with a mental illness is for society to change so that it can empower them. To empower here

means to furnish others with enough power and authority so that they become equal in value and status to others. This change amounts to no less than a *transformation of society*. Here participants provided solutions on how a *transformation of society* could be accomplished. As envisaged by participants, they would be empowered if society treated them with justice and if society provided effective help. Actual experiences of how participants were empowered by members of the general population, health professionals, religion and family members were included. These were the positive experiences participants had. Participants hoped that if such a *transformation of society* were implemented it would lead to a better society, not only for themselves, but for everyone.

What society needs to do in order to transform itself is the most important part of this study because it has the capacity to positively influence or even forestall the occurrence of *the experience of disempowerment*. This has not been recognized to date. If a *transformation of society* were accomplished, *life is a struggle* would not be brought on and people with a mental illness could live in peace without having to go through the long and arduous journey of *transforming oneself*. The *transformation of society* therefore shows the way forward to relieve the desperation of people with a mental illness and provides hope of a better life. It also points to the benefits of such a society for everyone. This conclusion, that a society transformed so that it empowers people with a mental illness as the most important factor of making a difference to their lives, is entirely new.

It was paramount that the theory in this study was developed independently of other literature so that new and better solutions that work could be discovered. Literature was therefore only added after the completion of the formulation of the theory and interwoven with the accounts of participants. It consisted of international writings of other people with a mental illness and of associated studies. Some studies on people who did not have a mental illness were also included as part of how participants transformed themselves in chapter 3 to show that the solutions developed by participants are universally applicable.

Chapter 5 then broadens this literature further by comparing the theory of this study to other writings in the field. The comparison of this study with other theories and models examines how each empowers people with a mental illness. It concludes that a civil rights movement, here called the mental health rights movement, having empowerment as a core value mirroring the transformation of participants and society in this study, is the most appropriate and lasting way for improving lives. Examples are included of how other groups of people have already been empowered by civil rights movements.

Chapter 6, the last chapter of this book, presents recommendations for how you can contribute to a mental health rights movement. It explains how you as a person with a mental illness can empower yourself, and you as a health professional, you as a policy maker in a government or health service and you as a member of the general population can empower other people thus affected. Some recommendations can be implemented in personal encounters straightaway whereas others require society-wide longer-term measures. An example is also given where these recommendations have already been implemented in a health service to show their feasibility.

It is hoped that this study and its conclusions will contribute to changing the lives of the many people with a mental illness so that they no longer must struggle and live in despair.

Chapter 1: Causative factors

Many people are desperately seeking ways to overcome their mental illness and live a similarly fulfilling life to the rest of the population. It is therefore important to explore what it means to live with a mental illness in Western society in order to find real-life solutions to improving their lives. This book went back to the grassroots and found out directly from the people diagnosed with major depression, bipolar disorder or schizophrenia what they say helps them. Although many studies have been carried out on the impact of mental disorders, the voice of people with a mental illness has not featured prominently. This study aims to redress this imbalance by reporting on what they identified as important, what they did about it and what they want society to do.

In addition to the interviews with people with a mental illness, referred to as participants in this book, relevant international literature was included as additional data. The interviews were analysed using the grounded theory method to formulate a comprehensive theory on how participants resolved their main concern. The main concern was discovered to be *life is a struggle*. Participants explained how *life is a struggle* was brought on, or caused, by *the experience of disempowerment*. *The experience of disempowerment* as a causative factor has to be explored first so that it can be understood how and why *life is a struggle* occurred. In *the experience of disempowerment*, contained in this chapter, participants reported on how they were deprived of power, authority and influence and were portrayed as weak, ineffectual and unimportant in both their personal and social spheres. In their personal sphere participants said they were disempowered because they were unable to control their mental faculties. Most importantly, many were disempowered because they had been abused in their childhood and/or adolescence. Disempowerment also occurred because of an intense feeling of wanting to be dead.

However, the most important disempowering experiences occurred in their social sphere. Participants related how they were disempowered when society did not believe what they said, even when it had nothing to do with signs and symptoms. They were disempowered by being devalued and dehumanised and by society's unwillingness to help them. To add further to their disempowerment, society mistreated them and let perpetrators get away with their abuse.

The experience of disempowerment necessarily contains the account of the many negative experiences participants had. Whereas they were fully aware of being disempowered, which served either as an antecedent to their mental disorder or as a consequence of it, they said that it was doubtful whether many members of society were cognizant of the devastating impact their disempowerment had on people with a mental illness. The possibility has to be emphasised here that many experiences described by participants in this chapter may be shocking and very upsetting for the reader, especially when participants tell of how they had been abused in childhood and/or adolescence. Some experiences related to participants' social sphere could also be seen as perturbing and even confronting, such as those pertaining to the views, values and behaviour of members of the general population, to the organisation of health services, to clinical treatments and to the attitude and behaviour of health professionals. Health professionals referred to were nurses, doctors, psychologists, occupational therapists, social workers and counsellors. The experiences of participants could be seen as confronting because the general population, including health professionals, regards these views, values and behaviour as normal and the

right thing to do. However, participants insisted that it is important to fully lay open their shocking and confronting experiences, so that they could be recognised and addressed: "People need to know".

The next chapter, chapter 2, details the impact of *the experience of disempowerment* on participants. This impact turned their life into a struggle. Chapter 3 charts their long and arduous journey to find real-life solutions to overcome *life is a struggle*. Chapter 4 contains the real-life solutions for society participants had devised to counteract or even prevent their *experiences of disempowerment*. Here participants also included the positive experiences they had had. A comparison of the study with other theories and models in chapter 5 concludes that a mental health rights movement is the most effective way to improve the lives of people with a mental illness. The book closes in chapter 6 with recommendations for how you can contribute to such a movement through empowering people with a mental illness. It finds that the real-life solutions devised by participants are practical and implementable.

An overview of chapter 1 is now given:

The experience of disempowerment as related, firstly, to one's personal sphere was:

Having a mental disorder

Having been abused in childhood and/or adolescence

Wanting to be dead

The experience of disempowerment as related, secondly, to one's social sphere was:

Society does not want to believe what people with a mental illness say

Society devalues and dehumanises people with a mental illness

Society is not willing to help

Society mistreats people who have a mental illness

Society lets perpetrators get away with their abuse and mistreatment

The experience of disempowerment related to one's personal sphere

In their personal sphere participants said that they had no power over having a mental disorder, having been abused in childhood and/or adolescence and wanting to be dead.

Having a mental disorder

Participants explained that *having a mental disorder*, referring to the experience of signs and symptoms during an episode of illness, disempowered them because they lost the ability to control their mental faculties. They said that at times the loss of control was so severe that it could be likened to a terrible evil, "demonic" force that had taken hold, disempowering them to such an extent that it had taken away or "stolen" their "birth right to be a viable, alert person". They described the various ways in which they had lost control over their lives, which occurred irrespective of diagnosis:

"I was screaming and throwing things around and accusing them of destroying my life. I was trying to stop myself, I kept telling myself, 'Stop it, * [name of participant],

just get back to normal. But I couldn't. I couldn't control it. I KNEW the things I was saying were untrue, and I knew it but I couldn't stop myself. "

The loss of control also affected participants' thinking during an episode. They described how they had not been able to control their thoughts or could not decide which events were real and which were not: "I didn't have the filter in my brain that filtered out what might be real and what might not be real". Other participants spoke of being unable to control their emotions or of being unable to depend on their own perceptions over their physical surroundings to tell them what was happening: "Nothing, the things you see, the things you hear, the things you feel are not real when you are having an episode". At times the loss of control was so great that participants said they had changed to someone they hardly recognised, which proved to them that it was the mental disorder making them behave in this way and not their character:

"I remember I went shopping with my son and I was just out of control. I mean literally out of control. I was like yelling at shopkeepers and this is not my nature, not at all. I'm not an aggressive person."

Another participant described how the loss of control due to *having a mental disorder* had overridden her better judgment and turned her from being a law abiding and family orientated person into someone who smashed expensive items against her will because a voice in her head told her to: "At that time, someone, I wasn't myself, someone was controlling me totally. But it wasn't I. Someone was telling me, 'Today you want to break this [item]'. Then I go and break it". The inability to take control was so disempowering that participants really thought what they experienced was real:

"You totally believe that's it. You don't question it because to you it's logical. You can't sit back and say, 'Hey, hang on a minute, that's wrong'. You don't think that way. You're thinking that other way, so it must be right."

Participants pointed to possible physical changes in their brain to account for the disempowering inability to exert control over their behaviour, thoughts, emotions and perceptions of surroundings and began to use physical terminology to describe what was happening with them. For example, they compared the start and end of an episode to a switch in their head that turned on and off. Others likened the physical changes to bubbles popping in their brain: "It feels like bubbles inside your head here. It is like, 'click, click, click', like air bubbles [popping]". They explained that after these physical changes had occurred something akin to a festering wound had been opened up, which never healed and left them susceptible to the occurrence of further episodes of illness.

Affirming the theory of a physical origin, participants pointed to the genesis of their mental disorder as either something that had just arisen as a mutation or as being genetic, naming many other family members who were also affected. Importantly, participants could remember that they already had signs of the developing disorder in childhood or in their early teenage years: "I knew from very early there was a woeful problem". They described what ranged from being "miserable" and being "very absent minded and unable to concentrate" to having hallucinations and delusions: "I used to have these electronic or radio discharges going on in my head then. The whole works, the vision, and I was only a five year old kid".

In other autobiographical writings, people with a mental illness also reported not being able to control the signs and symptoms of their mental disorder: "I cannot will control of my mind"¹. Likewise, they indicated a loss of control over their emotions: "[They were like] blazing fires that I could not put out"² and over their perceptions over their physical surroundings: "Horrible images flickered through my brain that I could not stop"³. A grounded theory study of 38 men in England also revealed that they were convinced that physical changes in their brain had occurred⁴. Other people with a mental illness also talked

of "air bubbles ... hitting me ... from every side"⁵. Shattell, Starr and Thomas' study⁶ with 20 adults with a mental illness living in the community uncovered that they also had had signs and symptoms since childhood: "I've had these visions since I was a little girl".

Having been abused in childhood and/or adolescence

The second experience of disempowerment in participants' personal sphere related to the severe physical and emotional abuse many participants in this study were subjected to as children and/or adolescents. For these participants the abuse left a lifelong legacy and became the defining part of their life: "See, when you have 15 years of hell, it leaves its scars". Participants linked the abuse directly to the occurrence of their mental disorder. Whether the abuse was a cause, a magnifier or a trigger, participants were convinced that their mental disorder was an inevitable consequence of this abuse: "If people have those kinds of things in their lives they are doomed basically. No wonder I had a mental illness". Participants could easily explain the link between the abuse and the occurrence of the mental disorder because they were certain that severe trauma had permanently altered the chemicals in their brain: "It locks in a pattern in your brain".

Having been abused in childhood and/or adolescence was such an important factor in disempowering participants because it took away the capacity to build a satisfying, enjoyable life and left participants feeling fragile and insignificant. They described how the abuse ranged from neglect to brutal attacks: "We lived in a house of horrors". They elaborated that neglect consisted of living in "dysfunctional" and "non-nurturing" families where participants were left uncared for in every way: "My mother totally neglected me". In some families there was no physical affection shown with the only physical contact a painful twisting of participants' skin. Other family members avoided them: "She didn't want anything to do with me. So she just ignored me basically". In some instances, participants' parents also had a mental disorder and consequently they left participants to care for themselves from an early age:

"My mum was never physically or emotionally there; she was so mentally ill. She died emotionally and mentally at a young age. When you have a good look at photographs of her when she was young, you could see there was nothing there. She was just like a cut off person; she was cut off from the world."

Other participants described the brutality of their family life: "Very abusive and very nasty". They relayed how sexual abuse consisted of abhorrent acts of rape: "I was sexually abused as a kid before the age of three up to God knows how long, years". Some participants told of how they had been passed around to several other people for further sexual exploitation: "He used to auction me off to his mates as well". Furthermore, they recounted how physical abuse, which manifested itself through savage beatings, was sometimes so severe that participants believed they would be killed: "Their definition of punishment was, you had to be black, blue and bleeding. They forced me to strip off and just start working on me and there wouldn't be a piece on me that wasn't bleeding, black and blue". Psychological abuse, as remembered by participants, referred to threats: "I remember my * [abuser] threatening to castrate me" and prolonged attacks on participants' dignity and self-respect. Acts of humiliation were common, as in the example provided by the following male participant: "She made me dress in a woman's dress; sit on a stool with a dummy in my mouth, nursing a doll. I was 14".

In the literature, other people who had been abused also characterised this abuse as "brutal"⁷, "barbaric" and "inhumane"⁸. Brechter⁹ referred to her own childhood experiences

as "horror". Female child abuse survivors thriving in adulthood described their home as a "nightmare house" or "hell"¹⁰. A United Nations Children's Fund¹¹, a statistical analysis of violence against children that is the largest compilation of statistics on violence against children to date covering 190 countries, documented that 60% of children worldwide are subjected to physical punishment by their caregivers, 17% of these refer to severe physical abuse. An additional 7% of girls and 1% of boys are experiencing sexual abuse. In selected European countries the report found that severe physical abuse happened to between 4 and 6% of children. Sexual abuse occurred to between 2 and 7% of girls and between 1 and 3% of boys in the same European countries, and between 17% and 4% respectively in the United States of America (USA).

As in this study, Erdmans and Black¹² also found in their study that 27 young mothers who had been sexually abused in childhood made "direct connections" between their abuse and the development of mental health signs and symptoms. The prevalence of abuse in people with a mental illness was demonstrated by a study from Sweden¹³, which revealed that 51% of women using mental health services had been abused. In the USA, the prevalence of abuse of people with a mental illness ranged from 48% for males¹⁴ to 98% for females¹⁵.

Wanting to be dead

The third experience of disempowerment related to the personal sphere was expressed by participants as a wish of "wanting to be dead". Many participants, whether they had been abused or not, experienced this wish at some time during their life. They described it as being a generalised feeling: "I just wanted to die. I was totally happy just to die". Some participants said that this generalised feeling had already been present since childhood: "It's like a vivid memory. I mean you can't really remember much when you are five but it's really vivid, this feeling of wanting to be dead. It is obviously something you are born with".

The intensity of participants' feeling of *wanting to be dead* disempowered them to such an extent that they had no control over when it occurred: "I couldn't stop it. It was continually in my head all the time. I couldn't get rid of it. It just went on and on and on". The feeling was so intrusive and constant that participants experienced it as innate, or "in me anyway". They explained how the feeling had come "uninvited into my brain" without prior warning or any initiating situations: "I can just wake up in the middle of the night and think, 'I don't want to be here'. I'd just think, 'I wish I would die. I wish something would happen to me and I would die'".

For many of the participants the generalised feeling of *wanting to be dead* then progressed to specific thoughts about committing suicide. They said that these thoughts were so powerful that they seemed like they were pushed to kill themselves for no reason. Some described this aptly as an awful force that precluded any free will. For instance, suicidal thoughts appeared during completely innocuous activities like walking along a road: "I'd be walking my kids to school and be walking home across the bridge and I'd stop and contemplate jumping off". The following participant likened the power of these unexpected and uninvited thoughts to being swamped by a king wave that suddenly appeared in a calm sea:

"They come in waves, and it's like when you are swimming. You are quite happy swimming along and then you get hit by a wave of these thoughts. And you come up for air and you get hit by another wave. It was horrid, absolutely horrid."

The same disempowerment also occurred when forced to make plans for how to commit suicide: "I was at the level, all the time of wanting to do things. There was always a

plan. I always had a plan going. I would work it through in my head every day, all day". Making plans became so pervasive that it was incorporated into everyday activities such as driving along a highway: "I would drive everywhere wanting to drive into everything I saw. I'd be driving down Reid Highway wanting to hit all the pillars on the road".

Participants were then just as disempowered when it came to exerting control over stopping their attempts to take their life. These attempts were sometimes performed nearly every day: "I just walked into the room, simple as that, shut the door, locked the door, put all my pills into a glass, filled it up with water and just glug, glug, glug". This loss of control led to their suicidal behaviour becoming habitual at times: "I just kept taking tranquilizers, just kept wanting to black out, continually just taking them, overdosing". As these attempts occurred so frequently participants began to view them as natural or normal. They concluded that the disempowering force of *wanting to be dead* had reduced the threshold between a desire to stay alive and *wanting to be dead* to such a degree that there was little difference between the two: "Sometimes there is only a fine line between life and death itself". Consequently, it did not take much to tip participants over the edge into wanting to go through with suicide.

Other people with a mental illness also spoke in publications about their wish to be dead: "I ... wished I was dead"¹⁶. Like participants in this study, they told of the intensity of this wish and the lack of control they had over it: "I obsessed about dying"¹⁷. They also indicated their disempowerment: "I was driven on many occasions to attempt suicide"¹⁸. Durkheim¹⁹ reported in one of the first extensive studies on suicide that suicide was a "vague aptitude", an "irresistible impulse" or an "irresistible force". He wrote that due to this vague aptitude, no particular reason for the wish to commit suicide and therefore no explanation for its occurrence could be found: "I have no reason to kill myself"¹⁹. Joiner²⁰ also concluded in his study on why people want to commit suicide based on accounts of several hundred people that suicidal acts were certainly not "impulsive" nor "'spur-of-the-moment' decisions". He stated that his informants habitually thought about suicide, as did participants in this study. Durkheim¹⁹ wrote "there is nothing which cannot serve as an occasion for suicide".

The experience of disempowerment related to one's social sphere

Disempowerment in the social sphere for people with a mental illness arises from the views, values and behaviours of society. Society can be defined as "the aggregate of people living together in a more or less ordered community" and their "system of customs and organisation"²¹. In this study, society consisted of families, friends, workmates, employers, health professionals and organisational systems, such as the judicial system and mental health system. Participants emphasised that their disempowering relationship with society was of primary importance in bringing about *life is a struggle*: "Society is a major, major disabling factor. That would be great if it's put somewhere in there [in this book] in big letters. The mental illness itself could be easily dealt with if it wasn't for all these other social factors".

Repper and Perkins²², by drawing on the accounts of many people with a mental illness and their own experience as patients, concurred: "The specific cognitive and emotional difficulties that led to a diagnosis of mental health problems are usually less disabling than the discrimination and exclusion that accompany them".

The five experiences of disempowerment in the social sphere in this study were: Society does not believe what people with a mental illness say, society devalues and dehumanises them, society is not willing to help, society mistreats them and society lets perpetrators get away with their abuse and mistreatment. These experiences ranged from

society's view of people with a mental illness, where they did not believe what participants said, to their attitude changing from devaluation to dehumanisation. This attitude then laid the foundation for society's reaction in not wanting to help and justified mistreating people with a mental illness. It also fostered an atmosphere of letting perpetrators get away with their abuse and mistreatment.

Society does not believe what people with a mental illness say

Society's view of people who have a mental illness was reflected in seeing participants as so unreliable and dishonest that they were not believed. Not being believed was such a pervasive factor underpinning participants' disempowerment that it affected most of their interactions with others.

Participants identified that society did not believe what they said for two opposing reasons. On the one hand, participants were not believed when they told other people that they had a mental illness: "A lot of people out there still think that you are making it up". Even experts in the mental health field dismissed some participants' reports about their illness, as relayed by one participant who had been living with his mental illness for 60 years: "They think that you don't know what you are talking about". On the other hand, participants were not believed for the simple reason that they had a mental illness. Once this fact was known, everything participants said was disbelieved, even when it had nothing to do with signs and symptoms. For example, a technical suggestion put forward to his professional organisation by a participant was not considered valid despite his long and distinguished career within the area: "Being a professional * [name of occupation] no one takes me for my word. They think I'm a nut-case". The same happened to other participants when they put forward suggestions to improve health services.

A consequence of society not believing what people with a mental illness said was that issues brought up by participants were brushed aside and their interests disregarded on a daily basis: "Nobody would take any notice of you". Decisions on vital matters directly affecting them were made without taking into account what they wanted. Furthermore, participants' comments as mental health representatives at government-sponsored meetings were ignored: "You'd be on the minutes having said something and they never follow it up. They never do it. It's just shit; all that stuff".

Supporting literature also reported that people with a mental illness were not believed. Other people with a mental illness wrote that what they said was consistently brushed aside and ignored²³. A study based on focus groups with 18 people diagnosed with schizophrenia found that they had "not [been] seen as an important party for receiving information or being included in the decision-making process regarding treatment"²⁴. Another set of focus groups with 249 people with a mental illness stated that their goals and choices were routinely disregarded²⁵. Moreover, Cutcliffe and Happell²⁶, in their examination of power relationships between people with a mental illness and nurses, came across examples where nurses insisted on making decisions about their best interests over the head of people with a mental illness.

Another consequence revealed in this study of society not believing what people with a mental illness said was that other people were not interested in wanting to understand them and to gain any knowledge on mental health matters: "They need to learn, and that is something they are not doing. They say, 'Oh, you've got the problem, deal with it'. Well, you need more than that. You need some understanding". Of great concern to participants was encountering similar sentiments amongst health professionals: "If you went to talk about something they'd stop you. They didn't want to know". Participants pointed out that this led to

a grave lack of understanding: "I realised that the medical profession was woeful in understanding mental health". Despite ample education in mental health theory, health professionals did not comprehend the "intricacies and the depth of mental illness" nor did they understand some common signs and symptoms: "[Health professionals described dissociation as] 'indecisiveness, poor memory'. I mean don't they understand that you dissociate because there is something so bad there [such terrible experiences, such as the abuse in childhood and/or adolescence]?"

Participants also found a profound lack of understanding amongst health professionals with regards to *wanting to be dead*, which drove participants to want to kill themselves due to seemingly insignificant difficulties. The following participant recounted how his health professional thought it was not justified to write a sick certificate instead of trying to understand that even temporary difficulties, such as insufficient funds, would escalate his suicidal thoughts: "This could have been a death sentence just for not having one day of a doctor's certificate". Other people with a mental illness also wrote about health professionals who were disinterested in understanding them: "[They make no] effort trying to get to know exactly where you're coming from"²⁷.

Participants in this study pinpointed why health professionals were not interested in understanding them. They thought that health professionals were unaware of their own lack of knowledge even though they had ample contact with patients. Participants explained that health professionals only knew the mental health theory they had learnt during their studies. This theory is based on contemporary psychiatry focusing almost exclusively on identifying signs and symptoms for diagnostic purposes without seeking to find out what precipitated these signs and symptoms. Participants explained that many health professionals' knowledge of mental health matters was divorced from their patients' real life experiences. Participants had the impression that health professionals were confident in their abilities to practice, despite the apparent dissonance between contemporary psychiatric theory and how patients presented: "The * [health professional] kept saying she knew everything but she spoke as if she knew nothing".

Participants also came across health professionals who persisted in treating them although, in participants' eyes, they were not equipped to do so: "I think some of them do take that task on perhaps without having the right background and skills to do it". For example, participants spoke of some health professionals who did not seem "au fait" enough to prescribe the right medications or the correct dosage: "Some * [health professionals] really aren't up to the mark with knowing enough about it". In addition, participants pointed out that many health professionals did not seem to be aware that the lack of their own life experience prevented them from grasping what was important to understand: "I think she had absolutely no clue what she was tangling with". A third example saw health professionals work outside their level of competence, for example, when they took it upon themselves to treat the participants' childhood trauma although not qualified for this kind of work:

"It was a profession that should never have been done this work with me on childhood trauma. Imagine having a bottle filled with explosive material and it says, 'Do not shake, do not shake'. And you shake it and then you open it and of course what happens? Very dangerous practice to deal with childhood trauma in an unprofessional way. No wonder I am not dead."

A last consequence of society not believing what people with a mental illness said was blaming participants for *having a mental disorder*. Participants said they were blamed because they were viewed as weak and incapable or because they were thought of as possessing "bad morals". Due to this blaming, society was free to argue that it was incumbent

upon participants to get over their mental disorder and saw them as failures if they did not succeed: "Think differently. THINK differently is the big thing. Don't think like that".

Feeling blamed for *having a mental disorder* was also voiced by 20 female participants in Humphreys and Thiara's²⁸ thematic analysis of interviews with them. Alongside participants in this study, Van Der Tillaart, Kurtz and Cash's study²⁹ found that people with a mental illness were disempowered by not being listened to.

Society devalues and dehumanises people with a mental illness

Society not believing what people with a mental illness said then progressed to the second experience of disempowerment in participants' social sphere, which revealed society's values towards people with a mental illness. These values were so widespread and deep-seated that people with a mental illness were not accepted as being equal members of society, which was disempowering for them: "The present system prevents people [with a mental illness] reaching their proper place in society. Society reviles them". How devaluation consisting of degrading misconceptions progressed to condemnation and prejudging participants will now be explained.

To devalue a person is to see them as lower in status, as not worthy of consideration and respect, and not important enough to ask for their counsel or their opinion. Consequently, a devalued person can be easily dismissed as inconsequential and irrelevant. Participants in this study described how they were devalued by broadly circulating misconceptions that were not only wrong but also degrading: "There's a lot of misconceptions about * [the person with a mental illness]". Common misconceptions that participants came across were beliefs that mental disorders could be controlled by a person's willpower. Therefore simplistic ways of how to overcome these disorders were advocated, possibly in the belief that they would help participants, such as: "You just need to pull your socks up and get on with it". As participants were not able to follow through with these admonitions they were regarded by others as irrational cases beyond comprehension. Participants' failure in this regard then resulted in them being singled out as stupid and helpless creatures with no value. It was seen as all right to attach the most demeaning terms to them: "Crackers", or: "Some sort of freak". In line with general society's adoption of devaluing misconceptions, some participants encountered health professionals who harboured the same misconceptions. They treated participants as if they were stupid, for example when participants asked for assistance: "They basically treated me like I was stupid. They just said, 'we don't deal with people like you'".

The devaluation of people with a mental illness was consistent across other parts of the world. Lundberg, Hansson, Wentz and Björkman³⁰ reported from Sweden about the devaluation occurring amongst the 200 people with a mental illness in their study. Connor and Wilson³¹ quoted people with a mental illness living in Northern Ireland who were confronted with similar derogatory terms. They reported how they were called names such as "'headbin', 'loony' ... and 'monsters'". People with a mental illness in Spain were called "lazy or overdramatic"²⁴. Read and Baker³² found in their English study that families of people with a mental illness urged them to "'pull themselves together'" and displayed the same lack of understanding as participants had experienced in this study.

Condemnation was then added to devaluation: "Of course mental health has always been that, the condemnation. There is something weird; there is something wrong with you". Participants said that this condemnation was then applied across the board to anyone just because they had a mental disorder: "It just sort of tars everyone with the same brush". It was now easy to see how all people with a mental illness are viewed as being the same and

prejudging them becomes such an effortless option that happens automatically and becomes ingrained. For example, participants said they were prejudged to be untrustworthy and seen as guilty whenever they came in contact with the law.

Health professionals also prejudged people with a mental illness. Participants met some who were, in their opinion, even more judgemental than other people in society: "I felt at the time, and still do, that health care professionals are often the most judgemental of [people with a] mental illness. I think more so than the general community".

Devaluing people with a mental illness then changed into dehumanising them. Dehumanising is to "deprive of human attributes; make impersonal or machine-like"²¹ or "to deprive of human character"³³. To dehumanise someone is to see them as a depersonalised object rather than as a human being. Consequently, people who are dehumanised are not regarded as equal to other human beings. People do not wish to identify with them and do not want to connect with them on an emotional level. Participants in this study described being dehumanised because the demonised attribute of *having a mental disorder* came to be seen as the only attribute that was important in interactions with others. All of their other attributes and qualities became invisible, along with their societal rights and powers. How dehumanisation occurred both amongst the general population and in the general health service and how it was then applied in the mental health field will now be explored. Both resulted in a distorted view of people with a mental illness.

Amongst the general population, dehumanisation changes the demonised attribute of *having a mental disorder* into a stigma. Stigmatisation is the attachment of discrediting labels on a whole group of people¹⁷, in this case on those with a mental illness. Participants explained that stigmatisation occurred because mental disorders could not be scientifically explained and therefore society's "bigoted, narrow-minded" view endured. They realised that stigma could easily defame them because they remained an enigma as human beings and were not understood in how they led their lives.

In this study, this was the point at which the public's attitude changed from broadly devaluing people with a mental illness towards only seeing the demonised attribute of *having a mental disorder* in them. This turned people with a mental illness into one-dimensional figures. In this study, participants of all ages, whether they were in their twenties or seventies, said that they were affected by stigma, where they were marked out permanently as non-persons who were not part of the human family. The following participant dismissed the view that stigma against people with a mental illness had decreased and said that, according to her experience, stigma had actually increased in her lifetime: "That stigma has disappeared, no. It is actually totally well entrenched. We have got to be kidding ourselves. It is a myth to say that, 'Oh, everything is changing'. It is not; it is far worse".

Participants pointed out that stigmatisation was not only wielded by individual members of society but also beset the general health system: "Of course stigma and discrimination hasn't gone when you've got a [health] system that uses it really well [and where it has become] systemic, ingrained". Participants could point to instances where the stigmatising attitude of the health system had infiltrated health professionals. This was particularly disturbing to participants because these health professionals seemed to see themselves as stigma free but displayed these attitudes nevertheless without, perhaps, being aware of them: "There is a stigma attached to mental health. I just felt it stronger and more pigeon holing [with health professionals] in the health care system". This was evident when participants overheard health professionals calling other people with a mental illness by derogatory names, such as "loopy and loony".

That people with a mental illness are vulnerable to stigmatisation has also been reported in many other studies. In Australia, 80% of surveyed people with a mental illness reported being stigmatised³⁵. A survey of 778 people with a mental illness in England confirmed participants' suspicion in this study that stigmatisation had increased and that attitudes towards them are "ingrained, entrenched and debilitating"³². Sartorius³⁶, along with participants in this study, stated that health professionals also stigmatise people with a mental illness.

Dehumanisation in the mental health field occurs differently. Here the demonised attribute of *having a mental disorder* is transformed into a list of signs and symptoms. These are then compared with the diagnostic criteria published in one of the two world-wide classification systems, also referred to as manuals, the Diagnostic and Statistical Manual of Mental Disorders, now in its fifth edition, (DSM-V) or the International Statistical Classification of Diseases and Related Health Problems, 10th edition (ICD-10). The DSM is used more in English speaking countries such as Australia and the USA and the ICD in mainland Europe. As psychiatry focuses on this list of signs and symptoms, participants in this study saw this focus as a way of dehumanising them: "I have experienced a psychiatrist whose attitude towards me was basically, 'you're nothing but a bunch of symptoms. You are not a human being, you're a mental illness, you're a bunch of symptoms'". Some mental health professionals saw participants as mere objects, or as "a block of wood". This way of dehumanising participants then led on to mental health professionals believing that the humanness in their interactions with them could be dispensed with: "They've forgotten what heart felt stuff is". Participants said that they could readily recognise this but that it seemed to be invisible to the health professionals themselves: "They lose that gentleness. They lose their soul. You can't reach them anymore. They have gone, disappeared. You can actually see it. You can't reach them. Even their language changes. It's sad to see it. They are not themselves".

Other studies described similar experiences. Malins, Oades, Viney and Aspden³⁷ found in 33 interviews to elucidate the views of people with a mental illness on health services that they were not treated "like a person". Lilja and Hellzén³⁸ talked to 10 former patients in Norway who also reported being only seen "as a disease". Other people with a mental illness also agreed with participants in this study about the dehumanisation of mental health professionals: "I think doctors become desensitised. All feelings sort of disappear"³¹.

As a result of the dehumanisation of people with a mental illness society formed a distorted view of them. The distorted view amongst the general population was that people with a mental illness are dangerous. Participants spoke of a deep-seated fear in the public: "People just brand you. They are frightened of you". Participants said that people were frightened because they were convinced that participants would just go out and hurt or even kill other people, and their merely owning a power tool produced fear in others. Participants explained that this very pernicious one-dimensional public-held view, where society mistook rarely occurring manifestations of *having a mental disorder* as the norm, had become the only yardstick by which they were judged. According to participants, this view was widespread: "That's what you get when you got a mental illness".

Participants found that the distorted view of people with a mental illness as dangerous was then reinforced in the media: "People just have this misinformed information about people that are mentally ill through the media and it makes them scared". Participants pointed to how people with a mental illness were depicted in newspapers and chat shows as the worst kind of person, usually reserved for sordid fantasy novels: "Mad, axe wielding maniacs". According to participants' experience, these exaggerated, unrealistic media representations

inevitably led to calls for all people with a mental illness to be locked up: "What they are trying to say to society, 'This nut case did this. Lock him up'. Him or her. 'Lock him up because he's got a mental illness. So, lock him up. He doesn't deserve to be loose". In participants' eyes, what made these representations in the media even more hard-hitting was that the public believed that these depictions were correct: "Society looked at it and said, 'Oh, well, there must be some truth to it'".

As with participants in this study, other people with a mental illness came across portrayals in the media of people with a mental illness being "killers"³¹ and calls to lock them up were encountered: "'Crazies' must be locked up and drugged for their own good"²⁵.

A distorted view of people with a mental illness also occurs in the mental health field. Participants in this study said that this view was "twisted and distorted" because, by focusing solely on signs and symptoms, the background of what had happened to them was not recognised as important: "I am viewed from a scientific gaze that has no thread attached to my life". Participants explained that this scientific gaze had been put forward to justify the objectivity of the mental health theory, which was aimed at "minimalising" their experiences. As a consequence, even the most traumatic and blatant abuse predating the mental disorder was blacked out by mental health professionals as if it had never happened and had had no effect on participants:

"I didn't just arrive here all of a sudden in a psychiatric unit. I had a world way before I had arrived. I was a wounded soul. My wounded soul was wounded way before I got to your units and you couldn't see that. That doesn't show 'cause it is something that is not seen."

Participants realised that this blacking out led to mental health professionals believing that these underlying terrifying causes of mental disorders did not exist:

"They got no idea what was going on inside me. They got no idea. No idea. (Participant is crying.) Every day you've been raped as a child (pause) and they write shit things like that. I've looked at these [writings] and I tell you, they are disgusting."

Participants thereby concluded that they were not the ones to see reality in the wrong way here but that a distorted view of people with a mental illness was inherent and promulgated in the mental health field: "Who's got the distorted lens? I don't think I have". Other people with a mental illness quoted by Connor and Wilson³¹ also stated that their "life experiences were never taken into consideration". Humphreys and Thiera²⁸ in their study on people with a mental illness who had a history of domestic violence concurred: "The 'mental illness' becomes the treatment focus reified from the abuse context".

A consequence of the distorted view in the mental health field was revealed in the way psychiatry operates. Participants in this study identified that their signs and symptoms were not recognised as such if they did not exactly fit those described in psychiatry's manual. This happened to the following participant whose mental health signs and symptoms had not been recognised for many years: "All the doctors missed it". On the other hand, participants' normal emotions and behaviour were mislabelled as pathology because they looked similar to those in the manual:

"Some people who work in the mental health field are always looking for everything that you do to link it to your mental health to pathologise you. If you cry, 'Oh, maybe that is a sign of your depression', or if you laugh, 'Oh, are they manic again?'"

Participants said they especially encountered this type of mislabelling when they were angry about how they were treated: "It's like as though you shouldn't be angry. So they then

take that for being my * [mental disorder]. 'Let's give her some more pills. Up the medication'. That's what they said".

Other mislabelling resulted in making a mental health diagnosis where no signs and symptoms were present. The following participant related how she got diagnosed with a mental disorder merely as a consequence of some of her statements when she pleaded for help after her childhood abuser had moved into the neighbourhood:

"I went to a psychiatrist and I walked in and I said, 'Look, I am a nutcase. I sit in my corner. I can't leave my house 'cause I don't want to run into him [the childhood abuser]. Someone's at my windows every night scaring the shit out of me. I don't know what to do. I am paranoid, but I am justifiably paranoid'. That's what I said to him. He goes, 'All right, you are paranoid schizophrenic' and he put me on this medication for being a paranoid schizophrenic."

The British Psychological Society agrees that mental health assessment is "subject to variation and bias"³⁹ and regards psychiatric diagnoses as having "limited reliability and questionable validity"⁴⁰. Rosenhan⁴¹, in his landmark study in 1973, described that health professionals could not distinguish between healthy 'pseudopatients' and real patients. The reverse has also been demonstrated when a woman with a severe mental illness was diagnosed as healthy and placed in an Australian detention centre for illegal immigrants instead of a mental health facility⁴².

Another way of how the distorted view in the mental health field has affected psychiatric practice is that medical conditions other than mental disorders, even life threatening ones like cancer, are dismissed as not worth looking into. Participants in this study were told instead: "This is not our brief". Taking no notice of physical ailments is also a common theme in the literature: "I suffered from severe general health problems for several years - no-one would listen and everything was put down to my mental health problems"³¹. Lawrence, Holman, Jablensky, Threlfall and Fuller⁴³ looked specifically at cancer mortality rates in Western Australian mental health patients and established that although the incidence of cancer was the same as in the general population an excess in mortality occurred. Moreover, patients with a mental illness in eight states in the USA who suffered from general medical conditions died between 10 to nearly 30 years before comparable patients without a mental illness⁴⁴. This was put down to "difficulties accessing [general] health care ... [and] erratic [medical] compliance with [general] health screening and treatment".

Due to the distorted view promulgated in the mental health field, participants in this study concluded that it was based on false premises: "The very theories that psychiatrists base their treatments on are false". Participants had even come across mental health professionals who did not seem to quite understand how to apply this theory: "They are confused themselves". However, despite this confusion, participants said that mental health professionals were so dominated by the distorted view perpetuated by psychiatry that nothing was seen outside its framework: "They just have their world-view and you can see when you are talking to them, they don't get it". Therefore, any acknowledgement of its failings was impossible. It was accepted and even encouraged by the public, highlighting yet again the disempowerment of people with a mental illness: "It is socially sanctioned political power over people with a mental illness".

Society is not willing to help

The third experience of disempowerment pertaining to participants' social sphere contained society's reaction to people with a mental illness. Due to their devaluation and dehumanisation it was no surprise that society often did not want to give them any help: "They don't want to help". Participants felt barred from being helped by diverse groups of people who were well placed to provide help but did not respond to calls from them. These were family members, friends, employers, work colleagues and governmental departments. However, participants singled out some groups of health professionals in particular who were not willing to help although their whole vocational ethos was based on helping others. Participants recalled how they did not even receive help on the most basic level but were left to fend for themselves:

"I used to turn up at the community clinic for my appointments, and I used to walk up the bloody highway in the middle of the summer or rain or whatever. I was quite grubby and dishevelled and obviously very unwell but nobody like said, 'look, look, come' and sat me down and tried and assist me."

Participants in Brody's study²⁵ on first hand experiences of 249 people with a mental illness in California called the society's unwillingness to help a "help vacuum". In this study, *society is not willing to help* was manifested in two ways: people were not willing to support participants and they did not want to care for them.

One way of society being unwilling to help is not to support people with a mental illness. Participants remembered how unsupportive family members had not wanted to talk about mental health issues with them and had decided to switch off instead when the topic of mental health came up. They also did not visit them in hospital when they were sick. Consequently, when crises occurred in participants' lives they were left on their own. Even life-shattering experiences were not acknowledged and dealt with. The following participant recalled how her family had not wanted to support her after she had been raped: "Mental health wasn't discussed. The rape was very much buried under the carpet by my family and so there were no police involved, no medical treatment, no discussion about it at all. It was just shut off". Other people with a mental illness also remembered how their mental disorder was ignored by their family members: "My mental illness became the elephant in the living room - unmistakably present, yet totally ignored"⁴⁴.

Participants in this study voiced some of the reasons why other people did not want to support them: "You are in the too hard basket". Other people decided to cut off contact instead and told participants this bluntly and without any false pretence: "You can see the ten-foot barge pole just about that they put between you and them. People never look at you the same. People won't talk to you. People won't let their kids near you". Some family members did not allow participants back home after their first hospitalisation and some employers terminated participants' employment: "I got sacked from my job".

Other participants experienced exclusion by indirect means. They were not made welcome, they were not included in conversations as if they were not in the room, or they were left out of social activities: "They didn't want anything to do with me". Participants were even ignored when they were suicidal: "She said, 'F*** off and stop being a drama queen' and hung up on me". Often underhand tactics were deployed, such as choosing to cut off contact at those times when participants could not protest: "He [husband] went to court when I was in hospital. He won the battle and got the kids". Some family members took even more drastic steps by trying to get participants locked up in mental health institutions. The following participant related how her family member sought advice from his doctor on how to get her admitted to a psychiatric hospital when he was angry with her:

"He got cross with me and his psychiatrist said, 'If she is getting under your feet and annoying you, ring the Psychiatric Emergency Team'. So, he did, and I ended up in * [mental hospital], please. Yeah, you got to be very careful in this State. A spouse can do that. You didn't know, but they can."

Participants knew that other people contacting mental health services was a good way of getting them permanently locked up: "I know that my relatives want to make me totally, no sorry, permanently incarcerated so they will never have to see me or hear from me again". They had even encountered fellow patients who had been abandoned in these mental health institutions because no one supported them.

Cutting off contact with people with a mental illness was also a common theme in studies conducted in the USA²⁵, Canada²⁹ and England³². Furthermore, in the English study³², 34% of people with a mental illness were dismissed or forced to resign from their jobs.

A second way of society being unwilling to help is not to care for people with a mental illness. Not caring for another person means not to feel concerned for them and not to be bothered with helping them out, whether directly or through institutions. Participants in this study had the impression that many individuals of the very professions whose reputation was built on caring for other people, did not care: "[The health professional] was the pits. He couldn't have been worse. He didn't care at all". Other people with a mental illness taking part in Joyce, McMillan and Hazelton's study⁴⁶ conducted in New South Wales, Australia, also reported on health professionals who did not care: "I found them mostly uncaring".

However, participants in this study singled out elected governments for not caring for those of their citizens who happened to have a mental disorder: "The state doesn't care. I proved that". Participants were clear that governments did not care for the welfare of people with a mental illness because the services they set up "write human beings off as beyond help". This left people with a mental illness languishing in "appalling conditions, which no one should have to bear". This uncaring attitude of governments was puzzling to participants because they were convinced that Western governments had the wherewithal to set up services to care for them adequately but for some unknown reason chose not to: "The statistics are yelling. Surely the government can hear that".

To participants, governments' unwillingness to care for them was encapsulated in the deficiencies of the mental health services. Participants stated that these services, often referred to by them as the mental health system or merely as "the system", were "shocking" and "terrible". Participants emphasised that the uncaring attitude found in the mental health system had been especially disempowering because it was a major factor in bringing on *life is a struggle*: "The mental illness is bad and it is disabling but the mental health system is the most disabling factor in it".

Governments' uncaring attitude is revealed in the violation of human rights, in the way they allocate funding and in the inadequacy of organisational regulations. With regards to human rights, the formulation of internationally recognised human rights is supposed to pressure governments to safeguard the basic rights and freedoms of all their citizens and protect the individual against "undue coercion"⁴⁰. However, participants in this study realised that they were obviously not included as such citizens because, according to their experience, the proclamations on human rights in the mental health field were often only empty statements: "They are starved of everything enjoyed by most people as their human right". Other people with a mental illness had also noticed how their human rights were disregarded, for example in the focus groups set up by Brody²⁵ in California.

Participants in this study referred specifically to the human right to make one's own decisions. They said that this human right had been taken away by the state when governments passed acts of parliament that gave health professionals the legal authority to override participants' right to make their own decisions, disempowering them profoundly:

"There is a book put out by the Mental Health Law Centre giving the rights of mental patients. Well, I say put it in the rubbish bin. They have no human rights. None. No rights at all because every time they want something a psychiatrist just has to say, 'No', and then they haven't got it."

Participants in this study pointed to two groups who were especially at risk of being disempowered by having their human rights violated. Those on Community Treatment Orders, who receive psychiatric treatment against their will whilst living in the community if this treatment is deemed necessary by psychiatrists, had no right to decide what they wanted, especially over whether they wanted to take potentially poisonous medication:

"People [with a mental illness] have got no control once you've got a Community Treatment Order. You've got to do anything they [health professionals] say. They can force drugs down you that are like totally toxic, can kill you. I mean, that's violating human rights."

The second group at risk of having their human rights violated, according to participants, were those patients residing in locked wards of mental hospitals: "I cannot forget the terrible injustices I have witnessed in * [name of mental hospital] and other places like it, where man's inhumanity to man is at its worst". Participants had either personally experienced or had seen first-hand the injustices other patients were subjected to in these locked wards. They compared the conditions as being "stuck in dreadful human cages", where the lack of human rights to make one's own decisions was entrenched: "They don't have freedom". Participants described how they had come across instances where patients were denied the right to make decisions with regards to how much water they wanted to drink despite the compulsory administration of medications that produced excessive thirst, and how much they wanted to eat. They were denied their right to decide upon how they wanted to spend their own money, for example, whether they wanted to pay a lawyer who would help them to get out of the hospital. They were also prevented from deciding whether they wanted privacy as they were constantly watched, or whether they wanted to smoke cigarettes as blanket bans on smoking on hospital grounds had been implemented.

Other people with a mental illness also reported on the injustice in these hospitals and commented on the denial of their basic rights: "All your rights are no longer yours"⁴⁸. Short⁴⁹, a writer with a mental illness, also thought it worth mentioning that the lack of privacy was undesirable: "Having someone in a room watching your every movement was uncomfortable".

Another area where governments' uncaring attitude has been made manifest is in not providing sufficient funding for services or a misallocation of available funds, resulting in inadequate services: "There's not enough services and it's just all crumbling". Authors¹⁹ from Europe also pointed to a "reluctance to invest resources into mental health care".

Participants in this study encountered a lack of funding for hospitals and services in the community alike, including for accommodation. This was supported by Kadmos and Pendergast⁵⁰ who found that "46% of inpatients in public mental health acute units could have been discharged if there had been suitable community alternatives". Participants in this study said that a misallocation of funding saw high profile acute services prioritised and low profile services that would help participants in the long-term neglected. Hence both a lack of

funding and a misallocation of available funds then led to insufficient access to services. Participants found that access to general practitioners, specialist services, hospitals, non-medication focused treatments and community services was so restricted that often the only possibility of getting any health care was at the hospital emergency department. Although access problems also existed for patients with general medical conditions, participants thought that it was far worse in the mental health system, underscoring the neglect of these services by governments. Participants suspected that even a cash injection of some large sums of money had not made sufficient difference:

"I went to a meeting where they said that the government is putting one and a half billion or however many billion into the health system. Well, I was thinking that it wouldn't go to the right places; it wouldn't go to the right people. It wouldn't be used the way it should be used. It would just be used to make it worse, to perpetuate this unjust system. This system, which crushes people. It crushes people; it doesn't help."

Participants in this study pointed out that this lack of funding for mental health services and the misallocation of available funds, "especially in a country enjoying the wealth and high living standards of Australia", seemed to be in pointed contrast to the much more adequate allocation of funds of general medical services. They therefore suspected that they were not regarded with the same priority for care as other patients with non-mental health conditions.

In Australia, spending on mental health has increased by 85% in real terms since 1993, according to a report by the Department of Health and Ageing⁵¹. This accounts for 6.8% of total expenditure on health care. However, the same report notes that the proportion of spending in comparison with general medical services has remained stable, as there has been a concomitant increase of spending on general medical services. Furthermore, 49% of mental health money is still spent on hospital-based care instead of on community-based services.

The last area where the uncaring attitude of governments is evident is in the inadequacy of organisational regulations. Participants in this study pointed here to deficiencies in how health services were organised, specifically to inadequate communication channels within services. They gave examples of how the inadequate communication channels within services in the public system required them to retell their mental health history over again as almost every time they had an appointment they encountered a new health professional: "The worst thing about having to see multiple people [doctors] is going through the whole process again. I had to do that a few times and, God, I hated that". Similarly, people with a mental illness in Sword, Busser, Ganann, McMillan and Swinton's study⁵² described disconnected care pathways, having to consult different doctors, long waiting times and limited service availability.

Society mistreats people who have a mental illness

The fourth experience of disempowerment in participants' social sphere explains how society mistreated them. Participants said that few other groups of people were subjected to such disdainful treatments as they were: "It is the worst treatment of human beings in peacetime". At the same time they realised that, as the devaluation and dehumanisation of people with a mental illness was so ingrained, this mistreatment often did not register as such: "Human beings can be so cruel and maybe they don't even know".

Most mistreatment that participants encountered was not against the law but was ethically incompatible with generally agreed values of how to treat other people: "Nobody is

trying to treat these people [with a mental illness] with how they themselves would like to be treated. Isn't that what they call the golden rule?" Corroborating this rule, a participant in Connor and Wilson's study³¹ also defined generally agreed values of how to treat other people as "common sense, just treat them the way you would want to be treated if you were in the same situation. It's not rocket science, it's just basic human values". Two types of unethical actions were identified in this study: The first was due to other people feeling superior and the second concerned mental health treatments.

The first type of unethical action occurred because other people, both members of the general population and health professionals, thought themselves superior to participants. In feeling superior, they automatically lowered participants' status to an inferior position and thus disempowered them. Members of the general population, participants recounted, believed that they had the right to tell participants what to do: "The trouble is, you see, once people know that you had a breakdown, they feel very important, and they think that they can tell you what to do and they treat you like a complete absolute idiot". Furthermore, participants said that these people thought that they knew better what participants' needs were and that they were in a better position to determine how participants should conduct their life: "They try and run your life. They don't just leave you be. They got to run your life how they reckon you should live".

Participants recalled how some members of the general population, in feeling superior, then felt justified in taking advantage of participants financially. For example, they asked them to do unpaid work or did not pay them back money they owed as promised: "I got used". Other people tried to get at participants' financial assets by asking to become legal guardians because they considered participants not fit to look after their own money: "They came to me and asked me to sign a power of attorney. Can you image that?"

Moreover, participants in this study had the impression that members of the general population thought, in feeling superior, that it was perfectly all right to tell lies because lying to people with a mental illness did not matter: "He tells lies because he thinks it is all right to lie". Likewise, some written statements made by health professionals about participants were lies: "A misleading and deliberate lie". Other participants had even encountered people who had gone so far as standing up in court lying about them:

"I had a woman charge me once. You know what she reckoned I did to her? I was supposed to have broken all her teeth, and cracked 13 of her ribs and poured petrol over her and two dogs and threatened to set it on fire and all these sorts of things. Did I? Did I? You know, I've never touched her."

People with a mental illness in other studies also reported being taken advantage of. For example, in Browne, Hemsley and St. John's study⁵³ on housing following discharge from hospital reported being "vulnerable to being exploited by unscrupulous people". Participants in González-Torres *et al.*'s study²⁴ on stigma and discrimination mentioned being lied to by family members.

In this study, participants found some health professionals who seemed to feel themselves as superior even more so than the general population in that they believed people with a mental illness to be "subhuman", giving them a right to dominate them:

"They are the superior almighty gorgeous people. You are human rubbish. That's how you are made to feel and treated. 'WE are the bosses and WE, we'. They enjoy feeling superior. There is no doubt about how, because of how they behave towards people [with a mental illness]. 'Oh, we are the superior ones. We are going to be dominating all these human inferior beings'".

Participants regarded this belief of health professionals that they were superior as an abuse of power: "Abuse of the first order". Power confers authority, influence and control over people and the abuse of power applies this authority, influence and control in harmful ways. Participants noted that the abuse of power was so widespread in the health industry that it was found in the whole gamut of professionals starting at the top of the hierarchy down the ranks to those dealing with people who had a mental illness on a daily basis: "The Minister of Health has got the wrong attitude. So has everybody down the line. If the top is wrong, everybody is wrong".

Participants identified some reasons why this abuse of power occurred in the health industry. They speculated that health professionals possibly saw it as the right thing to do because they made no attempt at concealing it: "They do not disguise their hatred and condescension. They don't try to hide that". Furthermore, participants suspected that many health professionals even regarded the abuse of power as beneficial because they were not aware of what they were doing: "Maybe they are not aware".

Health professionals thinking of themselves as superior and regarding people with mental illness as "being the underdog" was also identified in Johansson, Skärsäter and Danielson's Swedish study⁵⁴ on the health-care environment on a locked psychiatric ward. People with a mental illness in Northern Ireland witnessed other patients being treated "like cattle"³¹. In an article on the process of recovery by Spaniol, Wewiorski, Gagne and Anthony⁵⁵, people with a mental illness speculated why health professionals abuse their power: "The power of having power over another person goes to their heads".

Participants in this study described the following tactics used by health professionals to display their superiority and abuse their power. Withholding information, giving conflicting advice or no education was one tactic. Participants said that they were not told important facts, such as what diagnosis they had been given or what type of medication side effect to expect: "As if it was none of my business". They also did not receive education on their mental disorder: "That was frustrating on top". When some education was forthcoming, they were spoken to in jargon-filled phrases: "I think they talk in this pompous way just to confuse you". Participants had the impression that a lack of education occurred so that they were not able to look up information for themselves in order to make up their own minds based on their own research.

Undermining participants' self-worth was another tactic used by health professionals. Participants had been told: "'You are absolutely no good; no good'". Other examples pertained to how participants had been belittled, how they had been told off like naughty children, how they had been threatened with chastisement or withdrawal of services if they failed to comply: "If you don't want to accept the advice of a specialist go somewhere else".

The display of power was then matched with the concomitant behaviour: "People can sink to terrible depths of behaviour". For example, participants' most desperate pleas for help were fobbed off in the coldest way as if they were not worth anything:

"I'd be highly suicidal, and my * [health professional] would say, 'Oh, we'll change you onto this medication, go home'. I'd lie on the floor in her office and said, 'You can't send me home. I'm going to kill myself, I just feel so desperate'. She goes, 'Sorry, I can't talk to you now, I've got another patient coming'."

Participants concluded that health professionals abusing their power were "brutal, bullying, abusive, and totally wrong for such work". Participants insisted that their own suffering was perpetuated by this abuse and that it was therefore not surprising that they were driven to attempt suicide. However, even with regards to suicide, participants said that health

professionals treated them with derision as the following participant related: "A * [health professional] actually said to him [another patient], 'Well, do you want me to get the gun for you, mate, and show you how to pull the trigger?'" Participants therefore questioned the whole purpose of health care, whether it was to help them or to create an environment to keep health professionals in powerful positions: "'Because, after all, our [health professionals'] livelihoods depend on keeping people [with a mental illness] under subjugation'".

In similar research, other people with a mental illness described comparable tactics used by health professionals. In an interpretive phenomenological analysis of hope and first episode psychosis Perry, Taylor and Shaw⁵⁶ mentioned the lack of information given before and during time spent in hospital. Likewise, participants in Agar-Jacomb and Read's New Zealand study⁵⁷ on what people with a mental illness needed when in crisis and in Malins, Oades, Viney and Aspden's study³⁷ on their views of Australian mental health services identified that they were not once told what their diagnosis was or were given information about medications. As participants in this study, other writers with a mental illness described health professionals as "rude and unapproachable"⁴⁹, "military-like, with no compassion or understanding"⁵⁸ and displaying "bossiness ... bullying [and] verbal abuse"³¹. Other study authors²⁶ also identified how people with a mental illness were spoken to was disempowering and concluded that health care was not about treatment but about control: "A health care environment that was overshadowed by control ... [and] attempted to [be] maintain[ed] ... by means of rules, routines, coercion and pressure"⁵⁴.

The second type of unethical action mentioned by participants in this study concerned mental health treatments. Participants gave many examples of how they had been "damaged" by these treatments: "Psychiatry has never, in my experience, and I've seen hundreds of people being treated, done any good whatsoever, only the opposite. It destroys every aspect of a person's life". Participants described how they had been damaged by the treatment with medications and with electro-convulsive therapy (ECT), and during their stay in mental hospitals.

Participants especially singled out the treatment with medications. They explained how they had been damaged by being prescribed medications when they were not warranted or were not the right ones, the latter happening sometimes for decades. Participants recalled that many medications had such severe side effects that they interfered with participants' lives to the point of debilitating them: "So he gives me some tablets and just turned me into a donkey". Being debilitated by medications occurred in all areas of life: physically, leaving participants with gross weight gain, bladder problems, life threatening organ damage and permanent disabilities; mentally, producing extreme tiredness, often adding other signs and symptoms to their mental disorder or making it impossible to think: "Like a lobotomy"; and socially, where they could not fulfil their wish to have sexual relationships due to side effects. Participants described that many medications were so damaging that they prevented them from functioning even on the most basic level: "I was dumbed down with medication that was absolutely useless, damaged my whole physical well-being and my psyche, and wrecked me for years".

The psychiatrists Sebastian and Beer⁵⁹ documented the same damage wrought by mental health medications. Other writers with a mental illness, such as Francell⁶⁰, explained that some of the side effects of medications were so serious that they "become the primary effect of the medication". Participants in this study therefore did not like the heavy emphasis on treatment with medications, which often neglected the use of non-medication focused treatments that they considered as being much less harmful.

Some participants in this study also singled out the administration of ECT as damaging. They recounted that when all possible medications had been tried and found to be unsuccessful they were offered the last resort treatment, ECT, touted as the only hope left to improve their signs and symptoms when they were told: "If you want to get better, you have no other option than ECT". However, instead of improving these, ECT often made life worse: "I reckon it damaged my brain". Participants complained of severe headaches during treatment, inducing balance problems leading to falls, and prolonged and permanent memory loss: "I couldn't remember that we'd got a third child. I couldn't remember that we'd moved house".

Despite these treatments with medications and ECT, participants said that the core problems still had not been addressed because the causative events of their mental disorder, such as having been abused in their childhood and/or adolescence, were still ignored. For example, when participants reported that they could not sleep well due to the haunting memories of their abusive experiences, health professionals thought that this could be treated by merely increasing the sedative medication.

Participants also detailed how they had been damaged whilst being a patient in a mental hospital. Many participants, although living in the community at the time of being interviewed, had been in a mental hospital at some point in their life, some for extended periods. They reported that the physical surroundings of some of these mental hospitals were not conducive to healing but, on the contrary, would induce anguish in anyone: "I've been there, in those things. Like rabbit warrens. The only thing missing from those things is the bars at the windows. They are disgusting places. They are just about the grossest".

According to participants, much of the treatment in these hospitals mirrored the prison-like surroundings: "Psychiatry is the only branch of medicine where punishments are part of the treatment". The impression was given that punishment was meted out just because participants had a mental illness: "Ah, mentally ill, do something to punish that". This something, as experienced by participants themselves and also witnessed by them in other patients, was the administration of an undue amount of medication for the purpose of subduing them and thereby transforming them into helpless individuals:

"They punished her [the patient] with drugs. I've seen her drugged too much. She's been unable to get up off the ground, unable to speak coherently, unable to sign her name, and she gets diarrhoea all the time. She was vomiting. I think it's disgusting. She's been victimised."

Participants reported that this level of damage experienced in mental hospitals disempowered them and other patients like them to such a degree that it left them as near empty shells without the wherewithal to conduct a meaningful life, even when they were discharged: "A stay in a mental hospital deprives people of what they might have got out of life. It ruins any chance of normalcy in what's left of their lives, if and when they get out".

People with a mental illness in other studies also perceived their stay in a mental hospital as being in prison-like surroundings. They used terms such as "being 'banged up' ... [to] convey the sense of imprisonment"⁵⁶. They also had the impression that the treatment they received was meant as punishment: "Those were the ways they used to punish me" as recorded in Hughes, Hayward and Finlay's study⁶¹ on patient's perceptions of the impact of involuntary inpatient care on self, relationships and recovery. Similarly, other people with a mental illness reasoned that treatment was applied in such a coercive manner that patients would "act as the staff wanted"³⁸. An Australian study on nurses diagnosed with a mental

disorder quoted them as describing their stay in hospital as "an overwhelmingly counter-therapeutic experience"⁴⁶.

Up to now, most unethical actions of society mistreating people with a mental illness were legal and completely within the realm of behaviour acceptable to society because participants had been thoroughly devalued and dehumanised and thus disempowered. However, there were actions that were criminal in nature, in addition to the abuse participants had been subjected to as children and/or adolescents.

These criminal actions, according to participants' experience, were not as common as the unethical ones. Nevertheless, participants realised that they were more at risk of becoming victims than people who did not have a mental disorder because they thought they were seen as vulnerable and considered easy targets. Participants were sure that certain members of the population were even attracted to them as they smelled blood as from a wounded animal: "They turn on the traumatised".

Participants recounted that the criminal actions perpetuated on them included theft and physical attacks or threats of such, including threats to rape them. These occurred in everyday life situations such as at workplaces. For other participants physical attacks happened in their marriage when they got violently assaulted by their spouses:

"She threw a reamer at me. She'd come in the shed and carried on and picked up a reamer. It is like a drill bit with four blades. You could shave with it; it is that sharp. She threw it at me when I wasn't looking and it just missed me. Concrete chipped off here."

Participants had even encountered criminal actions being perpetuated in mental hospitals. They reported that despite the constant surveillance they had come across instances of theft and rape: "I know a guy got raped while I was there".

That people with a mental illness were more likely to be victims of crime has also been established in other countries. In the USA, rates of adult physical and/or sexual assault on people with a mental illness have been reported as high as 67%⁶². In Sweden, the numbers were 46% for women, compared to 25% for women in the general population⁶³. In agreement with participants in this study, Marley and Buila⁶⁴ also found in their survey of 234 people with a mental illness sourced from two support organisations in the USA that they were "singled out for victimisation because of a specific characteristic".

In addition, criminal actions occurring in hospital have also been reported elsewhere by other people with a mental illness. For example, Happell²⁷ mentioned in her study from Victoria, Australia, how a patient had been assaulted. Steele⁴⁵, a writer with a mental illness, was gang-raped in a mental hospital. Several patients have even been murdered⁶⁵⁻⁶⁶. In all these instances, the perpetrators were other patients, which indicated that the hospital authorities were unable to protect the victims.

Society let perpetrators get away with their abuse and mistreatment

In the last experience of disempowerment pertaining to the social sphere, participants in this study noted that those people who had abused them, either as children or adolescents, or had mistreated them as adults through unethical or criminal actions, got away with what they had done: "They are getting away with it". This is particularly pronounced with regards to children as the United Nations Children's Fund¹¹ statistical analysis of violence against children revealed. Their report pointed out that children lack legal and ethical protections in most countries and therefore violent acts against them are seen as inconsequential and even

normal, as the consequence conferring impunity on perpetrators. In this study, participants explained that perpetrators were getting away with their abuse and mistreatment because *society does not believe what people with a mental illness say, society devalues and dehumanises them and society is not willing to help them.*

Participants found that *society not believing what people with a mental illness say* provided a foolproof way for perpetrators to get away with almost any awful act they dreamed up: "Many people use this fact to safely perpetuate all sorts of cruelty and injustices knowing their victim will not be believed. The more bizarre the abuse, the easier it is to get away with it". As a result of not being believed because they had a mental disorder, participants in this study felt utterly disempowered because they could not claim any credibility, and therefore the perpetrators were listened to in preference to them: "They have taken his word over mine". Participants said that they were not even believed when they reported grave matters such as ongoing assaults, and their accounts of life threatening situations were given no credence:

"They don't check out [the information]. Is this person [the abuser] she [the participant] is charging really like what she says he is 'cause he's got a house full of guns and he's a dangerous man? He put a gun to my head, radi-radi-ra. They were just like pretty much under the impression that it was all in my head."

As a result of participants not being believed about perpetrators' actions participants could easily be blamed for the very acts that had been perpetuated against them. Being blamed for *having a mental disorder* was now extended into blaming them for what had happened to them: "It is your own fault". The habit of blaming them for the abuse and mistreatment perpetrated by other people led to participants being seen as scapegoats for the awful behaviour of others. The following participant explained how this had played out in her family: "I lived in a very domestically violent abusive relationship and the mental disorder was a big crowbar and a lever for him to be even more so". She said that using the excuse of her mental disorder as a crowbar and lever the abusive family member justified victimising her. He accused her of being irrational instead of admitting that she acted in her own best interests.

Families using their relatives who had a mental disorder as scapegoat also occurred in other studies, for example in a survey of people with a mental illness on their first-hand experiences and perspectives on stigma and discrimination²⁵ and in an examination of life trajectories of female child abuse survivors thriving in adulthood⁶⁷. Humphreys and Thiara²⁸, in their study on domestic violence, noted:

"Part of the repertoire of threats used against women by the abuser is that 'she is crazy'. Her referral to mental health services can act as confirmation of this verbal abuse, supporting his distorted perceptions and deepening her sense of disempowerment and loss of self-esteem."

Participants in this study had noticed that even whole organisations resorted to making people with a mental illness scapegoats when things went wrong:

"The person with a mental illness is the one that can be dumped on [when there are any problems with the organisation]. You can honestly see how the person with a mental illness is the scapegoat for everybody who wants to do something wrong or thinks that they don't have to act with integrity. They can really take advantage and that person becomes the scapegoat for society's crap."

Society devaluing and dehumanising people who have a mental illness is also replayed here, which set the general population, the person in the street as well as its

institutions, up against people with a mental illness: "Society seems to have it against you". Participants realised that due to their devaluation and dehumanisation perpetrators were more highly valued by society than participants would ever be. As a consequence, perpetrators could easily make up excuses for their behaviour, which were readily accepted by society: "They make these weak excuses".

One of these weak excuses was used to paint the abuse and mistreatment of people with a mental illness as being all right. They were seen as ordinary, even normal events: "[The perpetrators] have been doing it for so long, their brutality is regarded as normal". Weak excuses were then used to justify the actions of perpetrators at all levels of society. For example, participants had uncovered that excusing the abuse and mistreatment of perpetrators was instigated right at the top of the political system influencing people in many lower positions: "It is systemic. Parts of the system are rotten and that filters down into what * [others] can get away with, in behaviour and stuff". It was therefore easy to cover-up any mistreatment and was used to prevent the publication of any potential scandals: "They just went into overdrive to try and protect their reputation and distance themselves from this problem [the criminal actions]". In an extreme case, participants suspected, people with a mental illness could even be locked away from the public so that society's actions were kept out of sight: "They are hidden away, like some human refuse while enduring their undeserved captivity".

Lastly, *society not being willing to help* contributed to letting perpetrators get away with it. Participants said that society, in not being willing to help, aided the perpetrators in that nobody demanded that perpetrators behave with any sort of integrity. Participants said that integrity was not upheld because organisations responsible for holding perpetrators to account were tainted with the same values as the perpetrators and had been set up to protect this behaviour: "The world is highly politically set up to foster the perpetrators".

Participants gave examples of two governmental departments that were not willing to help and thereby, in their eyes, let perpetrators get away with it. Participants were convinced that proceedings in the justice department had been stacked up against them due to the court responding to the fears of the general population with regards to people with a mental illness:

"Their [people with a mental illness] trials are always a formality, whose outcomes are decided beforehand, by the press, the public and all concerned with the trial. Their trials are not real trials, since people's irrational fear of the mentally ill prevents them from being able to see, or wanting to know, the truth about the nature of the person and what happened."

Participants explained that, therefore, the outcome of many trials was unfair in that many perpetrators were acquitted and others jailed for only short periods of time not befitting the horrific acts they had committed.

Evidence that crimes were not reported to the judicial system at all appears in Agar and Read's study⁶⁸ on what happens when people disclose their sexual or physical abuse to staff at a community mental health centre. Erdmans and Black⁶⁹ found, when interviewing young women with a history of child sexual abuse, that only very few crimes that were reported were prosecuted.

Participants in this study reasoned that the unfair outcome of trials lay in how judgments were made. They thought that, at the best of times, they were made so arbitrarily that they seem to depend on pure luck: "One man [the judge] making a decision, maybe it is like 50:50 [how the judgement goes]. It's Russian roulette him making that decision". However, participants knew that most of the time the judge's decision was a forgone

conclusion because it usually went in favour of the perpetrator: "He [the judge] would tend to err on the side of caution. As soon as he hears mental health, 'Ohhh, well, we have to give the other party the benefit'". Participants were therefore justifiably worried that malevolent people would take full advantage of these unfair proceedings because of the near certainty of acquittal. Humphreys and Thiara²⁸ also found that in order to discredit a person with a mental illness during, for example, custody cases, contact with mental health services is brought up in court appearances.

The other governmental department that participants pointed to with regards not helping and therefore in *letting perpetrators get away with it* was the mental health system. They implicated the mental health system because it came across to them as standing by and letting criminal acts happen without taking a stand on participants' behalf. They remembered instances where the mental health system had brushed aside the existence of the terrible assaults on participants without helping: "He bashed me up through the whole house and the bed went flying across the room, and I had another snapped head and black eyes. The mental health system ignored all those things". Participants went further in accusing the mental health system of becoming complicit in the crimes committed against them because health professionals knew of the abuse and let it happen:

"They [health professionals] actually allowed him [the perpetrator] to [continue with the assault]. They are culpable for going along with it. They are perpetrators as well because they go along with these people. I've seen it, I've seen them; they still do it."

Rice⁷⁰ concluded, in her study on why health professionals in the USA did not take any action in response to the abuse and mistreatment reported by mental health patients, that health professionals came to accept this violence. She reckoned that this amounted to the patients being "forsaken". Participants in Joyce *et al.*'s Australian study⁴⁶ on the experiences of nurses who had a mental illness explained bluntly the reason for health professionals letting perpetrators get away with their abuse and mistreatment: "If someone's being kicked, everybody joins in, that's the way the culture [in the health service] is".

Due to the perpetrators not being brought to task by the legal system, and participants in this study seeing the mental health system as standing by and not being responsive when criminal acts were committed, participants knew that they had nowhere else to go: "I had no redress". In fact, they feared that their situation might get even worse if they complained: "The poor victim knows what's going on but if he tells anyone, he will end up in a far worse situation, locked up for years in a mental hospital".

This concludes the first chapter. As the context of the study consisting of *the experience of disempowerment* has been set, the next chapter explaining its impact on participants can be proceeded with.

Chapter 2: What needs to be solved

This second chapter explores the impact of *the experience of disempowerment* on participants. This impact turned their life into a struggle. In the last chapter participants, who were people diagnosed with severe depression, bipolar disorder or schizophrenia, described how they were disempowered in both their personal and social sphere. In their personal sphere they were disempowered by having no control over their mental faculties in *having a mental disorder*; by the severe physical, sexual and emotional abuse they had been subjected to as detailed in *having been abused in childhood and/or adolescence*; and by the disempowering force of *wanting to be dead*. They emphasised, however, that the disempowerment in their personal sphere was minor in comparison to that occurring in their social sphere. Here participants reported how they were devastatingly disempowered by *society not believing what they said* even if it had nothing to do with signs and symptoms, and by *society devaluing and dehumanising them* which resulted in seeing people with a mental illness as inconsequential and irrelevant. This attitude then provided justification for *society not willing to help them* and for *mistreating them*. It culminated in *letting the perpetrators get away with their abuse and mistreatment*. One participant explained how the impact of *the experience of disempowerment* had been imposed on her, followed her around and haunted her all her life: "You never escape from it. It has been like a shadow permanently, just a permanent shadow".

Many participants spoke of their *life is a struggle* explicitly as a problem: "The focus is on the world being really difficult and that life is a struggle". Other participants concurred, for example in the simple statement of "I struggle" or in a more expansive form: "It is a daily struggle" and: "I am struggling with everything in this life". Those participants not directly articulating that their *life is a struggle* provided many examples that typified the similarities of the experience for them.

This chapter covers what needs to be solved, namely *life is a struggle*. It explains why and how participants struggled. As will be shown, the unremitting struggle left participants without power to take charge of their personal and social life. Aspects of this struggle did not occur in isolation but were cumulative, piling up one upon another.

Aspects of *life is a struggle* was grouped into three areas: the struggle within oneself, the struggle with relationships, and the struggle with trying to survive through daily life. The pivotal aspect of *life is a struggle* occurred in the struggle within oneself and was called the struggle to identify any intrinsic value in oneself as a person. Participants here laid their powerlessness bare when they described themselves as being worthless, inadequate, without self-esteem and as their life having no meaning. The struggle within oneself also contained the aspect of the struggle with having a mental disorder where participants explained that they were powerless to overcome it; and the aspect of the struggle with staying alive during which participants fought against the disempowering force of *wanting to be dead*.

The second area in *life is a struggle* concerned the struggle with relationships. Participants explained how the aspect of the struggle with responding to the impact of having been abused had left them powerless because they had not been able to develop a sense of personhood, and had no positive hopes and aspirations for the future. In the aspect of the struggle with establishing credibility they found themselves powerless due to the overwhelming impact of *society not believing what people with a mental illness said*, how *society devalued and dehumanised them* and how *society mistreated them*. In the aspect of the struggle with having been let down by the mental health system participants recounted how

they were left powerless to deal with the health system because they had no influence in the way the system was organised, in the way they were clinically treated and in the way many health professionals behaved. Participants were also left powerless in the aspect of the struggle with maintaining normal relationships with individuals as they seemed unable to pursue them.

Finally, the hitherto existential struggle culminated in the struggle with trying to survive through daily life. In this aspect participants struggled with being left powerless to handle the mundane, such as studying, working and stress. Some recounted that they had felt at times so overwhelmed by the struggle with trying to survive through daily life that they had become incapacitated.

Chapters 3 and 4 will present participants' real-life solutions of how to resolve *life is a struggle* by gaining power on a personal basis and how society can empower them to counteract *the experience of disempowerment* from chapter 1.

Overview of this chapter:

The struggle within oneself includes:

The struggle to identify any intrinsic value in oneself as a person

The struggle with having a mental disorder

The struggle with staying alive

The struggle with relationships consists of:

The struggle with responding to the impact of having been abused

The struggle with establishing credibility

The struggle with having been let down by the mental health system

The struggle with maintaining normal relationships with individuals

The struggle with trying to survive through daily life

The struggle within oneself

The first area of *life is a struggle* pertained only to what participants experienced within themselves and excluded anything referring to relationships with other people. It explored the following three aspects: the struggle to identify any intrinsic value in oneself as a person; the struggle with having a mental disorder; and the struggle with staying alive.

The struggle to identify any intrinsic value in oneself as a person

This aspect was pivotal to *life is a struggle*. Participants asked themselves whether they had any intrinsic value, or worth, as a person. They identified the reasons why they thought they had no value. One was the loss of the ability to control their mental faculties, as explored in *having a mental disorder* in chapter 1: "When I first had that breakdown, I described that like being kicked in the guts, like just being kicked in the stomach. I am just knocked down". Being knocked down by the occurrence of the mental disorder had such a dramatic impact on participants' sense of value that they felt crushed by it: "It knocks you flat". They compared it

to having the lifeblood drawn out of them when they had no pleasure, enthusiasm or passion left for living: "I lost my zest for life".

A second reason for *the struggle to identify any intrinsic value in oneself as a person* was induced by *having been abused in childhood and/or adolescence*, also from chapter 1. Participants described this impact as having every part of their self-worth eliminated:

"When you're told that you are nothing, you are a piece of garbage etc., etc. over that many years; you believe it, especially when you are only this high, and I believed all of that, you see. I never thought I was worthy of anything."

The third reason for bringing on *the struggle to identify any intrinsic value in oneself as a person* was *society devaluing and dehumanising participants*, in particular being viewed as non-persons and sub-human: "I just felt like a useless piece of dirt". Participants regarded themselves as only fit to be discarded: "I felt like I was a blotch on society that had to be removed. It was very awful".

The struggle to identify any intrinsic value in oneself as a person left participants without any power: "I felt like this totally pointless, purposeless individual". They said their self-worth was zero, they had no self-esteem; they believed that everything they stood for was wrong and that they were completely inadequate:

"I felt like everyone had value. Everyone else's opinions mattered. Everyone else's lives mattered but not mine. It was difficult to think that anything I said would be true or right. Everything I thought, every one of my thoughts I felt was faulty. My feelings felt like they were invalid. They weren't to be listened to."

As a result they regarded themselves as worthless: "Like rubbish. In reality that's where I was at". Even those participants who had been capable and self-assured people at one time had lost their self-reliance and doubted their judgement, ability and authority. They said that they experienced a profound loss of self-confidence with feelings of insecurity and a premonition that things were slipping from their grasp.

As part of *the struggle to identify any intrinsic value in oneself as a person*, participants struggled with finding meaning in life: "There is absolutely nothing in life. I don't feel I've got a life". In order to discover any meaning, they asked themselves the question why it had been them who had been struck down by a mental disorder and why their life had been so completely annihilated by it. Some fell back on religion to find an answer: "I've suffered from * [mental disorder] for over 40 years, if not a lifetime. So, I say to Him, 'Look, why me? Why are you doing this to me? What was the purpose of it?'". Another way of finding an answer was to add up the positives and negatives in their lives in the hope of the positives outweighing the negatives. However, the negatives always outnumbered the positives, and thoughts about life not being worth living surfaced. Participants concluded that life was best wound up and terminated like a business with a negative balance sheet:

"I can remember weighing it up like a business, thinking if you had a business and it was going to go bankrupt, you wouldn't keep putting energy into it. You wouldn't keep putting money in it. There is no point in it and I had to get to look to my life like that."

Other people with a mental illness similarly *struggled to identify any intrinsic value in themselves as a person*. They described themselves as a "no-thing in a no-world and you are not"¹ or as having "no value"². Damone³, a writer with a mental illness, recalled being told: "You're nothing, you're no one and you have no opinion". Other studies linked the *struggle to identify any intrinsic value in themselves as a person* to the same experiences of

disempowerment as in this study. For example, a participant in Browne *et al.*'s study⁴ on the perspective of people with a mental illness on recovery mentioned: "Having a mental illness knocks your confidence about and you end up having a low opinion of yourself". Participants in a study⁵ on childhood abuse in Swedish female users of psychiatric services linked the low value they had of themselves to having been abused. An introduction to ideas about recovery for people with mental health problems by Perkins⁶ also asked "'Why me?'" and participants in a grounded theory study on 38 men in England wondered "'What am I doing in the world?'"⁷. Likewise, other people saw suicide as an answer to the worthlessness of themselves and their life, as documented in Aldridge's⁸ and Joiner's⁹ theories on suicide.

The struggle with having a mental disorder

Participants linked this second aspect of the struggle within oneself directly to *having a mental disorder* as in: "When I was not so good [had symptoms] I'd be struggling" and "The struggle with mental health". They said that they were struggling due to *having a mental disorder*, meaning that they were powerless to control their mental faculties, because these were terrible disorders to have: "It is one of the cruellest sicknesses that you can get". They explained that this struggle was so hard that they called it a battle: "Battling with my * [mental disorder]". They mentioned it was so hard because they thought that, by chance, they could overcome it but they felt powerless to prevail over its impact. Despair at having been affected followed: "When you are * [sick] they may as well shoot you".

Supporting these sentiments, other people with a mental illness also described their *struggle with having a mental disorder*, as expressed directly in the process of recovery from schizophrenia by Spaniol *et al.*¹⁰: "Struggling with mental illness". Rowe¹¹, a writer with a mental illness, also called it a "battle". Some referred to their mental disorder a "hell of the condition"¹² and to getting it as "a catastrophic and life-changing experience"¹. As participants in this study, they felt powerless to prevail over its impact, as reported in a study on views of people with a mental illness of Australian mental health services¹³.

Participants in this study said that they were powerless to overcome *having a mental disorder* for two reasons: They were left helpless and they could not make sense of what was happening.

Participants felt that they were left helpless because their life had been taken over by the mental disorder to the extent that they had lost control over most of lifes' facets: "The mental disorder just takes over and you feel that you have lost control of your life". They likened their loss of control to the loss of control over getting cancer: "You can think as positive as you like but if it is going to get you, it is going to get you". Likewise, they compared the way their disorder advanced with the course many cancers took because they felt that the mental disorder was inexorably eating away at them inside. They were therefore left helpless with regards to influencing how their disorder progressed:

"When the process [episode] starts, whatever path it takes is completely independent of me. Whether it's just going to be a little stumbling in my path or whatever, or whether it's going to be a complete fall is not up to me. It is not up to my doctors and it is not up to any decision that we make. It's either going to happen or it's not."

Participants said that it was also not under their control to get better and they were unable to get a hold over their symptoms. As a result of their powerlessness they found that they had been unable to act any differently when ill: "I can honestly say that there is nothing I would have been able to do differently".

Feeling helpless was further exacerbated by not being able to make sense of what was happening: "I got into quite a state with everything just going kaput and it was like I didn't know what was happening". Participants said they could not make sense of what was happening when their disorder first appeared, as to why symptoms occurred, what caused those symptoms and what treatment was about. Not being able to make sense of what was happening was also frequently mentioned by other people with a mental illness, such as in a study¹⁴ on the perspectives of young people with a mental illness, in a study¹⁵ on people with a first episode of psychosis and by 'Joe'¹⁶, a writer with a mental illness.

As a result of being left helpless and not being able to make sense of what was happening participants in this study were frightened: "It was the most frightening time of my whole life, and I'd been through a few things". Other people with a mental illness also recalled how they had been frightened by the appearance of their signs and symptoms, for example in a study by Connor and Wilson¹² on mental health experiences in Northern Ireland.

Participants in this study were also intensely worried. Those participants who had children were first and foremost worried about their children also getting a mental disorder due to a possible genetic influence resulting in them having to go through the same struggle: "It's pretty strong in the bloodline, which makes me worried about my children". They were also worried for themselves with regards to their disorder getting worse and about it progressing to other even more serious conditions. This worry about their own future was at times so intense that they thought it was not worth living any more: "I thought as I got older I'm going to be worse and worse and worse. I used to always be praying that, 'Good God, let me go home in my sleep' to cancel out [end my life]".

The struggle with staying alive

This third aspect of *life is a struggle* was brought on by *wanting to be dead* from chapter 1: "It was a real struggle to stay alive". It appeared at every turn and added a terrible burden to everything else. Participants said that staying alive was a struggle because it was a hard fight against the disempowering force of *wanting to be dead*. Although participants felt the strength of this force, they were terrified of the prospect of having to bring about their own death and just the thought of suicide was "too much to bear". The struggle with these contrasting forces between *wanting to be dead* and staying alive tore participants apart and left them powerless to choose between them: "You feel in between a rock and a hard place. Your brain is saying, 'It is all too hard. Why don't you just end it?' And the other part of your brain is saying, 'But, no, you can't'".

A struggle "against a desire to give in to suicide" was also mentioned in a review of studies on suicide¹⁹. Other theories relayed how people who were suicidal described a sense of powerlessness⁸ and confirmed how difficult it was for suicide to be carried out⁹.

The struggle with staying alive in this study occurred along a continuum. At one end there was certainty about wanting to commit suicide and at the other end uncertainty about whether it was the right thing to do. Over a period of time that was sometimes as short as a few hours, participants were swinging from one end of this continuum to the other: "You think, 'Yeah, I want to finish it all', and later on you think, 'Gee, to even think that way was really stupid'. The next time you think, 'Oh, I want to end it again'". Five points along this continuum were visited by various participants.

The first point was at the certainty end of the continuum. Here participants were certain that suicide was the right thing to do: "It was the right thing to do, the only thing to

do". They were "desperate" to end it all and could not see any merit in wanting to survive: "I had NO hope, or even consideration, of surviving. I just really, really wanted to kill myself". To help them with the struggle in reaching this heart-wrenching decision they thought of "logical" reasons for wanting to go through with it: "That was the only way I could handle trying to get rid of myself". Participants explained this logic as follows: Suicide was the right thing to do because it was not only beneficial to themselves but also to other people. They argued that other people would be able to lead a happier and more productive life if participants were not around anymore as they were only a burden to them:

"I actually have these thoughts that are going, 'You know, what? If I wasn't here, I wouldn't be so much of a drain. I wouldn't have my brother worrying about me. I wouldn't have my mother worrying about me. My partner would be free to go and actually find somebody who is sane and who is together. My friends would be ok with it and they'd be happy not having to worry about me. I would no longer be on the dole and therefore I would be less of a strain on the economy'. It all makes sense, it does."

People contemplating suicide in other studies also thought along the same lines. For example, interviews with 30 child abuse survivors revealed that they thought suicide was the right thing to do because it was not only beneficial to themselves but also to other people¹⁸. Joiner⁹ found that people thought of themselves a burden to others and therefore wanted to be dead.

Those participants in this study who adhered to this line of thinking were determined to go through with suicide: "There was no going back". To make sure they achieved their aim they made detailed plans with safeguards in place so that they would not be caught out:

"I was determined not to let this time have it go wrong. I booked myself into a hotel and said, 'I've been travelling all night and I don't want to be disturbed'. Having gone round to all the doctors the day before I had a lot of tablets and I just took them all."

When participants were then saved by circumstances beyond their control they were very angry. They were either angry with themselves because they had messed up their plans inadvertently: "I was so angry, 'Urgh, urgh [growling noise], I can't even do this properly'" or with the other people who had interceded:

"I was really angry at everybody. I was angry at * [family member] first, for finding me. I was really angry at the doctors for keeping me alive. They had to put me on life support, and it was sort of quite bad."

The second point along the continuum was characterised by an emotional kind of thinking about suicide: "The emotional kind where you are really sad or you are really sort of angry and, 'That's it. I am going to kill myself. It's all sort of in the heat of the moment". Those participants who were at this point said that here it was easier for some doubt to creep in about the merit of carrying out suicide than with the calculated logic employed at the first point. They were therefore prepared to call someone who was in a position to "talk me down" before proceeding.

Those participants who were at the third point along the continuum between certainty and uncertainty were ambivalent. They saw the two ends of certainty and uncertainty as being equally valid and regarded suicide as merely a credible "alternative" to the "miserable" life they were leading. They were hesitant about wanting to die and were weighing up the pros and cons of staying alive: "I didn't particularly want to die. It was a horrible thought of having to do something". Yet even here, being dead was preferable to staying alive, as "the thought of living was more painful than the thought of dying". This was reflected in how

participants planned their suicide. They started with half-hearted attempts of self-harming before becoming more serious about contemplating going all the way:

"It just started off as not as intention to kill myself but as it progressed I'd be really aggressive about it and say, 'If I die I don't really care'. Trying not to set out to kill myself but if it happens it is a bonus."

At the fourth point along the continuum between certainty and uncertainty more doubt over the merit of committing suicide became apparent. Those participants who were at this point had doubts about whether the available methods were reliable and whether they would survive the attempt: "What if you didn't actually kill yourself? What if you just got back in hospital and you were still alive?" Despite these doubts participants went ahead with implementing their suicide plans.

However, the greatest amount of doubt appeared at the fifth, or last, point along the continuum, identified as uncertainty. Here participants considered that they might make a mistake in committing suicide because they could glimpse the possibility of a somewhat happier life in the future:

"What if you were making a mistake and something was going to change down the track? Or what if you were going to miss out on something later in your life that you would have really enjoyed and you wouldn't have the chance? 'Cause I knew it was very final, and I had it in my mind, 'It's final, it's final'. So, I had to make sure. There was always that little tiny 'What if, what if' right at the end of it all the time that was holding me back. That was the only thing that was holding me back."

Those participants at this fifth point therefore engaged in a prolonged time of contemplating the merits of proceeding: "I am going over things in my mind and thinking, 'Oh, well, maybe I should. What would happen if?'" This was also the point at which they were least likely to contemplate going through with their suicidal wish. That people who were suicidal were at times ambivalent and carefully weighed up the reasons against dying was also emphasised by Joiner² in his theory on suicide.

The struggle with relationships

The second area where *life is a struggle* pertained to participants' relationship with other people. Many interviews dealt extensively with the struggle with relationships: "I struggle now with the social aspect of it all". Participants regarded the struggle with relationships as highly significant because they desired nothing more than to be friends with others. This was also the case in interviews with 71 people with a mental illness in the United Kingdom, which found that "the dominant theme ... was the role and value of relationships with other people"¹⁹. Participants in this study classed having good relationships with other people as a struggle because members of society largely refused to reciprocate their great desire to be friends:

"I spent my life [wanting good relationships], and it was a struggle, a daily struggle [to get them]. You want to talk to people, you want to make friendships, you want relationships, but you can't because people shy away from you."

Therefore, the most significant part of participants' lives, good relationships with other people, had turned into the worst: "I find the worst thing is relationships for me". The struggle with relationships added to the already difficult struggle within themselves and made participants' lives even harder. Four aspects of the struggle with relationships were identified: The struggle with responding to the impact of having been abused, the struggle with

establishing credibility, the struggle with having been let down by the mental health system, and the struggle with maintaining normal relationships with individuals.

The struggle with responding to the impact of having been abused

This aspect was concerned directly with the relationship to participants' abusers. Those participants who had been abused as children and/or adolescents related that *the struggle with responding to the impact of having been abused* came about because that impact had been enormous: "This abuse had a huge impact on my life". They said that the memories of these "traumatic" events were extraordinarily painful: "Like being in hell". They were also so enduring that it affected participants for the rest of their lives.

Participants explained that having been abused had turned their life into a struggle because their right to grow up in a safe and secure environment was absent and the foundation on which to build a satisfying and enjoyable life had been destroyed. In addition, participants found that their trusting, loving, carefree nature as children had been eviscerated: "Like everybody else is 14 and confident and going to cricket and you are all sort of lost and mixed up and it is all too much". Likewise, their hopes and aspirations for a bright future had been shattered, as the following participant expressed ironically: "I distinctly remember thinking, 'Well, I'm going to grow up and be the world's best prostitute'". Participants reported that the impact was so disempowering that their sense of person-hood had been torn apart: "When you get abused it does something to your psyche or something; it just does something to you".

Other people who had been abused, whether they had developed a mental disorder or not, also felt that they had been robbed of their innocence and childhood, such as 27 young mothers with a history of childhood sexual abuse²⁰. Herman²¹, in her theory on trauma and recovery, also reported that people who had been abused had no plans for the future. Participants in Perry *et al.*'s study¹⁵ with people after their first episode of mental illness described that their "personality" had been "shattered" by the abuse. A United Nations Children's Fund²² statistical analysis of violence against children also backed up this study by citing research that showed that any type of violence against children has lifelong and severe detrimental physical, psychological and social consequences.

Participants in this study recounted that the impact of the abuse on them had been both physical, as in permanent physical damage, and emotional. They said that they struggled particularly with the emotional impact: "So that's why it's been a struggle, I've had all these emotions sitting there over the years". They explained that these emotions made them feel powerless because their abusers held them emotionally captive. This came in the form of threats of further atrocious acts if they did not submit: "They [the abusers] are so powerful all the time over you. You will always be captured by them because if you start breaking away they put it on you". One participant compared this way of being emotionally captured with Stockholm Syndrome, a term coined in connection with adult hostage taking. In these situations hostage-takers intimidated hostages to such a degree that they were prepared to do anything to avoid further abuse and showed signs of loyalty and obedience that was controlled with being emotionally captured. Participants in this study described how their loyalty and idolatry of their abusers continued despite not wanting it to: "Even to this day, when I think of him, I still can't get this idolising thing out of my head".

As a result of *the struggle with responding to the impact of having been abused* participants explained that they were living in fear. They recalled that this had overshadowed any possible joyful experiences they might have had as children and/or adolescents: "I've

observed children. Now children who are free can express their feelings. They scream with joy; they yell in the park. I never got to do that as a child. I always lived in fear". As this fear remained in adulthood it added a second layer to the fear experienced in *their struggle with having a mental disorder*.

Furthermore, participants were blaming themselves for having been abused. The feeling that they had to blame themselves was so complete and internalised that participants utterly believed that it was their fault that they had been abused: "How many years did I put it on myself that I was the one who was the problem. I did. It was constant. It was me. I was at fault. It was me who was the cause of it all". They were aware that they blamed themselves because they had fully adopted the degrading values the abusers had inculcated in them. Those participants who put it into a spiritual context reasoned that they had adopted these values because the abusers' sinfulness had infiltrated their mind: "Their evilness or their bad spirit comes into you and goes into your mind".

Participants were also blaming themselves for having been abused because they did not want to shatter the revered image they had built up of their abusers. They told how they had put their close family member who had abused them on a pedestal to be worshipped, and instead of shattering this revered image by blaming the abuser they blamed themselves:

"Rather than recognising that it is the * [close family member] who is doing the abuse it is better for the child to be blaming themselves or thinking they are the ones [at fault]. Because to realise that the * [close family member] is the one who is at fault is so devastating."

As a result of blaming themselves some participants felt so ashamed that they did not tell anyone of the abuse. This left them feeling desolate as they could not see a different future free from abuse: "It was just like a nightmare". Consequently, some participants entered into a series of self-injurious activities: "I just grabbed a razor and slit my wrists. I did it for years". Others went further and actually tried to carry out suicide as *the struggle with responding to the impact of having been abused* was too much to bear.

People in other studies who had been abused went through similar struggles as participants in this study. They felt "trapped and caged by the abusers' strategies of control"²³, lived in constant fear²⁴ and blamed themselves: "I've been raped, beaten and humiliated since I was a little boy ... This doesn't happen to everyone - it's got to be something wrong with me"²⁵. Moreover, Van der Kolk, Roth, Pelcovitz, Sunday and Spinazzola²⁶, in their study on an empirical foundation of complex adaptation to trauma, found that 36% of people who had been abused in childhood idolised their perpetrator. The risk of suicide also went up in a variety of publications^{5, 8,9,18,27-30}.

The struggle with establishing credibility

In the second aspect of the struggle with relationships participants found themselves powerless in the face of the overwhelming impact of *society not believing what people with a mental illness say, how society devalues and dehumanises them and how society mistreats them*, all from chapter 1. Participants struggled with responding to this impact with valiant attempts to establish their credibility as trustworthy and honest citizens: "First you've got to prove that you are not a crackpot". Participants knew this was hard because even illicit drug users' standing in society was higher than their own: "It was almost better to be assumed that it was marijuana or this and that [illicit drug] when people think you are not all here today [display signs of a mental disorder]". Participants felt ashamed at being regarded as dishonourable and improper and explained that this had taken a terrible toll on them.

Participants responded to *the struggle with establishing credibility* in three ways: They tried to reason with other people, used supporting evidence and tried to defend themselves. Firstly, they tried to reason with other people to convince them that they were worthy of being believed and that what they were saying was true. For example, they put forward what they thought were rational arguments to try and explain that their mental disorder was not different from a physical disease: "It is not a visible ailment but it is still an ailment. Just because you can't see diabetes, you can't see internal bleeding, it's still there". Participants knew that physical diseases were acceptable to society as it was scientifically proven that they existed. Although scientific proof was lacking with mental disorders they hoped that using this analogy would also legitimate their condition.

Secondly, participants used supporting evidence that would prove that what they were saying was true to establish their credibility. For example, during the interviews conducted for this study they showed me samples of their work, provided documents such as character references and letters, and even x-rays to back up their statements: "Just to show you that it's not all hokum-pokum". To the police they provided witnesses to back up the credibility of their statements about what had happened to them to counter the view that they had invented certain events: "My sister was a witness to that, and my cousin".

Thirdly, participants tried to defend themselves in *the struggle with establishing credibility*. In particular, they tried to defend their reputation against what they regarded as false and demeaning accusations. The following false and demeaning accusations were particularly grating and participants felt insulted by them. One was being blamed for *having a mental disorder*: "People don't chose to be like that". Another one referred to other people's belief that participants were not trying hard enough to overcome their mental disorder. Here participants asserted that episodes of illness did not disappear just because they wanted them to and that it was impossible to get better by willpower alone. They also stressed that their mental disorder could not improve by merely changing the negative thoughts to positive ones as advocated by society because negative thoughts were not at the root of the disorder: "To change your thinking doesn't change the way you feel". However, despite knowing that willpower alone was not effective in overcoming the mental disorder, participants emphasised that they were not malingerers who did not want to help themselves: "Because, quite honestly, I [am not able to] try any harder [to get better]". Participants emphatically stated, in defending themselves, that they were the ones, more than anyone else, who looked desperately for a cure and would take advantage of any treatment that showed the slightest prospect of helping them.

The last false and demeaning accusation, however, was the most offensive for participants. It pertained to the accusation that they were dangerous people and should be locked up: "That's how it is a struggle every day". Corrigan *et al.*³¹ concluded in attitude questionnaires of 213 people from the public and in drawing from other research over four decades that the belief that people with a mental illness are dangerous was "perhaps the most pernicious of the stigmatising attitudes about mental illness". Participants in this study were especially offended by the portrayal in the media of people with a mental illness as violent killers because it affected their reputation directly: "It's [television] shows like that that give people like me [a bad reputation]. It might sell the movies but it doesn't do anything good for the * [person with a mental illness]". Participants tried to defend their reputation by pointing out the truth that many people with a mental illness were generally "passive" and that they would rather harm themselves than anyone else:

"The reality is a lot of people who struggle with mental health wouldn't normally deliberately want to inflict any harm on anyone. At the end of the day they would

harm themselves but they wouldn't go and hurt no one. And a lot of people don't, normal people don't think like that. They think it is the other way around."

These three false and demeaning accusations affronted participants' self-worth and increased their *struggle to identify any intrinsic value in oneself as a person*.

Participants also tried to defend themselves by standing up against the injustice of mistreatment. They thought that by standing up for themselves their credibility would be increased. For example, they tried to defend their right to decide what was best for them and what their needs were in response to the unethical actions detailed in *society mistreats people who have a mental illness*. Participants were particularly aghast at the injustice of getting blamed for the mistreatment by others when they had been innocent: "It is not their [people with a mental illness] fault. It is the society's fault". Furthermore, participants insisted that members of society had to take the responsibility for treating them in a shocking way: "Is it my responsibility to change the way I do things? What about the bloody abuser? Excuse me, why should I change? Isn't it the perpetrator who should be changing? Excuse me!" Participants asked themselves who was really crazy here, people who had a mental illness and did not want to harm anyone, or those people who mistreated them and in so doing violated ethical standards and criminal laws and got away with it:

"This is why it is such a crazy world we are living in. We are called the crazies. There are more crazies that walk past * [the mental hospital] than there are in there now. I tell you. Because it is the crazies out there who put us in * [the mental hospital] and they don't lock them up. They lock the ones who are driven crazy by the crazy world; they lock them up. They lock us up."

Despite participants' best efforts at trying to reason with other people, at producing supporting evidence and at trying to defend themselves, *the experience of disempowerment* related to participants' social sphere was so great that no matter what arguments, evidence and defences participants put forward they realised they were powerless to make any difference. This powerlessness increased the feeling of being left helpless in *the struggle with having a mental disorder* and further deepened *the struggle with responding to the impact of having been abused*: "All the parasites [perpetrators] were trying to use you and they wouldn't take 'no' for an answer. They just kept at you until you go down". Participants pointed out the stark reality that society was winning: "It is like the survival of the fittest", and that people with a mental illness had lost out in their efforts at leading a decent life in peace. Many participants had therefore come to the conclusion that their lot in life would always be unjust and that they would always be seen as disempowered "second-class citizens".

As a result of losing *the struggle with establishing credibility* participants had become afraid of being further exposed to the mistreatment by others. This was the third layer of fear, in addition to the previous two layers of being frightened in *the struggle with having a mental disorder* and living in fear in *the struggle with responding to the impact of having been abused*. They also realised that they had become totally isolated: "The sheer isolation of it and the ostracism".

People with a mental illness taking part in Read and Baker's³² survey of the stigma, taboos and discrimination experienced by people with mental health problems also spoke of their loneliness and isolation because they were "shunned" by society. Participants in this study knew that the isolation and ostracism imposed by society had caused them a lot of suffering, permanently affecting their mind, referred to by them as "brain bruising". This

suffering and brain bruising often culminated in suicidal acts: "See, that's why a lot of people with mental illness end up killing themselves. Because of the way they've been treated".

The struggle with having been let down by the mental health system

The third aspect of the struggle with relationships deals with the impact of the mental health system. Participants' powerlessness was further deepened by being let down by it. They said they were struggling with having been "let down" because they had difficulties with coming to terms with their deep disappointment over what they thought was the most important source of help for them. Participants in Connor and Wilson's¹² grounded theory study in Northern Ireland also expressed the same sentiments: "I am sure most people have felt let down [by the mental health system], I know I have". Participants in this study found that they had been "written off" by the way the system was organised, by the way they were clinically treated and by the way many health professionals abused their power, all detailed in chapter 1.

Participants recounted how *the struggle with having been let down by the mental health system* had come about. Initially they had put all their faith in the ability of health professionals: "I put all my faith and my life in their hands". They had put them "on a pedestal" and they had truly believed whatever they said: "I remember sitting there, just totally believing him". Participants recalled that their faith in health professionals was due to declarations that they were the profession with all the solutions. However, participants described that they slowly came to realise that what many of these health professionals said was not what they practised and that they were, in fact, just pretending to want to help: "[Health professionals] are such hypocrites". Participants felt let down by this hypocrisy and started to mistrust what they said. Participants knew of other people with a mental illness who had also lost trust in the mental health system and were now able to understand where those people were coming from: "They have an inherent distrust for the system and I can, NOW, actually understand that distrust". People with a mental illness in other studies also related how they had lost trust in health professionals in a study on determining the effectiveness of mental health services³². Vassilev and Pilgrim's treatise³³ that they called risk, trust and the myth of mental health services explained that "'trust' and its betrayal" had arisen from "routine care and its corruption".

As a result of *the struggle with having been let down by the mental health system* participants in this study were angry. The depth of this anger was reflected in the strong expressions used: "There's things that happen in the mental health system that really piss me off". Participants were angry at how the mental health system was organised, at the way clinical practices were conducted, and at the attitude and behaviour of health professionals: "I just got so mad with the * [health professionals]". Despite this anger many participants realised how powerless they were to exert any influence to change the mental health system for the better and that, in fact, they had been made helpless. Their feeling of being made helpless increased their feeling of being left helpless as part of *their struggle with having a mental disorder*. It also further undermined *their struggle to identify any intrinsic value in oneself as a person*.

As a consequence of being made helpless by the mental health system participants felt trapped. They felt trapped because they had nowhere else to go to get help. They also felt trapped because there were no alternatives to the use of damaging medications or the use of electro-convulsive treatment in some instances and because they could not see any way to escape the abuse of power by health professionals. They found themselves in a no-win

situation. This feeling of being trapped increased being emotionally captured by their abusers in those participants subjected to *the struggle with responding to the impact of having been abused*.

A second consequence of being made helpless by the mental health system brought on a terrible fear. This added a fourth layer of fear, in addition to being frightened as part of *the struggle with having a mental disorder*, living in fear in *the struggle with responding to the impact of having been abused* and the fear experienced in *the struggle with establishing credibility*. This fourth layer of fear appeared when merely thinking of finding themselves helpless, for example, by an admission into a mental hospital or by treatment failing. Both these instances would also increase being left helpless in *the struggle with having a mental disorder*. A further consequence of having been made helpless was losing hope of ever escaping from the mental health system, especially from the clutches of the locked wards: "Horrid. They do people for unlimited years".

In response to having been let down, participants regarded themselves as deserted by the system: "It felt like abandonment". This feeling of abandonment added to the isolation and ostracism already occurring in *the struggle with establishing credibility*. Participants also felt increasingly mentally wounded: "It is a very wounding experience". They said that instead of finding hope and a healing experience, the mental health system had had the opposite effect. They, therefore, held it responsible for being a major contributor to both their pain, which was already severe as a result of *the struggle with responding to the impact of having been abused*, and to their suffering, imparted under *the struggle with establishing credibility*. For these reason, participants turned to well-established behavioural patterns because they could see no way of ever getting better: "I just thought, 'I'm just going to live in hell for the rest of my life. I'll be better off dead'". This was the second reason identified by participants why their life was like living in hell.

People with a mental illness in other studies mentioned similar consequences to those expressed here in *the struggle of having been let down by the mental health system*. Anger was expressed in a report on research evidence and implications for practice on the process of recovery from severe mental illnesses¹⁰. Powerless was spoken of in an article on Australian mental health services¹³ and the feeling of being trapped revealed in an interpretive phenomenological analysis of hope and first episode psychosis¹⁵. Fear^{12,35,36} and a feeling of having been abandoned⁵ were also common in the literature.

The struggle with maintaining normal relationships with individuals

This fourth and last aspect of the struggle with relationships was the hardest to bear for participants in this study. They had already been hit hard by the many ways *the disempowering experiences* had impacted them so far, but they were "devastated" by the fact that *society was not willing to help them*, particularly the lack of support they received from their family members: "That is all I ever wanted". By not being supported they felt "neglected, abandoned and ignored" and so hurt that they thought that there was no reason for going on with life without this support: "If she's [family member] not going to be there, it's just no point. I can't survive without her". Again they sought to commit suicide: "I tried to commit suicide, not once but three times".

As a result of not being supported, participants in this study *struggled with maintaining normal relationships with individuals*, where normal relationships were characterised as those found in most families and between friends. In this struggle, participants tried to identify who was responsible for normal relationships breaking up. They

weighed up the reasons for and against their own culpability. They knew that they were obviously not at fault in some instances, for example, when their parents had abandoned them as children. However, doubts about their own responsibility surfaced in less clear cut cases. To help them identify whether they had been responsible, they remembered instances that would absolve them. For example, they asserted that they had never been a danger to anyone, particularly not to their children: "I have never beaten them, never thumped them or anything like that". However, despite this, doubts remained in their minds as to whose fault it was, especially when participants remembered some of their behaviour that was not conducive to maintaining normal relationships. They stressed that this behaviour had solely occurred as a result of *having a mental disorder*, over which they had had no control.

As a result of doubts of who was responsible participants questioned whether they had been good enough at maintaining relationships: "I struggle with feeling like I am a bad deal". They suspected that they had been a bad deal because they had been unable to live up to their family members' expectations: "I've been a failure at relationships". The following writer who also had a mental illness voiced similar sentiments: "I began to believe that I was undeserving and unworthy of meaningful relationships with others"³⁷.

As a consequence of not being able to maintain normal relationships participants in this study felt utterly lonely. This loneliness was described as the worst part of *the struggle with maintaining normal relationships*: "It's the being alone that I find the killer, really". This deep sense of loneliness came on top of the isolation and ostracism already experienced as part of *the struggle with establishing credibility* and the abandonment in *the struggle with having been let down by the mental health system*. Self-blame again plagued them: "I was the crazy mixed up father who messed everything up". Whereas blaming oneself here for relationship break-ups was not all encompassing, it still amounted to increased feelings of self-blame experienced by those participants who were also *struggling with responding to the impact of having been abused*.

The recurring theme of blaming oneself, however, had two sinister consequences in this context. The first was participants' willingness to become scapegoats: "I was willing to be the scapegoat for the dysfunction in my family" and to take on the burden "for making it better". As a result they thought that it was incumbent upon them to put things right: "The responsibility for making it better was mine". This ready willingness to accept the scapegoat-role played further into the hands of *society letting perpetrators getting away with their abuse and mistreatment* from chapter 1.

A second consequence of blaming oneself was the feeling of "enormous guilt" of having been a "torment to my family". In feeling guilty for having failed at relationships and regarding oneself as a torment to one's family, participants got further embroiled in *the struggle to identify any intrinsic value in oneself as a person*. It revealed their powerlessness at being able to preserve the most significant part of their lives, that of maintaining normal relationships with individuals.

The struggle with trying to survive through daily life

This last area of *life is a struggle* occurred due to an accumulation of the struggle within oneself and the struggle with relationships. Participants described how they struggled with just getting through the day: "Trying to survive through daily life". Daily life referred to the mundane, in contrast to the existential matters covered so far, where participants grappled with who they were as a person and with their place in society. However, even in the

mundane participants were proved powerless as *the struggle with trying to survive through daily life* testified.

A contextual study of daily living strategies of five people with a mental illness, which observed the daily tasks and ask questions about strategies, also noted their "struggles of daily living"³⁸. One writer who had a mental illness described how that was for him: "I began to struggle to put one foot in front of the other, to make it through each and every day"³⁹. In this study, *the struggle with trying to survive through daily life* involved the struggle with studying, working and with being brought down by stress. For some participants it culminated in being incapacitated.

Participants explained that they were struggling with studying, whether at school or higher education institutions, because they were powerless to control their mental faculties as a result of *having a mental disorder*. They recalled how an absence of motivation or the presence of hallucinations interfered with their ability to learn. In addition, they felt excluded by their fellow students and teachers: "I hated every day of school". This was supported in a study by Moses⁴⁰ who found that 35% of school students diagnosed with a mental disorder reported being stigmatised by school staff "who expressed fear, dislike, avoidance and under-estimation of their abilities". For participants in this study, the struggle with studying further increased the feelings of being isolated, ostracised, abandoned and of being utterly lonely.

After studying participants encountered the struggle with work: "My biggest struggles are at work, always". They explained how important work was for them, pointing out that they wanted to feel fulfilled in life through work and also wanted to support themselves financially, just like other people: "They have to understand, we are also people. We also need to earn money to live". Despite the great importance of work, participants said that they struggled because their work performance was adversely affected by the inability to control their mental faculties which did not allow them to do their work in the way they would have liked. Participants recalled that the quality of their work suffered to the point where even simple requirements were hard to meet: "It was a real mess".

The struggle with working was then further deepened by the treatment participants received from their colleagues and employers. Even with their best efforts to get on with other people at work and overcome the shortcomings due to *having a mental disorder* they were powerless at avoiding trouble with these people: "I work very, very hard at my jobs and despite that manage to somehow get myself into big, irreconcilable conflicts". Despite having had a great passion for their work, which they had previously loved, as a result of this struggle work had turned into a nightmare: "It was just living hell for me". This was a third reason why life was compared to being in hell.

The struggle with working was also a theme in other studies, such as that on nurses with a mental disorder who reported on their work environment⁴¹. A survey of 556 people conducted by The Mental Health Foundation in England¹⁹ remarked on the bullying occurring at the workplace.

As a result of the struggle with work many participants had lost their jobs. Being retired against their will "floored" them as they realised the value of their work capabilities had permanently been assigned to the scrap-heap. They grieved over the loss of value that work had bestowed on them. In addition, some participants, in having lost their jobs, had to resort to social security benefits, which left them without sufficient financial means to get by. They often did not have enough money to buy healthy food or live in decent accommodation: "My living conditions are like being back in the Boys' Scouts and camping". Living in circumstances of poverty, participants felt ashamed and guilty that they were no longer able

to work and had to draw on welfare. This deepened the already shame felt in *the struggle with establishing credibility*, and the guilt experienced when they blamed themselves in their *struggle with maintaining normal relationships with individuals*. In addition, they now found themselves under a regime of frequent reviews for welfare eligibility, fostering a sense of fear and insecurity with regards to the provision of lodgings and their daily bread and butter.

Participants in this study who had lost their jobs were not alone. Marwaha and Johnson's⁴³ review found that in most Western countries only 10 to 20% of people with serious mental disorders were employed. Borg *et al.*⁴⁴ also identified, in examining the role of material resources available to people in the recovery period from severe mental illness, that poverty and substandard living conditions were among the "major struggles" people with a mental illness faced. Spaniol *et al.*¹⁰ highlighted the importance of financial security to people with a mental illness: "Dealing with poverty was a greater challenge than dealing with mental illness". As did participants in this study, Caswell³⁷, a writer with a mental illness, talked about the guilt he felt when he was unable to get a job.

The struggle with studying and working then became part of being brought down by stress: "If there is any stress, stress will bring me down. That's one of the worst things on me". Participants explained that even minor stressors "absolutely threw" them. However, by looking at their entire life, it can be seen that these minor stressors were able to knock participants over because participants were already weighed down by all the other aspects of *life is a struggle*. Therefore even minor stressors seemed like major ones to them: "Any little thing can turn into World War III. I can assure you". Being brought down by stress further deepened *the struggle to identify any intrinsic value in oneself as a person*. Participants pointed out they had taken on board the explanation given by health professionals that they had a "narrower allowance" than other people for stress. This said susceptibility made them out to be weaklings: "You are weak because you haven't been able to handle what life has chucked at you".

With even minor stressors having such a disruptive impact on participants' day-to-day living some were not far from being incapacitated, which completed participants' powerlessness. They described how they struggled with wanting to do things but were unable to due to a lack of energy. This lack of energy was compared to having a flat battery, which did not have enough charge to start an engine: "The battery is absolutely flat, rrrh, rrrh (making a sound of an engine not starting). You want to go and it won't go". Participants indicated that the lack of energy affected whatever they wanted to do, from making simple decisions to doing household chores and cooking: "I was ending up eating baked beans and bits of bread every two or three days".

Being incapacitated could further deteriorate to a point where participants were unable to do anything at all. They described how they were sitting in a room for extended periods of time without doing anything: "I sit in a dark room, the last time for three days and three nights". They likened it to being paralysed, both physically and mentally. Physically they were unable to move: "I'm talking about literally not moving unless I had to go to the loo". Mentally they were unable to talk or even hear and it seemed to them as if there was "nothing in my head". Deegan⁴², a writer with a mental illness, described her own incapacitation as a feeling of being "among the living dead".

As a consequence of *the struggle with trying to survive through daily life* in this study participants' mental disorder was made worse: "It got me down and I had a nervous breakdown". Moreover, *the struggle to identify any intrinsic value in oneself as a person* was further compounded. Participants felt a loss of value by not being able to do even simple chores and their self-esteem plummeted: "I felt inadequate".

Participants now felt crushed. They were convinced that their life had come to a standstill; that it was dead and devoid of everything, and that they were virtually decaying: "I just lay there all day, rotting". In this situation participants asked themselves: "What's the point of struggling with everything in this life?" They came to the conclusion that they did not care any more about anything, particularly about keeping their life together: "Let everything fall apart". Therefore suicide was again an obvious choice: "One night I sat down and carved myself up. I just sat there, and blood was going everywhere. I was too weak to move. I lay on the bed, too weak to move for a week".

Conclusion

Life is a struggle presented participants' account of the impact of *the experience of disempowerment* from chapter 1. They explained why they struggled and how they struggled. This struggle left them so powerless that, most importantly, it was destructive to their sense of value as a person and to their sense of value of their life as explained in *the struggle to identify any intrinsic value of oneself as a person*. They described that they had no self-worth or self-esteem and felt profoundly insecure. Their life was empty and without meaning. Their self-worth and self-esteem were further lowered by *their struggle with having a mental disorder*, by unsuccessful attempts at establishing credibility, and by feeling inadequate during their studies and at work. Participants who had lost their jobs further lost a sense of value by being unable to contribute to the work force. Their insecurity was heightened by the precarious financial situation when on social security benefits. As a result they were not able to face even minor stressors. Some participants deteriorated to the point where they were incapacitated and unable to do anything at all.

In addition, participants felt a loss of power due to a deep sense of fear. This fear was brought about by helplessness and by a feeling that they could not make sense with what was happening due to the impact of *having a mental disorder*. In addition, participants were continuing to live in fear due to *having been abused in childhood and/or adolescence*. Fear also resurfaced in *the struggle with establishing credibility*. Fear appeared at the mere prospect of needing mental health treatment and, once participants had entered treatment, this treatment then failing, in *their struggle with having a mental disorder*.

Other feelings of powerlessness ranged from being puzzled and confused, because participants could not make sense of what was happening in *the struggle with having a mental disorder*, which also encompassed the worry they experienced about the implications for their children and their own future.

Participants' powerlessness was revealed by feeling helpless and trapped when they were emotionally captured by their abusers in *the struggle with responding to the impact of having been abused*. Furthermore, they felt helpless and trapped by the abusive power in the mental health system and because there was nowhere else to go to get help.

Being powerless left participants feeling cut off from receiving any meaningful help. They regarded themselves as being abandoned by the mental health system and by many of those most dear to them, their family and friends. Again, they internalised the blame for having been abused and for relationships not working out and looked to themselves as being responsible. They thought they had to feel ashamed for the fact that they had been abused and for not being able to establish their credibility. They also felt ashamed for being unable to work like other people and for having to draw on welfare to survive. Despite some doubts, they readily accepted responsibility for not being able to maintain normal relationships. They felt guilty at having brought about a break-up with their families. Guilt was also felt when

they were finally not able to do anything at all. This highly stressful situation was added to by stress at school, at work, by being poor and by the many other small stressors that were part of daily life.

However, the final power-sapping aspect of *life is a struggle* was the impact of *wanting to be dead*. Thoughts on *wanting to be dead* were constantly present and occurred at every occasion. Participants justified giving in to *the struggle with staying alive* by reckoning that their life was worthless. They gave reasons for wanting to commit suicide as no longer being able to endure the pain during *the struggle with responding to the impact of having been abused* and the suffering and hurt they experienced at having been isolated, ostracised, abandoned and at being utterly lonely. They argued that there was also no reason for carrying on living when they had lost the support of their family members. They saw suicide as a means of a viable escape when they felt trapped in no-win situations or when they had lost hope of a better life when treatment failed. It was also seen as the right thing to do in *the struggle with trying to survive through daily life*. They nevertheless felt anguish at having to decide about whether to go ahead with ending their life and were terrified at having to bring about their own death.

The powerlessness brought on by the impact of *the experience of disempowerment* seemed complete, with one exception: anger. As will be seen in the next chapter, anger was the only emotion that contained within it the seeds for spurring participants on to resolving *life is a struggle*.

Chapter 3: Real-life solutions to one's personal life

This chapter contains a comprehensive account of how participants succeeded to resolve *life is a struggle*. It presents their long and arduous journey that led them to devise real-life solutions to manage their own personal lives successfully. Participants were people diagnosed with severe depression, bipolar disorder or schizophrenia. They had told in previous chapters how *the experience of disempowerment* had brought on *life is a struggle*. *The experience of disempowerment* in their personal sphere comprised of *having a mental disorder, having been abused in childhood and/or adolescence and wanting to be dead*. More devastatingly, *the experience of disempowerment* in the social sphere consisted of *society not believing what participants said, devaluing and dehumanising them, not willing to help them, mistreating them and by letting the perpetrators getting away with their abuse and mistreatment*.

As a result of the impact of *the experience of disempowerment* life was a struggle for participants. They explained how they were left powerless in the unremitting struggle to take charge of their personal and social life. The pivotal aspect was *the struggle to identify any intrinsic value in oneself as a person*. Here participants detailed how they struggled with seeing themselves as worthless, inadequate, without self-esteem and as their life having no meaning. In *the struggle with having a mental disorder* participants recalled how they were powerless because they were left helpless and could not make sense of what was happening; and in *the struggle with staying alive* participants fought against the disempowering force of *wanting to be dead*. However, the most important aspect of *life is a struggle* pertained to the struggle with relationships. Participants told of their powerlessness in *the struggle with responding to the impact of having been abused* as it had undermined their efforts of developing a sense of personhood. They were left without positive hopes and aspirations for the future. Their powerlessness was further deepened in *the struggle with establishing credibility* where at every encounter with others they had to prove that they were not "crackpots". Furthermore, in *the struggle with having been let down by the mental health system* participants were left powerless to deal with the health system because they had no power over how the system was organised, over how they were clinically treated and over how many health professionals abused their power. With regards to pursuing normal relationships with family and friends participants were left powerless in *the struggle with maintaining normal relationships with individuals*.

Finally, the cumulative effects of existential struggle with who participants were as a person and what their standing was in society resulted in *the struggle with trying to survive through daily life*. This struggle explored with participants' powerlessness to handle the mundane, such as studying, working and dealing with stress. For some participants this was so severe that they became incapacitated.

In order to deal with *life is a struggle* participants went through a process called *transforming oneself*, the topic of the current chapter. Transformation refers to making considerable changes. Due to the suffocating and seemingly insurmountable *life is a struggle*, participants' *transforming themselves* was a feat that was very difficult to achieve as the obstacles to overcome were so great and there was no plan on how to proceed. This feat was therefore highly admirable for its originality and power of execution. The psychiatrist Bloom¹ agreed: "I feel compelled to state that we have treated some of the strongest and bravest and cleverest people we can ever hope to meet ... [They are] tough, resilient and often ingenious".

In *transforming themselves* participants in this study changed themselves from people who were helpless and powerless to people who were confident and assertive and in charge of who they were and how they ran their lives. They compared *transforming oneself* to a metamorphosis, such as the metamorphosis of a caterpillar to a butterfly. A caterpillar appears unseemly and is unable to take to the air but after a long incubation period breaks out of its cocoon and emerges as a fully-grown butterfly. It displays beautiful wings and is free and able to fly off to wherever it desires, as described by the following participant:

"I am almost that, coming out of the cocoon and the butterfly has broken out and it is just ready to flutter its wing. Its wings are just in the stages of getting dry. The colours are all coming out."

The term transformation was also used by Spaniol *et al.*² in describing how people with a mental illness overcame their difficulties. Coleman³, a writer with a mental illness, described his own transformation as going from "victim" to becoming a "victor". He likewise identified that at "its very heart [is] the reclamation of personal power"⁴.

Participants in this study said that the process of *transforming oneself* involved a long and arduous "journey" that took a long time to complete, ranging typically from between 20 to 50 years. It consisted of two stages: trying to deal with life is a struggle and getting better as a person. These stages were separated by the turning point and concluded in being at peace. Although interviews were only conducted at one point in time, it was possible to identify this process because participants described what they had done at earlier periods in their lives. In addition, it could also be established at which stage participants were positioned during the time of the interview. For example, some were still in stage 1, whereas others had just emerged from the turning point into stage 2. Only a few participants, however, had gone through the full process. This is not a value statement as to participants' ability to go through these stages because the process discovered in this study was not readily identifiable to those in an earlier stage. Despite trying their utmost these participants could not have known how to proceed along the path towards fully resolving *life is a struggle* as it typically took decades to learn how to navigate through its entire length.

In the first stage of *transforming themselves*, participants found that neither not wanting to deal with anything nor trying to get on top of having a mental disorder was successful in resolving *life is a struggle* despite their best efforts. In their powerlessness at making a difference to their lives they reached a breaking point, which became a turning point, where they were forced to confront their hopeless situation. The successful confrontation marked the change from their hitherto powerless position into one where participants had some power for the first time. They pinpointed this as the beginning of their transformation.

In stage two of the process of *transforming themselves*, participants built up their power by deciding to tackle *the struggle to identify their intrinsic value as a person* first rather than focusing on trying to get on top of having a mental disorder. By refocusing on what they termed getting better as a person, participants managed to develop a new, positive identity, which in turn allowed them to learn new strategies and take action that made a difference in their lives. *Life is a struggle* was resolved when participants felt at peace.

An overview is giving here:

Stage 1: Trying to deal with life is a struggle

Phase 1: Not wanting to deal with anything

Phase 2: Trying to get on top of having a mental disorder

The turning point

Stage 2: Getting better as a person

Step 1: Developing a new, positive identity

Step 2: Learning new strategies

Step 3: Taking action

Being at peace

Literature on people without a mental illness, but also in desperate situations, will be included as additional data in this chapter. This will show that the process of *transforming oneself* is common to both groups, people with and without a mental illness.

Stage 1: Trying to deal with life is a struggle

Entry into the first stage of *transforming oneself* occurred with the advent of *the struggle with having a mental disorder*. Two phases were identified: not wanting to deal with anything and trying to get on top of having a mental disorder.

Phase 1: *Not wanting to deal with anything*

Participants frankly stated that in this first phase they did not want to deal with anything in life: "Not have to deal with anything". They said that this phase most often occurred at the beginning of an episode, especially in the first few years of an illness, and when stress became too much to handle. In their powerlessness due to the cumulative nature of aspects of *life is a struggle*, participants turned to the only strategy they could think of and employ at this point of *not wanting to deal with anything*, that is, to withdraw.

Participants indicated that this act of withdrawal was instinctive: "Something flicks inside, 'withdraw'". They explained that the purpose of withdrawing was to be "taken out of circulation, to get out of here". It meant to get away from everybody and not to have to deal with anything: "Not wanting to face anybody, just wanting to run away, get away from it all. Escape from it all".

One reason participants gave for wanting to withdraw was that they did not want to deal with *the struggle with having a mental disorder*. Participants did not want to admit to themselves who they really were, namely someone afflicted by one of those demonised mental disorders. They, therefore, withdrew from the knowledge of *having a mental disorder*. They thought that it was easier to pretend that it was not there, to "ignore it" and deny its existence: "That's a part of the denial because so long as you can keep yourself well out of mental illness and the knowledge of it, it's like you haven't got it". They said that as part of this denial they also stayed clear of mental health professionals: "A lot of people [with a mental illness] think, 'Oh, my goodness, if I see a psychiatrist I am really mental'. So they don't want to deal with that". Thinking along the same line, they also convinced themselves

that medications were not necessary as they regarded themselves as being all right and therefore thought it was pointless taking any.

The second reason participants gave for wanting to withdraw was that they did not want to deal with the struggle with relationships. In particular, they were afraid of being exposed to *society devaluing and dehumanising people with a mental illness*: "People are going to look at me funny and they are going to laugh at me and they are going to point, and I can't deal with it". The shame participants felt at being someone dishonourable and improper also contributed to not telling anyone about their illness and deciding to hide away instead: "You grow up a closet person because of the shame of it".

Supporting this study, other people with a mental illness gave similar reasons for withdrawing. Boydell *et al.*'s⁷ analysis of the perspectives of young people with a mental illness also found that they had decided to "try and forget about it [the mental disorder]. That was my way of dealing with it!" Likewise, Brody⁸ recorded in focus groups on the first-hand experiences and perspectives on stigma and discrimination that people with a mental illness often did not seek treatment. Aldridge⁵, in his theory on suicide, noted that his participants concealed the fact that they had a mental disorder because they were ashamed. Repper and Perkins⁶, drawing on many accounts of people with a mental illness, recognised that they did not want to deal with their mental disorder because they wanted to "reject the images of themselves as dangerous and incompetent".

The easiest way to withdraw from the struggle with relationships for participants in this study, so that they did not have to deal with anything, was to remove themselves physically from associating with other people by either going away: "I just disappeared off the face of the earth" or by locking themselves in their home, not answering the phone nor opening the door to anyone. Even those people who wanted to help were not responded to. Some participants chose to physically withdraw by just temporarily going to sleep for a lengthy period of time so that they would not have to deal with anything: "I wanted to get out of the world, basically".

A more complex way of withdrawing from the struggle with relationships was to withdraw mentally within oneself. Those participants who had not been abused in childhood and/or adolescence withdrew mentally behind a façade. This façade took on the form of a happy-go-lucky face so that their true feelings stayed hidden when they came into contact with other people: "You can joke and you can look happy and people think you are ok but you are not. Sometimes the worse you feel the more you withdraw behind a façade".

Those participants who were faced with *the struggle with responding to the impact of having been abused* withdrew mentally within themselves to a much larger degree. This was necessary because withdrawing mentally behind a façade was not sufficient because the impact of the abuse had been too great. These participants therefore needed other ways that were realistically achievable for them. They described how they withdrew from the memories of the abuse by burying them deeply within their minds and putting a seemingly secure lid over them, described as "a trap door", so that the memories could hopefully be forgotten forever.

Some of these participants withdrew mentally even further. They created a fantasy world into which they could remove themselves from the intolerable, hellish, real world: "My * [abuser] made my life so unbearable, so intolerable and for so long that I left the real world. Not deliberately. It just happened. There seemed no other way out. I started to fantasize". This fantasy world that participants created was concerned with living, albeit fleetingly, in a

realm where this abuse did not occur and where they could dream of being loved and cherished:

"I created my own world. I lived in a world of fantasy. I used to be glad to go to bed to go to sleep so that I could live in my imagination. I created worlds where I wanted a perfect father and [I created a] perfect [image of him]."

In some instances this fantasy world was then peopled by "imaginary friends". The following participant described how an imaginary friend appeared as part of her fantasy world when she was a child. He offered to shield her from *the struggle with responding to the impact of having been abused* by making it possible for her to *not want to deal with anything*:

"She [the abuser] belted the daylight out of me. So, I went running outside and I just lay down in the mud, just lay there. I could feel the rain on me. I don't know what happened. It just felt like as if my mind had shifted to a different dimension. I saw this child, probably a little bit older than myself, dressed in very old fashioned clothes, saying to me, 'When * [name of abuser] does these things to you, you just come to me'. Whenever these things were happening, I couldn't stop them, but I just sort of went into another realm with this person."

With this participant, the imaginary friend kept his promise and assisted her in not having to deal with other highly stressful situations. This safety mechanism that appeared in the form of an imaginary friend was so valuable that the participant refused to take mental health medications for many decades because these medications took the imaginary friend away from her.

However, other writers with a mental illness reported that not all 'people' in their fantasy world were as benign and friendly as the one encountered by the above participant. For example, Steele⁹ described his 32 years with voices that were relentlessly menacing, threatening and deprecating, telling him to: "Hang yourself. The world will be better off. You're no good, no good at all".

Some participants in this study went even further than living in a fantasy world and retreated mentally completely behind a protective barrier that had the function of cutting them off from the real world altogether. This protective barrier was described as a mental "brick wall". This mental brick wall was far more solid than the trap door that buried the memories of the abuse. Participants explained that behind this mental brick wall they felt that they were somewhere else instead, somewhere undefined: "Like I wasn't really here". They said that this perception of not really being here and being cut off from the real world had already occurred in childhood: "I've got a photograph of me when I was probably about eight years old. You can see I am completely cut off. It's this look that nobody's at home. I always felt like that, cut off from the world". This feeling of being cut off from the real world then continued into adulthood, especially at times of great distress: "It was like being in the corner of a room watching and listening to all this stuff happening. You are just not there. I know that it was me sitting there but it just didn't feel like me".

In order to assist participants to stay behind that mental brick wall but still be able to get through daily life, they operated 'on automatic'. They achieved this by using an outside persona that was separate from their inner true selves, which stayed behind the mental brick wall:

"I did it [things in daily life] as a task that I knew had to be done correctly. It didn't matter what I was feeling inside, I knew I had to behave a certain way. It was on a level that was outside of me. It wasn't really from me. It was just what was meant to be done."

Ridge and Ziebland¹⁰ quoted similar statements from their participants in a study on how people give meaning to recovery following depression. Their participants also mentioned that they had "built up a very good high brick wall and nothing came in or out", that they had "put on a front" and were "functioning like a machine".

Participants in this study further explained that they separated the outer persona from their true inner selves to such an extent that it led to a feeling of being split between an outer world, which was represented by the outer persona, and an inner world, dominated over by their inner true selves. This feeling of being split became so great with some participants there was no true interaction between the outer and inner worlds any more. Participants described feeling split as turning into two different people who were able to feel and display two different, vastly contrasting emotions. For example, the outer persona was presented as a false frontage that seemed to manage fine, whereas the inner true self was so desperate that it was ready to commit suicide: "I split into two people. This one person who just put on this act that everything was ok and that I was really enjoying myself [and this other person who was] just really determined to kill herself".

Participants found that the feeling of being split, or dissociated, was a very effective way of withdrawing from the reality of the abuse they had suffered: "I'm trying to dissociate myself from that childhood event". The reason it was effective was that the outer persona was shielded from being overwhelmed by the destructive influence emanating from the inner true self. Participants explained that this separation, "the out of body experience, this involuntary dissociation", became so strong that it turned into a reality experienced on an ongoing basis: "That mental thought of, 'I'm not here. It is not happening to me' can become a concrete thought". As a result, participants felt cut off from their inner true selves harbouring their real feelings, and perceived them as beyond reach. This reality of being split was then translated into actual physical experiences: "I used to have these blackout episodes, and I used to get these smells and all of a sudden my hands would look like shrunken".

Withdrawing mentally within oneself by separating the outer persona from the inner true self prevented participants from feeling like a whole person. They said they did not feel "altogether" because their emotions did not belong to a unified individual inside them: "I never felt right; I never felt like I was a complete person. I always felt like there was a conflict with what I was being and what I was feeling. There was always a very definite conflict". With this loss of feeling like a whole person, participants explained that any coherent identity of who they were meant to be disappeared: "I didn't know who the dickens I was and who I was supposed to be". Instead their identity became "jumbled. I couldn't figure out who was me out of it all". The lack of a coherent self-identity was so strong that it persisted even in the face of achievements participants had made in life. As a result they regarded themselves as "a nobody". This loss of a coherent self-identity reinforced the loss of value in *the struggle to identify any intrinsic value in oneself as a person* with demoralising effects: "It was just the most disastrous thing".

Other people with a mental illness also reported that they dissociated, for example in a study on what survivors traumatised by child abuse need from community-based mental health professionals in Canada¹¹. Van der Kolk, Roth *et al.*¹² established that dissociation occurred in up to 80% of people who have been abused before the age of 14 years, and in 59% with late onset abuse. It is defined as a "compartmentalization of experience"¹³. Bloom¹, in her substantive theory on the experience of trauma, explained that when traumas in life cannot be resolved, "then we must find a way to turn off the emotion. That is when we dissociate". Furthermore, exploring the experience of trauma Van der Kolk, Van der Hart *et al.*¹³ stated that people experiencing dissociation lose "an integrated sense of self" and can

"leave their bodies ... and observe what happens from a distance". Van der Hart, Nijenhuis and Steele¹⁴ reasoned that dissociation allowed the affected person to function in daily life.

The final way of withdrawing in *not wanting to deal with anything* in this study was through suicide. Both groups of participants, those with secure and non-abusive upbringings and those who were *struggling with responding to the impact of having been abused*, were united in their realisation that they could enact this way of withdrawing once and for all: "The thoughts of suicide and wanting to escape, wanting to get away, feeling trapped and wanting to get away". That suicide was an option to escape was also commented on in a review by Lakeman and FitzGerald¹⁵ on how people lived with suicidality.

Participants in this study described withdrawing through suicide as being highly attractive to them and were relieved in their realisation that it was available. They saw it as an obvious way to proceed. Although it formed the last rung in a line of thinking about options to withdraw, the decision to choose it was often reached very fast:

"I wanted to withdraw. That was the beginning and then you just lock up your hat. You don't talk to anybody and you don't want to see anybody. In my case I'd probably think that, 'Oh, well, my kids won't talk to me; my parents didn't love me, may as well just die. I'm going to die anyway'. That's how I used to think, 'Well, I will die anyway. So I may as well go now and get away from everything'."

Some literature on people without a mental illness will now also be included here. Surprisingly, a selection of only a small number of studies, including autobiographical writings, on and by people who either had been abused in childhood and/or adolescence but had not developed a mental disorder^{16,17}, had various chronic physical conditions^{18,19} or suffered from a terminal illness²⁰ found that many facets of *not wanting to deal with anything* explored in this study also occurred in them. This hints at universal means of dealing with problems. The same ways of withdrawing, including not wanting to accept one's illness and ignoring it instead, mentally withdrawing by going behind a façade, burying memories and operating 'on automatic' were reported. A synthesis of seven studies²¹ on people in chronic pain established that suicide became an option for them to escape an "intolerable situation and ... despair".

Withdrawing in order not to deal with anything, as revealed in this study, despite its seeming ineffectiveness, had advantages as it allowed participants to survive: "That's how you kind of survive". They pointed out that they were able to gain space and time, where they could rethink their lives, get back on track and start again on a better footing. They mentioned that life was also made tolerable because facing the fear and shame associated with the struggle with relationships and the fright and the worry related to *the struggle with having a mental disorder* were avoided. Deegan²², a writer with a mental illness, concluded that the denial that one had a mental disorder was "a normal reaction to an overwhelming situation. It was a way of surviving".

However, *not wanting to deal with anything* by withdrawing also brought disadvantages because withdrawal was eventually recognised as a deferment only. Those participants in this study who used withdrawal to evade knowing about *having a mental disorder* realised that this postponement could not be achieved for long: "The mental disorder doesn't respond well to being denied".

Due to the disadvantages of *not wanting to deal with anything* mounting up, participants reached a point where this way of trying to resolve *life is a struggle* was no longer viable. For the following participant that point came when he left school and had to find employment: "All of a sudden, life, the reality of life, was staring me so hard in the face

that I sort of couldn't retreat into that fantasy world any more". For other participants, the loss of their job or their role in the family, the loss of an important support person or another episode of mental illness unravelled their hitherto protective ways of withdrawing: "It was all encompassing. I was drowning in it". Participants found themselves as powerless as ever. At this point they realised that it had become detrimental to use *not wanting to deal with anything* because it made *life is a struggle* worse. Participants noticed that they had entered "a vicious cycle" because they had not developed better ways of dealing with situations. In order to find these better ways they entered into phase 2.

Phase 2: Trying to get on top of having a mental disorder

In this second phase of trying to deal with *life is a struggle* participants were looking at all possibilities as to what to do "to try and get on top of it [having a mental disorder]". After their failure at *not wanting to deal with anything* participants' focus now changed to *trying to get on top of having a mental disorder*. They said that they wanted nothing more than to get rid of it and, in addition, society placed great emphasis on it: "The focus on the mental illness was huge".

Participants said their overall goal of phase 2 was to be normal. They explained that normal referred to being free from signs and symptoms. Participants said that then they could organise themselves, have sufficient mental energy and would not be miserable anymore, all without having to resort to taking medications. In addition, they wanted to get back to what they considered to be a normal lifestyle with a steady job and a positive outlook on life. Importantly, they also did not want to be seen as "the odd one out". Some participants in Ridge and Ziebland's English study²³ on how people give meaning to recovery following depression also mentioned that they "just wanted to get back to how life was before * [the mental disorder and] feel 'normal'".

Participants in this study thought long and hard about what strategies they could devise to achieve this goal of being normal. Firstly, they wanted to rely on their own wits. They identified three methods here, each only indirectly addressing the point in question: delaying, trying to find a quick fix and overcompensating in areas other than *having a mental disorder*. They explained that they used delaying because they did not know what to do: "I really wasn't dealing with it because I didn't know how to". As a result their life further deteriorated: "I spiralled for quite a while before I did anything about it because I didn't really know what was happening". That they did not know what to do was also mentioned by young people who had a mental illness in Boydell *et al.*'s⁷ secondary analysis of other studies.

Participants in this study then tried to find a "quick fix" with the new aim of finding happiness, which they hoped would lead to a temporary relief from their misery. Participants used trial and error measures and tried out one quick fix after another in an unfocused and uncoordinated way. For example, they went to nightclubs, drank alcohol or smoked marijuana: "Because if I felt sad, I would just smoke that and forget it and feel happy".

When happiness was not found, participants said that they scaled their aim back from finding happiness to getting mere relief from their misery, described as "almost like feeling good". Participants here used band aid measures, which helped them to superficially gain some relief from their misery. In this endeavour they were more successful. For example, they said that they got some relief from simply crying or from finding anything that would provide them with some comfort, such as eating "comfort foods". To have a short time each day where some form of comfort was experienced turned out to be so important that it became the focal point of their life in this part of phase 2.

As a further method of relying on their own wits participants wanted to overcompensate in areas other than *having a mental disorder*. For example, they started to work even harder at their workplace because they felt that by overcompensating in this way they could overcome their misery: "The worse I felt, the harder I worked to try and make it go away". However, none of these strategies could *get on top of having a mental disorder*. Participants eventually found that all their own efforts were futile. It sapped their mental energy and they remained powerless.

Participants now turned to the second strategy of *trying to get on top of having a mental disorder*, where they sought out advice from outside sources. They had now truly left behind not wanting to know about *having a mental disorder* from phase 1 and were keen to comply with everything in this advice, including taking all the various medications available: "You need to take this'. 'Ok'. 'You need to do this'. 'Ok'". Participants went to great lengths to seek out education. They attended all the therapeutic sessions and workshops, and consulted all the books they could lay their hands on, sometimes for many decades: "You name it; I've done it". Cognitive therapy was also tried with the same diligence: "I've tried that for years and years and years". Furthermore, participants turned to alternative ways, which were not strictly medical but had been recommended nevertheless. For example, they started to exercise as they were told that exercise increased endorphin levels in the brain, a neurotransmitter that was linked to improving one's mood.

Other writers with a mental illness also remembered how they had been keen to comply with all advice²⁴. In Coleman's⁴ words, he had become a "good schizophrenic". However, participants in this study again found that complying with all this advice ended in disappointment, as none of it *got on top of having a mental disorder*: "It wouldn't help".

Participants were now left with the last strategy of *trying to get on top of having a mental disorder*, the use of extreme measures. These measures were classed as extreme because participants turned to them as a last resort. They felt they had no other options left. For example, some thought that the only thing over which they could still exert any form of power and control was their weight, so they stopped eating. To gain some power in the struggle with relationships other participants tried to express their need to get a response to their plight by "smashing things". Another sought to gain some power over getting help from health professionals by setting the hospital ward on fire: "It was a cry out for help, basically".

However, the consequences of this last strategy were disastrous because participants damaged both themselves and the relationship with other people. They damaged themselves by, for example, weakening themselves physically, by again turning to self-harming practices, by being put into straitjackets and by getting criminal records. They damaged their relationship with other people when "everything turned into a fight". The greatest damage, though, was to worsen *the struggle to identify any intrinsic value in oneself as a person* because participants thought that it must be their fault that they were not able to *get on top of having a mental disorder*: "You think, 'What is wrong with me then?'".

Due to all these strategies failing, participants eventually realised that they had come to the end of the road: "I don't know what more I can do, quite honestly". In their failure to make any progress, participants now became convinced that *getting on top of having a mental disorder* was beyond their reach and that there was nothing else they could do: "I'd just got to a point where I just couldn't deal with anything anymore". They pointed out that they could not deal with anything anymore because it was too difficult and they were overwhelmed: "Everything is too big, too heavy, too hard". Other people with a mental illness agreed. They reported that they had also been "overwhelmed by [their] defeat in ... attempts to [get on top of their mental disorder]"².

As a result of not being able to *get on top of having a mental disorder* some participants in this study became "resigned" to their situation. Becoming resigned, though, brought with it further stress in the form of grieving over the seemingly permanent loss of power. So, some participants in this study went back to revisit the first phase and started to withdraw again.

Other participants, however, remained determined to *try and get on top of having a mental disorder*. They said that they were resolute and willing to fight until their mental disorder was under control: "I will fight this thing to the end. [I am telling myself,] 'You are going to fight this. You are going to win'". This fight required the expenditure of large amounts of mental energy and a "never-ending effort". As a result, they became so worn out that they were "constantly exhausted and flat". Furthermore, their life turned into a state of "turmoil". In the face of this turmoil they concluded that they "didn't have that strength to continue" and that giving in to not fighting anymore was much easier: "If I had a gun next to the alarm clock like probably 20 or 30 percent of the days in the year I'd pick it up and go, 'shh' [making a shooting sound] 'cause it is just too hard to go on".

Participants now realised that they were stuck in a loop from which they could not escape and they capitulated: "I've had it". They had reached a desperately low point that became a breaking point for them: "I was ready to explode". At this point of total powerlessness they were forced to confront their hopeless situation. This was the moment when they started to advance through the turning point into stage 2.

The turning point

The separation between stage 1 and stage 2 of *transforming oneself* was the *turning point*. A turning point is defined as "a point at which decisive changes take place; a critical point"²⁵. Participants turned from being powerless at trying to deal with *life is a struggle* despite their best efforts, to discovering ways to gain power over what to do. This study found that a *turning point* was necessary in order to achieve the transformation that ultimately turned participants' *life is a struggle* into a life of *being at peace*. The *turning point* was either precipitated by a crisis or brought on by empowering experiences.

Turning point precipitated by a crisis

The majority of participants entered the *turning point* through the first possibility of experiencing a crisis. A crisis occurred either suddenly due to the appearance of one major event or as a result of a slower accumulation of many smaller events coming to a head. The major event was likened to a "cyclone", such as getting an especially devastating episode: "I completely lost it". However, more typically, several smaller events built up and accumulated over a period of time to the same intensity as the single major event. An example produced by the following participant described the many smaller events as consisting of her deteriorating mental health, her seemingly permanent stay in hospital from which she could not escape and the associated abuse of power by health professionals: "They treated me horrifically, really badly".

Whether the crisis occurred due to a sudden major event or due to an accumulation of smaller events coming to a head, it resulted in participants experiencing a hopelessly low point in their lives: "I was very, very desperate". Participants said they knew that there was no one left in the world able to help them, that they had nowhere else to go and no viable options left. Participants also realised that going back to phase 1 of *not wanting to deal with*

anything to ease the desperation and hopelessness for a short time was no longer an option, and that they only had two pathways left in front of them, either to kill themselves or to try again: "So I had to actually make a decision within myself, either I was going to kill myself, and that was that, or I would try again".

The decision to try again was the critical break-through point where participants broke out of the vicious cycle of the unsuccessful first stage that had merely served to increase their powerlessness. This break-through point signalled to them that something had changed inside them and this something was a change in their attitude. They realised that a change in attitude led them beyond thinking they were stuck at the desperately low point. It was the "wake-up point", which made them realise that they were able to take "ownership". This ownership was epitomised by participants stating that they themselves now had to determine what to do: "I thought, 'Screw it, no one else is going to help me. I'll have to do it myself. So I did'". Participants described this as the point at which they started to gain some power for the first time and pinpointed it as the beginning of their transformation: "I felt like I was a completely different person". With this realisation came a sense of great relief: "I sobbed deep within". A glimmer of hope surfaced indicating to them that they had the capacity to get through the desperately low point after all.

In the literature, turning points are described as permanent disruptions or deflections in the life course trajectory, for example by Wheaton and Gotlib²⁶ who examined trajectories and turning points over the life course in people with a mental illness. Other people with a mental illness also told of similar turning points to participants in this study, for example Abraham Lincoln: "To remain as I am is impossible. I must die or be better"²⁷. Robb²⁸, a writer with a mental illness, described it thus: "I had a decision to make - either kill myself, or get better on my own. After much deliberation, I decided to go with option number two". Seeing no other option but to change was also described by a participant in Rakeldt and Strauss's study²⁹ on how people with a mental illness reached their turning points: "I was up against a brick wall. I had to change". Furthermore, the critical break-through point resulting in an attitude change following a decision to take a different road also happened to other writers with a mental illness²⁴, as was taking ownership⁴. Taking charge was an important theme in Borg and Davidson's study³⁰ on the nature of recovery as lived in everyday experience.

Turning points were also described as occurring in the lives of people who did not have a mental illness. Those with a history of childhood abuse explained how they were "drowning, grasping at a straw ... I just couldn't go on any more"³¹ and how making a "big decision" was the turning point for them¹⁶. Turning points could be "precipitated by exceptionally severe events ... or cascades of disasters"³². Participants in a study on what it was like to live with a terminal illness described how they had taken charge of their lives²⁰ and those with paraplegia highlighted the importance of hope: "Hope was all you had"³³.

Turning point brought on by empowering experiences

A minority of participants in this study went through the *turning point* with the help of empowering experiences. They identified several of these.

The first type of empowering experience consisted of being told by others that they were indeed as powerless as a hunted animal upon which other beasts turned. This prompted a conscious decision not to be helpless any longer: "I am not lying here for other people to pick my carcass. I am not going to be the victim".

The type of second empowering experience drove participants to realising they were able to make their own decisions. It consisted of getting correct knowledge on what was wrong with them, which, in turn, spurred them on to finding out more about their disorder themselves and what they could do about it. This was so important that it "helped spare my life". Participants also put getting a clear head to think with in this category. They described how, due to the prescription of effective mental health medications, they could now think sufficiently clearly to make decisions of what they wanted to do in life: "I sat down one night and thought, 'right, come on, let's think this out. I've got my life back on track thanks to the little pills. So, how about doing something with yourself for a change?'".

The third type of empowering experience gave participants sufficient confidence to think they had the capacity to make positive changes. For example, affirmations, which were strong assertions or statements, helped them improve their opinion of themselves. Participants recalled how these affirmations worked when they were recited over and over: "They become part of who you are". Getting other people's confirmation that participants were people who were valued also lifted their self-confidence. They called it being validated, meaning that they were believed in and that their experience was understood as being valid: "Being believed and validated changed my attitude, not in a theoretical mental illness lens. Understanding me from my experience of the world and my experience from my whole life, as a human being".

The fourth type of empowering experience that brought about the *turning point* assured participants that they had not been totally abandoned and that they indeed had the strength to continue. Participants characterised this as a religious experience. They described how they had felt a presence coming into their lives: "I didn't hear an audible voice but it was like a strong thought came up". They sensed that this presence was something other-worldly: "The presence of whatever it was I now believe was angels or the Holy Spirit; I'm not sure". Those participants who had this experience indicated that this was the moment from which they started to pull through: "From that point on I started to recover".

The importance of empowering experiences in bringing about the *turning point* was also reflected in the literature. Longden³⁴, a writer with a mental illness, remembers her "breakthrough" moment that was a "crucial first step in the healing process". A psychiatrist empowered her by seeing her as a person and not merely as "a schizophrenic":

"It was the first time I had been given the chance to see myself as a person with a life story, not as a genetically determined schizophrenic with aberrant brain chemicals and biological flaws and deficiencies that were beyond my power to heal."

In other examples, male people with a mental illness living in rural Queensland talked of their turning point as gaining correct knowledge³⁵. Other writers with a mental illness emphasised the importance of being put on the right medications⁹ and using affirmations²⁴. A review of studies on how people live with or get over being suicidal mentioned the importance of being validated as facilitators for their turning points¹⁵. Moreover, people who had been abused in childhood and did not have a mental illness also spoke of a religious experience being "'an absolute pivotal moment', a turning point" for them in a study on how they thrived in adulthood³⁶.

After having gone through the *turning point*, whether it was precipitated by a crisis or facilitated by empowering experiences, participants in this study realised that despite the pain involved, this transition had been necessary and that it had been worth it: "It was a blessing". They also understood that without it they could not have moved into the second stage of the process of *transforming oneself* where they were now able to make fundamental changes to

themselves and their life. Having gained a small amount of power during the *turning point* participants now realised they could start on a new trajectory, a trajectory on which they were finally able, step-by-step, to build on this power in order to resolve *life is a struggle* in its totality.

Stage 2: Getting better as a person

Participants started on a new trajectory by taking the most important lesson learnt in stage 1 to heart, namely that they could not *get on top of having a mental disorder*. They now realised that they had to take a much broader view by going "far beyond the boundaries of mental illness and the biomedical model". They had to change their focus onto what was pivotal to *life is a struggle*, that is, *the struggle to identify any intrinsic value in oneself as a person*, and resolve that first. They said that this redirection of their focus led them to a "deeper understanding" that they could only resolve *life is a struggle*, and correct some of the errors they had unwittingly made in stage 1, if they concentrated on this one aspect first. They termed this refocus as getting better as a person: "I know I can't get better with my mental disorder but as a person I want to get better".

Getting better as a person had a personal and a social dimension. The personal dimension was illustrated by the following participant: "I want to get stronger. I want to be able to cope better". The social dimension pertained to participants' *getting better as a person* in their relationship with other people: "The only thing that makes a person better or worse is this: you are better if you can do good things like helping other people and you are worse if you do bad things like hurting other people".

The necessity of changing the focus away from *trying to get on top of having a mental disorder* by "minimising ... [its] significance [and] relegating ... [it] to a small and insignificant corner" was also recognised by other people with a mental illness⁶. Likewise, Steele⁹, a writer with a mental illness, identified that *getting better as a person* was important, both in the personal and social dimensions. In a study by O'Connor *et al.*³³ people who lived with paraplegia but who did not have a mental illness also insisted on refocusing away from their physical condition towards "a broader conceptualisation of self" because "focusing on the medical could be particularly damaging".

Participants in this study realised they had to find their own ways of how to accomplish *getting better as a person*: "Nobody taught me". They said that they could now find these ways because of the insight they had gained from their own experiences to date: "These are the benefits of being pushed through the grid mesh". Three steps, embedding both the personal and social dimensions of *getting better as a person*, were identified: gaining a new perspective, learning new strategies and taking action. Steps differed from the phases in stage 1 in that, by and large, one step built upon the last, and participants did not go back to previous steps unless they wanted to deepen their accomplishments further.

Step 1: Developing a new, positive identity

Through refocusing away from *trying to get on top of having a mental disorder* onto *getting better as a person* participants grasped the opportunity to look anew at who they were as a person. It slowly dawned on them that they had attributes that did not belong to the disempowered picture drawn up by society, and which they had so completely adopted in the pivotal *struggle to identify any intrinsic value in oneself as a person* in chapter 2. They realised that these attributes, hitherto obscured, indeed belonged to them and could be used to

lay the foundation to build a new identity that was positive. That was the start for their enduring empowerment. Participants said that they gained this realisation through becoming self-aware. Some used creative writing and visual arts to this end: "You find yourself in creativity".

Becoming self-aware of who one was as a person and one's place in the world was also found to be important by participants in Ridge and Ziebland's study²³. Likewise, Leete³⁷, a writer with a mental illness, thought it imperative to recognise positive attributes in oneself because these attributes were "the tools for rebuilding our self-image and thus our self-esteem". Secker, Spandler, Hacking and Shenton³⁸, in their study on empowerment and arts participation of people with mental health needs, also emphasised how doing art had empowered participants in their study "especially with regards to gaining a new perspective of who one is as a person".

Participants in this study discovered three significant attributes in themselves that became part of their new, positive identity: the ability to make choices, self-reliance and determination. They explained that the ability to make choices went far beyond the thinking of the dead-end possibilities in stage 1: "I just used to think, 'Do as you are told'. So realising now that you have [the ability to make] choices". Understanding that one had the ability to make choices brought with it a measure of power, such as the power to analyse complex situations. One participant gave an example of how she analysed in depth the complex ethics around choosing whether to take her abuser to court. This analysis involved weighing up her religious faith, which asked for forgiveness, the protection of other family members who might get hurt in the process of having to stand up in court as witnesses, and the requirement for justice. By justice she meant that her abuser had to own up to and pay for his crimes by going to prison.

As a result of participants' realisation that they had the ability to make choices, they recognised that they could now decide with whom they wanted to spend time. This freed them from much of the terror of having to associate with people who mistreated them, and straight away relieved a large part of the struggle with relationships: "You suddenly realise you don't have to mix with people that make you unhappy". They also found that it even extended to the power of making a choice over whether to commit suicide: "That [committing suicide] is something I can do because that is my choice". This simple realisation already eased *the struggle with staying alive*.

Self-reliance was the second attribute that led to a new, positive identity. Participants regarded self-reliance as consisting of being materially independent of other people, ranging from being financially independent and earning one's own living, to having secure housing and owning a car. Participants explained that self-reliance was important as it allowed them to gain the power and freedom to "run their own life". As a result of an increase in self-reliance they noticed an immediate improvement with regards to *the struggle with trying to survive through daily life*: "Things have just got so much better".

Determination was the third positive attribute participants discovered in themselves. Although they had had a lot of determination in stage 1, they now realised that to be effective in their determination this time, they had to redirect it towards *getting better as a person*. For example, they were determined to take full responsibility for what they wanted to do in life: "Now I take responsibility". Others were ready to complete their courses, thereby resolving the struggle with studying.

GAINING MENTAL ENERGY AND INNER STRENGTH

Participants realised that the positive attributes making up the new, positive identity could only be utilised in resolving *life is a struggle* if large amounts of mental energy and inner strength were available. Any small amount of mental energy needed to be nurtured. Some found it helpful to do physical exercise. The positive effect from physical exercise on increasing their mental energy contrasted with its lack of effect on lifting mood levels in stage 1. Participants in Crone and Guy's study⁴¹ on understanding experiences of people with a mental illness of sports therapy also found that they had more energy. Moreover, they reported that they felt mentally more positive with greater self-esteem when exercising because exercise gave them a sense of accomplishment and well-being.

Participants in this study found that resolving two aspects of *life is a struggle* in particular required large amounts of mental energy and inner strength: *the struggle with staying alive*: "It was taking sometimes all my energy just to stay alive"; and *the struggle with responding to the impact of having been abused*. Participants explained that it took an extraordinary amount of mental energy and inner strength to escape, for example, from the memories of being held emotionally captive: "Otherwise you're trapped by the past and it's got you in bondage". Without inner strength in this context, they knew that they would fail to get out of the trap that the past represented and that they would become bitter.

Participants now also realised that they could harness the mental energy that came from being angry. Anger, the one positive emotion that emerged from *life is a struggle*, gave them the inner strength and hence the power to stand up to those people who had abused them, who had not believed them and who had devalued, dehumanised and mistreated them. The strength garnered from anger became in some instances so great that participants seriously considered prosecuting their abusers:

"I have now got the strength to stand up in court and look at him [the abuser] one day and say, 'Look, I am not doing it from revenge. I am doing it because I am a strong person. You would probably have never thought that little * [name of participant] would be standing here at * [age] and looking you in the face and saying, "This happened"'. And he can lie to my face and deny it but then I might get even more angry."

Anger, not as a symptom of the mental disorder, but as an energising force was also a common theme in the literature emanating from people with a mental illness. Deegan³⁹ emphasised that anger is a "very sane response to the situation you are facing" and that it "moves [people] into action to change the injustice ... [they] face". Participants in Lucock, Barber, Jones and Lovell's study⁴⁰ on views of people with a mental illness of self-help strategies in the United Kingdom also found that this kind of anger brought empowerment.

RE-EXAMINING SOME PREVIOUSLY UNSUCCESSFUL ATTEMPTS AT RESOLVING LIFE IS A STRUGGLE

Utilising the gains of *getting better as a person* to date, that is, having started to develop a new, positive identity in general terms, participants were ready to look again at two aspects of *life is a struggle* in particular, namely at *the struggle with having a mental disorder* and *the struggle with responding to the impact of having been abused*. Participants went back time and again to try and resolve these two aspects because they were so difficult.

In *the struggle with having a mental disorder* participants were now set to re-examine what kind of person they were in this context. Whereas they had previously rejected this part

of themselves, they now realised they could not ignore and deny it being a part of who they were any longer:

"I have been in that framework, 'Oh, you just need to walk away from it'. But when we walk away from things [the mental disorder] we are running away from ourselves. We are running away from our own selves, a part of who we are."

As the mental disorder was a part of who they were, and in line with their new-found positive identity, participants rejected the idea that they were a bad person. They accomplished this by completing the challenging task of de-stigmatising their mental disorder. They began to regard it like any other physical disease rather than as a demonised condition: "It's no worse or no better than any other illness that we have". Therefore, they reasoned, they were not different in value from other people who had a physical disease.

With this notion that the mental disorder was like any other physical disease, participants came to understand that it had to be looked after like any other disease: "So, I am diabetic. So, I've got to look after my diabetes. So, I am mentally ill. So, I've got to look after * [the mental disorder]. That's how I see it". Looking after the mental disorder involved managing it: "You must control it, because it will just control you otherwise. You must find some way to control it".

Participants now recognised that, after having tried to deal with their mental disorder unsuccessfully for so long, controlling it in some way involved agreeing to get treatment. Therefore, treatment had to be de-stigmatised as well and regarded just like any other type of medical treatment: "I need to take my [mental health] tablets like some people need to take their blood pressure tablets or their vitamin pills". The same attitude was projected onto being hospitalised. Hospitalisation during an episode was now seen as just a minor disturbance in one's life and not as a major setback: "So what if I have to go into hospital for a few weeks at a time. I'll look at it as being an interruption. It's just an interruption because I'll be coming back out again". Viewing the mental disorder and the associated treatment as just another part of life, participants finally started to make sense of what was happening. They were no longer frightened and worried to the same degree. It also reduced participants' helplessness by giving them sufficient power to demote the previously all-encompassing and dominating *struggle with having a mental disorder* in importance: "It is a small, small part of my life now".

The second aspect of *life is a struggle* that participants had previously tried so hard to deal with in stage 1 was now also ready to be re-examined, namely *the struggle with responding to the impact of having been abused*. Again, their new, positive identity and the increasing amount of power associated with it helped participants to be now strong enough to face the fact that the abuse had happened: "Unfortunately, that event is my reality". This contrasted sharply from the first phase in stage 1 where they felt they had had no other option but to hide their memories under a trap door, withdraw into a fantasy world or split themselves into an outer persona and an inner true self. Instead they now realised, by looking at the long time that had elapsed between the abuse and the present time that they had indeed survived: "I am still here". Being still here proved to them that they were now safe and that they did not have to live in fear any longer: "No one is going to hurt me anymore". Now the wounds inflicted by the abuse could start to heal. Participants said that although the dissociation still "pops its head up at times" their wish to have a whole and intact sense of personhood was almost realised: "I wanted the two to be together so that I knew who I was and how I felt". To further reinforce the feeling that they indeed consisted of one person, participants said they had to constantly remind themselves of this fact: "I am still looking at the mirror and just touch my hand". They found that through these reinforcements the periods

of time where the disassociation between the outer persona and their true inner selves happened grew fewer and shorter: "It is getting less and less". The prospect of "getting that congruence so that I felt as one person, not two" was within reach.

Furthermore, they now saw the connection between the abuse and their mental health symptoms, which took away more of the helplessness associated with not making sense of what was happening in *the struggle with having a mental disorder*: "These outward symptoms that are manufactured from the trauma and the abuse I am now recognising them coming from the trauma and the abuse". Connecting the signs and symptoms to the abuse that had occurred in childhood had also been important to participants in Harper *et al.*'s study¹¹ on what people with a mental illness, traumatised by child abuse, needed from community-based mental health professionals.

ACCEPTING WHAT CANNOT BE CHANGED

After having developed a new, positive identity and gained sufficient power, participants were now strong enough to accept what could not be changed. For example, with regards to *having a mental disorder* they now accepted that they had one: "I accept it. I've got it. I accept it. I can't help that". To aid them with this acceptance, participants thought of three proofs that demonstrated to them that this was true. The first proof consisted of becoming aware of certain tell-tale symptoms that a mental disorder was present: "Something triggered that it could be right". This was especially pronounced when participants had come out of an episode and looked back at how they had been when sick: "Really, it was only in hindsight that I look back and think, 'You couldn't do that without being sick. You couldn't be like that without being sick'".

The second proof was provided when the taking of medications had reduced or even got rid of their symptoms: "I don't attempt suicide anymore and I don't have this * [symptom] I had before. So I must have the illness. It's the only way I can look at it". However, for those participants who did not feel any different when on medication, the third proof came when they had gained sufficient trust in health professionals to believe them when they told them that they had a mental disorder.

Alongside the acceptance that they had a mental disorder, participants were now also ready to accept that it was unlikely to go away despite the easing of symptoms when on medication: "At times in my life I am going to be * [a person with symptoms]. I must accept that". With this acceptance achieved they could also move onto accepting that they had to have treatment, and that this treatment had to consist of taking medications: "Unless there is some magic way of dealing with it, medication is the way that I am going to be helped". However, participants had to find the right medication that made a difference to them without side effects that were too damaging. Once participants had found it, some by changing health professionals, others by widely consulting Internet forums for people with a mental illness, they were glad that this medication existed: "When the medication kicked in it was like seeing in colour for the first time". Furthermore, participants came to the conclusion that medications were not an optional extra but had to be taken long-term so that they would not go "downhill" again. They now realised that their previous argument for going off medication, namely that the mental disorder had gone away, had been erroneous:

"I used to think it was like taking antibiotics, take it for the infection and it's gone. I used to believe that and go off them all the time and that was the worst thing I ever did. You must never, ever go off your medication."

This realisation turned them into dedicated medication takers: "It's absolutely necessary for me". Participants said that they were now also willing to put up with some of the unpleasant side effects because they realised that the benefits of taking the right medication outweighed the drawbacks: "If the medication doesn't agree with you, tell the doctor, but put up with it because in the end, it is doing you good". Likewise, electroconvulsive therapy was welcomed by those participants for whom it worked: "It's done the best for me. It's done wonders".

Acceptance also occurred in relation to *having been abused in childhood and/or adolescence*. Participants were now ready to accept that they had been traumatised in this way: "I am feeling some very deep-seated loss and grief that has been etched into my psyche from my earliest experiences. And I have accepted this".

Other people with a mental illness also accepted what could not be changed. In Ridge and Ziebland's study¹⁰ on how people give meaning to recovery following depression participants stated that they had accepted themselves, "warts and all". The writer with a mental illness, Deegan⁴², added that delaying the acceptance that one had a mental disorder until this time was wise because now one had "the resources to deal with it". As did participants in this study, other people with a mental illness then also accepted that taking medications was necessary in a study by Van der Tillaart *et al.*⁴³ on voiced realities of women living with a mental health diagnosis. Boyer⁴⁴, a writer with a mental illness, described the same experience as participants in this study after starting medication: "The color had come back into my world".

EVALUATING

The last task was to set the new, positive identity in context. Participants in this study achieved this by comparing themselves with what they called other normal people. This comparison made an evaluation of their new, positive identity possible. Participants said that in many respects they were like other normal people, meaning that they had the same needs and aspirations: "When you say normal, I eat, I drink, I breathe, like everybody else". They also had the same ambitions to further themselves in life, to be able to work like other people or to just go traveling with friends. Most of all, they wanted to stay in their own home and not be locked up in a mental hospital.

However, despite having many things in common with other normal people, participants also knew that they were not like them: "I am not like other people". They did not feel like other normal people because they had a mental disorder: "Basically my whole life I have never felt normal". The previous view of what normal meant in stage 1, which referred to a possibility that participants would be able to be free of signs and symptoms, had gone. Likewise, they now realised that their former goal of getting back to what was considered a normal lifestyle was unattainable: "That's what they [people with a mental illness] think can happen but it doesn't".

Participants said they were particularly not like other normal people because they held different ethical values. The ethical values held by many other normal people, according to participants' experience, were a readiness to go out and harm others, leaving all ethical norms of how to treat other people behind:

"There are so many people that can throw their morals and their integrity out of the window as if it is something of no value and be as evil as you can possibly imagine. I mean, that is just normal. That is just ordinary people."

Participants did not consider themselves normal in this sense: "I'm not as evil as it is normal to be. That's what it is". They said that their different set of ethical values consisted of treating everyone as equals. They maintained that this was the true yardstick one should be judged by: "That's how I grade people". By comparing themselves with other people using this yardstick, participants found that they were not of lesser value. They were not non-persons or sub humans, as many sections of society had made them out to be, but qualified as human beings: "I finally realised I was a human being". The writer with a mental illness, Deegan⁴², agreed: "The goal ... is not to become normal. The goal is to embrace our human vocation of becoming more deeply, more fully human". In this study, this insight finally resolved *the struggle to identify any intrinsic value in oneself as a person* for participants.

To complete this section of *getting better as a person* by developing a new, positive identity, correspondent literature about people who did not have a mental illness were included to illustrate that many people from the general population go through a similar process. In examining gender, contexts and turning points in adults' lives, Clausen⁴⁵ stated that, like participants in this study, people questioned their identity. Wethington *et al.*³² looked at turning points in mid-life and described how people had likewise gained awareness and new insights into themselves and into situational factors. Wheaton and Gotlib²⁶ explored trajectories and turning points over the life course and identified the occurrence of a transformation of identity.

Continuing with those who did not have a mental illness but had been abused told of how they had managed to face what had happened to them. Likewise, anger empowered them: "As the time passed and I faced honestly and openly what had happened, I got angry. And that anger became outrage. And outrage drove me forward with purpose and a new clarity"¹⁶. In a study²⁰ from Perth, Western Australia, participants with chronic physical conditions and also no mental illness described how they had looked at their illness in a different way. A Victorian study⁴⁵ on how young women with type 1 diabetes managed turning points and transitions included the acceptance of their illness.

Step 2: Learning new strategies

After having gained a new, positive identity, and before taking action, *getting better as a person* could now progress to devising new strategies: "A lot of it was strategies". Participants thought of four new strategies: formulating new goals, having a plan ready, using constructive ways of dealing with problems, and developing new skills.

The first new strategy started with "wiping my slate clean". Participants reasoned that any old goals from stage 1 had to be got rid of and new goals set so that the new strategies could reflect them. These goals had to be realistic: "Something that you felt that you could cope with". They had to be tangible, or within easy reach, such as losing weight. In addition, they had to be short-term, at least initially, as participants felt that planning for the long-term was not yet feasible for them. Having realistic goals and focusing on small daily tasks was also advised by other writers with a mental illness such as Repper and Perkins⁶.

Participants in this study found that these new goals had to be gradually implemented in small increments: "You just take the tiniest of steps, all in your own time". Furthermore, to make sure that participants did not overreach themselves they "set boundaries". Sticking to the new goals within the boundaries they had set themselves gave participants further power and they no longer felt overwhelmed by the many tasks required to resolve *life is a struggle*.

The second new strategy was to have a plan of what to do ready for when another episode loomed. Participants stated that being proactive in this way reduced the helplessness

experienced as part of *the struggle with having a mental disorder*. Having a plan ready consisted of increasing medications oneself straightaway before accessing medical help. Many participants also made sure their plan included having support people in place, such as family members and friends, so that they could be used when things deteriorated: "You have to have some key figure to act as security blanket so that you can mobilise the troops". These key figures could then take over in case participants were temporarily left helpless in case *having a mental disorder* recurred by, for example, arranging immediate access to treatment. The necessity of having a plan ready, often referred to as advanced directive, was also recognised by many other writers with a mental illness^{4,40,47-50}.

The third new strategy in this study was to use constructive rather than destructive ways of dealing with problems. Using constructive ways prevented the disastrous consequences of using extreme measures that had damaged both participants and their relationship with other people in *trying to get on top of having a mental disorder*. For example, participants explained that a constructive way to deal with problems was to ask for help from empathetic people rather than turning despair onto oneself: "Now I ask for help instead of self-harming".

Other constructive ways were employed towards resolving the struggle with working. Despite the great importance of work, participants' wish to find any kind of job, whether suitable or not, had now passed. Instead of sticking with the often toxic work environments and getting despondent and stressed, they now employed constructive ways at finding work. They formulated specific criteria for jobs that would suit them. They said that they were looking for jobs that were beneficial to them as a person, providing job satisfaction and contributing to meaning in their lives. Getting a living wage was also important: "It has to be something viable and profitable". Due to the difficulties in finding employment like this, some participants had decided to work for themselves. They had been fortunate enough to find a niche in the market place where they could work according to their own schedule, yet be productive, earn money and bring pleasure to other people at the same time: "Out of it all I've discovered a niche". In the absence of suitable work, some participants opted to do voluntary work, despite the lack of remuneration, as they were aware that it also would give them an enhanced feeling of value.

The fourth new strategy was to translate the different goals and constructive ways of dealing with problems into skills: "The skills that we need to live". An important skill was deciding how much to analyse problems. Participants knew that not all problems had to be analysed too deeply but that merely acknowledging them and then deciding to move on was often sufficient. This pertained especially to simple problems. In contrast, complex problems could not be skimmed over. For these, precipitating events and reasons for their occurrence had to be identified so that they could be avoided: "Try and stay away from anything that will cause you unnecessary grief".

If precipitating events could not be avoided participants had to learn to manage them. For example, the precipitating events that brought on stress: "I have to be very careful of my stress levels". They said that not to panic was important and achieved by trying to stay calm and relaxed. Certain types of exercise aided with this relaxation: "You got the rhythmic exercise, walking or swimming or whatever it is that you do. I did yoga. That was brilliant, just the breathing and the relaxation". Participants also found that slowing down, reducing the number of activities and sticking to a daily routine helped. Other writers with a mental illness also mentioned that it was important to be careful about stress levels²⁴. Lucock *et al.*'s study⁴⁰ on how people with a mental illness view self-help strategies in this context had also used "gentle relaxation" and had organised their life around daily routines.

Being vigilant about precipitating events was also used as part of resolving *the struggle with having a mental disorder*. Participants in this study explained that by becoming aware of precipitating events, warning signs that symptoms might return could be pinpointed. They now knew that even on the right medications symptoms could come back at any time and therefore they had to be watchful in an ongoing way: "I could crash again in a major way". Participants said that warning signs ranged from innocuous ones: "My main warning sign is if I wake up in the morning and think, 'Oh, my goodness, not another day'" to alarming ones, such as thought processes starting to change: "I get these irrational thoughts". Even suicidal thinking sometimes occurred as a warning sign before an episode started. Learning what these warning signs were, and not ignoring them was vital: "Notice warning signs. Don't ignore them. They are there for a reason. They are telling you something". However, even when an episode recurred, participants now saw it, for the first time, as something positive as it told them to be careful about those facets of their lives that were not conducive to living with a mental disorder "So, instead of pushing the door on it [ignore it] and then keep carrying on, like you have been doing, say, 'Ok, come for a visit'".

Being vigilant about precipitating events and heeding warning signs as part of resolving *the struggle with having a mental disorder* were also used by other writers with a mental illness^{50,51}. A participant in Ridge and Ziebland's study²³ on how people give meaning to recovery from their mental disorder explained that he had also changed facets of his life that were not conducive to living with a mental illness to reduce the likelihood of getting another episode: "It's rather like having a dream which is telling you something. I take no notice so it returns and recurs until I do".

Another important skill learnt by participants in this study was to wait for problems to pass. They realised that many problems in life did not last very long and passed sooner or later without any intervention. For example, symptoms and even whole episodes passed on their own accord: "I just have to wait it out. I just have to let time takes its course until it's better". Participants therefore decided to "just keep breathing through it [until the symptoms] eventually diminish". They were now confident in the knowledge that many other problems were only temporary: "Life is a roller coaster, it goes up and down and up and down. Even when it's really low, you know it's going to go up". Some suicidal thoughts were also treated that way:

"I made a deal with myself. In three days' time if I still felt like this suicidal, and I was still so sure that it was all sane and it all made sense and it was all very logical, then I would start putting a plan into action, and to do away with myself. Of course by three days later I wasn't feeling like that anymore."

Furthermore, participants developed new skills of how to handle problems. Participants said that this entailed, initially, learning what they could handle and what was too much: "I have learnt over the years now that I've got to do what I can only mentally, physically, financially do". This necessitated dealing with one problem at a time and not letting them build up as participants had done previously. They also started to prioritise them. Lastly, they stood back from problems and put them into perspective: "Being able to stand back from what is happening and looking at yourself from outside and seeing what different things are". Putting problems into perspective made it clear to participants that many small problems were not really large and important after all. People with a mental illness in Ridge and Ziebland's²⁴ study also used the same skill of putting problems into perspective.

Putting problems into perspective was also utilised in resolving *the struggle with having been abused*. Participants in this study were now able to stand back and realise that, on a global scale, many other people had also been subjected to similarly traumatic situations

and had managed to survive: "I realised, 'So, these things have happened. Wars have happened, people have had to struggle and live and survive'. My circumstances are just like another little bit in history. You realise, it's no different from other people". Furthermore, participants noticed that other families also had problems and that they had chased an unrealistic and unachievable dream of living in a perfect family. This awareness finally absolved them from blaming themselves for having been abused and contributed to giving them further power that freed them from being imprisoned by the haunting memories.

In addition, putting problems into perspective was employed towards resolving *the struggle with staying alive*: "I just think, 'Oh, well, really in the big scheme of things it is more important that I should be here', and I know that". By putting this aspect of *life is a struggle* into perspective participants could now see that what they previously thought as logical had been flawed: "I can see how, even though that's logical [at the time of feeling suicidal] it is illogical to think like that". Coupled with their by now strong willpower participants were able to convince themselves that suicide was "not what you want to do". They were also surprised at being glad that they had not succeeded in killing themselves previously, in contrast to having been angry when they had been saved: "First you are angry. But when you feel good and you come home again from hospital, you think, 'Ah, look'".

By putting problems into perspective participants in this study now felt more detached from them and therefore were able to take each day as it came without being overwhelmed: "I just take each day as it comes now and whatever happens; happens". Going about life this way, they realised that not everything needed to be solved and all that was required was doing the best one could within the realm of what was achievable: "For me, when I really struggle I just do whatever I can". Twomey⁵², a writer with a mental illness, had similar ideas: "Whatever I accomplished, however small, would be enough". This freed participants in this study from much of the guilt at not being able to handle *the struggle with trying to survive through daily life*.

The last skill participants in this study learnt was how to deal with distressing thoughts. For example, they were now strong enough to counter or oppose voices in their head by sternly talking back at them: "I started controlling my head, 'I cannot talk; I shouldn't talk to anybody'". Tormenting thoughts were discredited, knocked down and not succumbed to, such as the urge to carry out self-harming activities: "I haven't given in. I don't intend to give in".

However, the most widely used skill participants used in dealing with distressing thoughts was to actively try and change the length of time these thoughts occurred. They had another look at the technique of positive thinking that they had tried to use unsuccessfully in stage 1. They realised that they now had enough strength to shift the balance away from the previously overpowering negative thoughts towards having some positive thoughts instead: "Tell yourself to think of a better scenario". Participants said that the secret of thinking positively lay not in expecting that every thought would now be positive but in changing the balance in small ways: "Not going over the top positive thinking". Occasional positive thoughts could then be increased in number gradually so that they occurred more frequently until they began to outweigh the negative ones. With this progressively increasing level of control over negative thoughts participants came to appreciate that the positive thoughts, although sometimes few in number, especially to start off with, were very valuable. The ability to think in a positive way, even if only transiently, then helped with making changes in behaviour: "If one changes one's way of thinking you can behave in a different way".

Changing one's thinking from being less negative to more positive was also applied to reducing the times when the tormenting memories of *having been abused in childhood and/or*

adolescence were overwhelming participants. However, this was much harder to achieve: "What happened to me as a child was a very traumatic and overpowering event. Consequently the mindset that I took on was very strong and overpowering". Initially, participants brought out the tormenting memories about the abuse cautiously from under the trapdoor where they had been stored. Then they forced themselves to identify some pleasant events that had happened in their childhood and/or adolescence also and to focus on remembering these instead: "If you really sift through all the bad things, you can find good things. Think about the day * [abuser] took you to see Santa. Not the day she belted you". Participants found that gradually the length of time in which the abusive events were remembered diminished and the pleasant thoughts became more numerous: "Think about the positive and skim over the bad parts. I used to think about it [the abuse] all the time and dwell on it. It used to just crowd my mind. I don't do that anymore". Participants could now see that life was made up not only of the many tormenting memories but also of good ones:

"In my experience, most people that have had hard lives will think about the real bad experiences they've had. They see the thorns on the rose bush but don't see the rose. You got to look at the rose, too, because it's a whole package deal."

Finally, participants were ready to start letting go of the tormenting memories: "You've got to let go. Let go of the past". The following participant described leaving the bad memories behind, like leaving troublesome baggage behind at a railway station: "Being able to drop the baggage off saying, 'You are left at that station. And I am not picking you up again'. Letting the baggage go changed the previously ingrained train of thought that had been full of the awful memories onto a new and different track. This way the scars left by the abuse started to slowly fade.

People without a mental illness developed similar new strategies to participants in this study. For example those with type 1 diabetes⁴⁶ learnt to put their life with an illness into perspective. Those who had been abused learnt to deal with their memories by "choosing not to dwell on horrendous episodes [of abuse] but to hold on to [positive] memories"³¹. They spoke of "reprogramming" themselves, as described in Herman's³² theory on trauma: "I'd consciously impose other powerful images on the feeling (of the father abusing her) - like seeing a waterfall. If they can put SM (sodomasochism) on you, you can put waterfalls there instead". Like participants in this study, O'Gorman¹⁶, a writer without a mental illness, had also realised that he had, in fact, survived and stopped blaming himself for having been abused.

At the end of learning new strategies participants in this study felt that they had now got much better as a person on the personal dimension in that they were able to "cope" much better. *Getting better as a person* on the social dimension happened during the next step.

Step 3: Taking action

Some participants in this study had gained sufficient power when going through the *turning point* to take action very quickly, some as early as the next day, in order to get out of the vicious cycle characteristic of their powerlessness in stage 1. For example, some participants demanded to know how their health care could be altered so that the precipitating crisis was not repeated. Others took bold action to get out of the unbearable smaller crises that had enveloped them: "I got out of the * [type of mental health] system when I took them to Mental Health Law". However, the majority of participants needed time to take action after they had developed a new, positive identity and had learnt new strategies. Taking action

consisted of adjusting one's lifestyle, acting to protect others and oneself, helping others, and facing other people head on.

The most immediate action was concerned with adjusting one's lifestyle. Here participants started to take care of themselves, such as eating a balanced diet and getting enough sleep to reduce the possibility of getting another episode: "Because if I miss out on too much sleep that can send me down [into another episode] really quickly". Participants also pointed out that trying to keep busy helped, which meant staying occupied doing things that involved more than watching television: "Don't sort of sit around watching telly all day". For example, by staying busy with hobbies, participants said that they remained better anchored to logical thinking: "When you've got irrational thoughts keep busy doing things. That's what I found". Other participants explained that another purpose of keeping busy was to ward off loneliness and to keep one's spirits up, helping with opposing the loneliness experienced as part of the struggle with relationships. Keeping busy to "keep my mind off myself"⁵³ was also important to other writers with a mental illness.

The second action was to protect others from getting hurt. This was most important for participants. It was the first time that the social dimension of *getting better as a person* was addressed. The most important group that participants said they wanted to protect were their children. They emphasised that they were determined to protect their children with all their powers from any possible abuse by guarding and nurturing their carefree nature, including their sexual innocence: "You are determined that they are not going to suffer what you've suffered". In addition, participants pointed out that detecting any possible signs of a mental disorder in their children early would also ensure their ongoing good mental health and happiness: "I am actively watching out for it because I would like to nip it in the bud so they don't have to go through the same as me". Through protecting their children in this way participants reduced the worry experienced as part of *the struggle with having a mental disorder*. Some went even further by making sacrifices to protect any prospective future children by deciding not to have any at all: "That's why I've never married and had kids because I don't want to put a kid of mine through the hell I went through. I don't think I could live with myself if I did that".

Protecting one's children was also important in a study with fathers who had a mental illness⁵⁴ and in studies with people who had been abused but who had not developed a mental illness^{17,18,36}. A decision not to have any children was also common to both groups², including to those with a physical illness that could possibly be passed on to the next generation¹⁸.

However, most of all, participants in this study wanted to protect other people, particularly family members and friends, from the terrible hurt and shame they would experience if participants were to commit suicide: "They would all be completely devastated". Therefore, they vowed to never go through with committing suicide, almost completely resolving the doubt about whether it was the right thing to do in *the struggle with staying alive*: "I think of my son then and what it would be like for him when I'm gone. So that he keeps me here". Participants insisted that even people they did not know should not be hurt that way:

"The thing that stopped me from doing that [stepping in front of a car to commit suicide], I'd be on the curb and I'd go to do it, and then I'd think of how the driver is going to feel. And that pulled me back every time."

Joiner⁴⁷, in his theory on suicide, also quoted someone who said "I couldn't do that to so-and-so" and found that that was an important reason for not committing suicide.

In this study, some actions were also directed towards protecting oneself. Participants found that they had developed a thicker skin over time that protected them, for example, from giving in to the disempowering force of *wanting to be dead*: "I feel like I'm bullet proof with regards to suicide because I had to contend with it all the time". However, participants most commonly sought to protect themselves from getting hurt in the struggle with relationships. This was utilised especially by those who had been battered so severely that they were not willing to take any further pounding. These participants decided against any further attempts to keep in contact with family members after they had yet again been hurt by their rebuffs. The same applied to work: "I never want to work in a situation with bosses or people who are going to treat me like dirt again". Some participants went as far as choosing not to interact in a personal way with anyone at all because all their attempts at not getting hurt, as documented in the struggle with relationships, had come to nothing:

"I have shut off from everybody. I just don't want to know people. I don't want to know society. That's the only way I can resolve the daily struggle [with relationships] to keep everybody at arm's length. That's the only way I can do it."

This way of protecting oneself by deciding to shut oneself off from other people differed from the withdrawing in stage 1, as the latter had been instinctive. The shutting oneself off here, in contrast, was implemented as a wise measure to protect oneself after long and careful deliberation. It was no longer seen as a negative but regarded as power enhancing.

Shutting oneself off in this way also applied to the interaction with some health services. Those participants who had no positive encounters chose never to go back: "I gave up on them". Likewise, damaging treatments were discontinued "because I burned my ass". Participants even maintained that sometimes it was more beneficial to receive mere sympathy than to interact with this type of health service: "Look, here is 50 dollars, go and have a good meal'. That would be of more help than any other sorts of things he bloody does".

Likewise, other people also left work because of mistreatment as revealed in focus groups²³ on stigma and discrimination towards people with schizophrenia and their family members. Moreover, a decision to "stay away from anyone who has anything to do with the mental health system" was also taken by other people with a mental illness in a study⁵⁴ on the process of recovery from a mental disorder.

Through these protective actions, participants in this study gained power in a quiet way. They found that they could now bypass the fear, shame and self-blame previously associated with the struggle with relationships.

According to participants, another essential action in *getting better as a person* in the social dimension was to help others: "I do feel like I have things to give and I'd like to be able to give them". Participants realised that they possessed the qualities required of a good helper, such as being kind and compassionate. They also found they were able to understand what other people went through. These qualities were underpinned by a rule never to take superficial views of other people as an indicator of their intrinsic value: "I take you for what you are". In the case of other people with a mental illness, participants said that they were now able to "appreciate" them, in contrast to their view when they were still struggling with making sense with what was happening: "Before you think, 'Oh, people [with a mental illness] are mad'. But it is not madness". This included the understanding that people with a mental illness should never be blamed for their behaviour: "When they do something wrong it is not their fault".

Having these qualities set participants up to find people who needed and appreciated their help. They found groups of people who had been disempowered just like them: the infirm elderly, those who had a physical disability and those who, like participants, had mental issues in some way: "There have been a lot of people on the way who I know struggle too". Participants helped these people through simple acts like encouraging them in whatever they wanted to do. They also tried to talk to them about how to resolve *the struggle with staying alive*: "I sat up with him to three in the morning". They endeavoured to help those people who were still in mental hospitals to stand up for their rights, thus giving them a boost in power to get through *the struggle with establishing credibility* and *the struggle with having been let down by the mental health system*. Other participants helped other people by setting up support groups: "I had the desire to reach out and help other people". This ability and capacity to help others then provided participants with a purpose in life: "I kind of think that's what I'm here for". Thereby they had found another way of finding meaning in their life, apart from doing satisfying work, further progressing towards fully resolving *the struggle to identify any intrinsic value in oneself as a person*. The same happened to other people with a mental illness. They said that helping others gave their life purpose and meaning in studies from Northern Ireland⁵⁵ and Australia⁵⁶.

The corollary of helping others was accepting help oneself. Participants in this study finally realised that there were people out there who were willing and able to help, that it was possible to contact them and that it was important to take up their offer: "Listen to them; they are trying to help you". However, in contrast to stage 1, participants did not accept this help without any critical analysis as to its benefits. To this end, they attached two provisos. The first proviso concerned the demand to be attended to: "It is important to be pushy, push for help". The second proviso was to be selective as to the right type of help and the qualities of those who provided this help. The right kind of help consisted of being accepted and treated as the people they were, that is, as human beings who were to be valued equally. Participants were also looking for the right qualities in the people who wanted to help, such as being interested in and having a willingness to understand them. Being taken seriously and having the best interests of participants at heart were also important. Participants felt that these individuals, displaying true empathy, could be trusted and followed their advice to the letter: "Have faith in them. Do what they say you should do".

As a result of being helped, participants were very "grateful". In being grateful they emphasised that they now wanted to "turn it [the help they had got] back" in some way. Participants in other studies felt the same, for example a participant from a Canadian study⁵⁷ said: "I am not just a person here on earth meant to take, take, take, but I have something to give".

Participants in this study explained that returning the help they had got meant meeting their obligations to society. They saw these obligations as not being a "burden" to others, where a burden is defined as relying too much on others for help. For example, not being a burden to individuals involved not exposing one's problems unduly so that others did not become worried. Not being a burden to society meant not relying on the government for too much financial help: "So I can carry my weight if that is possible. That's my desire". Another form of returning help was to do something in society that was beneficial: "I am trying to be a good member of the community". By helping in these ways, participants' life gained further meaning, which added to resolving *the struggle to identify any intrinsic value in oneself as a person*.

As with participants in this study, other people who had been abused but did not have a mental illness also "felt compelled to give something back"³¹ by helping others. They said

that the fact that they had been abused enabled them to provide this help and also gave their life meaning⁵⁷.

The last action consisted of facing other people head on. It was reserved for those people who did not believe them, who devalued and dehumanised them, who were not willing to help them, and who had abused and mistreated them. The way of dealing with the struggle with relationships here was to show power openly. Participants proclaimed who they were, namely someone with a mental illness, because they did not care any more about being known as such: "I really don't give a shit. It is like, 'This is who I am. If you don't like it, too bad'". Any shame they had previously felt had gone. Likewise, participants no longer feared the expected adverse reaction from others and were, in fact, unconcerned with resolving *the struggle with establishing credibility*:

"If people can't handle it, honestly, they are not worth knowing. I've come to that point if someone doesn't like it and they treat me horribly I just say, 'Well, you know where the door is. Hopefully it doesn't bang you on the bum on the way out!'"

Furthermore, assertive behaviour was now also employed in insisting on being treated well in the health field: "I've actually had to sit them down and go, 'The way you are treating me is not helpful. It's making me feel worse'". Participants no longer accepted health professionals' reasons for abusing their power: "They have all the justification under the sun but I make them accountable". As a last resort participants made their concerns known to the top of the mental health hierarchy, often after years, or even decades, of being mistreated by the system. They were not afraid to challenge the whole system when they decided to publicise its failings: "I am not going to let them get away with it". Participants had now finally succeeded in gaining sufficient power to counteract being made helpless in *the struggle with having been let down by the mental health system*, and they no longer felt trapped, afraid and without hope. Some other people with a mental illness took a similarly assertive stance towards the health system, as in a study with 38 men in England²³. Coleman³, a writer with a mental illness insisted that "to be assertive in your relationship with the services ... is your right".

Moreover, some participants in this study set up advocacy groups to act outside the system so that other people with a mental illness could also be empowered to act in their own interests: "We are going off doing things on the outside ourselves and we are making real headway". Lastly, participants undertook the most difficult task, that of sending their perpetrators packing by facing them head on:

"I looked straight at him, and I said, 'No, I want you to hear this and look at me. What I want you to do is just go and get out of my life altogether. Go, get out'. And that's the last I ever heard from him."

Being at peace

The conclusion to *transforming oneself*, encapsulated as *being at peace*, signalled to participants that the long and arduous journey towards resolving *life is a struggle* was complete: "There is no doubt about it, it has been a struggle to have got to that resolution and peace". *Being at peace* was described by participants as *being at peace* with the fact that they had a mental disorder, with their place in society, and with who they were as a person.

Being at peace with the fact that one had a mental disorder

"I am at peace with it now" meant that participants had finally resolved *the struggle with having a mental disorder*. They now felt in tune with it: "I am very much in tune with my illness". As a consequence, participants were liberated from its disempowering grasp: "I am not trapped any more". They had taken power away from *having a mental disorder* in that it no longer ruled their life as it had previously done: "Normally in the past it would have stopped me absolutely from functioning completely, and I can't let that happen. It's still sad and I still feel it but I have to carry on". Participants also realised that they did not have to fight *having a mental disorder* any longer, as they had done in stage 1. They said that this had become irrelevant and was, in fact, counter-productive: "Fighting against it doesn't work. Fighting against it pushes more at you".

Ten participants in a Canadian study⁵⁷ expressed that they were now able to exert sufficient power so that they were no longer controlled by *having a mental disorder*: "You don't have to let your illness run your life". Likewise, participants in an English study²³ on how they give meaning to recovery from their mental illness also did not consider it helpful any longer to see the mental disorder as an enemy that needed to be fought.

Participants in this study now fully understood that *having a mental disorder* could not be banished as they had tried to do so strenuously in stage 1. Instead they had come to terms with it: "I've learnt to live with it". Learning to live with it meant enduring it as a part of life: "You have tears over it and you wish it wasn't there. You have all that. It's normal". Enduring it also entailed tolerating being incapacitated while an episode lasted although they knew that this incapacitation was not nearly as severe as it had been during *the struggle with trying to survive through daily life*.

As a result of *being at peace* with the fact that they had a mental disorder participants said they felt calmer in themselves, their thinking processes had become clearer and their "negative, fatalistic thinking, that was with me constantly went away". They found that the new strategies they had learnt largely worked and kept them relatively safe from any unwanted, uncontrollable, catastrophic slide back into *having a mental disorder*. Their previous fear and worry had abated. They said that they had now become content with how they handled their life: "I have to manage how I am living. And that's all I can do. And that's all anyone can do".

Some participants stated that if they had known at the beginning how long and arduous the journey of *transforming oneself* turned out to be they would definitely not have chosen to take it and would have committed suicide instead. Some doubted that it had been worth it: "If I could have it over again I don't know that I'd do it. I don't know if that was worth it". Yet others could see that resolving *the struggle with having a mental disorder*, although it had taken a terrible toll on them, had also had a good side: "The whole thing was meant to be. I wouldn't know what I know today if I didn't suffer from a mental disorder. It was for the good". They pointed out that it had given them strengths and capabilities they might otherwise not have had. They also knew that they were in a special position to help other people: "You know where they are coming from and so there is actually some great positives in it [in having a mental disorder]". This insight taught them that their suffering had not been in vain: "I am not going out of here, with this suffering and crap, for nothing. It's got to be worth something. That's how I've got to look at it". They pointed out that this realisation made them feel that they were in fact lucky to have a mental disorder as it provided them with a richness that they could not have gained otherwise, a richness, not in a material sense, but in a spiritual one: "That's richness, isn't it? How rich can you be in your soul and spirit?"

We are so lucky. I am lucky. You might feel mad but we are very lucky". This realisation made them rejoice:

"I am glad I've got a mental illness actually. That's all I can say, 'Hurray, I've got a mental illness'. If that's what mental illness has done for me then, 'Hurray, hurray!' If that's what it has given me, the depth of my spirituality and soul, and I am not talking about it in that kind of religious context, then, 'Hurray'. That is so good to have."

Caswell³⁸, a writer with a mental illness, also commented on the richness of his present life: "I'm now experiencing a richer, fuller life that is better than I could have imagined".

Being at peace with one's place in society

Being at peace also referred to *being at peace* with one's place in society: "I am [now] at peace with the world". Participants had finally resolved the struggle with relationships. They were now confident in their dealings with others. They also no longer felt responsible for and, by extension, did not blame themselves, for relationships failing. They knew they were far more astute in judging others and had become more cautious about whom to trust. At the same time, they realised that they were capable of holding down long-term, loving relationships. However, some had become reconciled to the fact that they would remain on their own and had gained "peace and quiet" that way. Many had adopted animals, instead of mixing with people, as animals never failed to appreciate them.

Being at peace with who one is as a person

For participants, *being at peace* with the fact that they had a mental disorder and with their place in society, now coalesced into *being at peace* with who they were as a person. Participants' realisation that they had many positive attributes had given them a new, positive identity. By cementing this to the fullest they had found meaning in their life, thereby fully resolving *the struggle to identify any intrinsic value in oneself as a person*. They knew they were capable people and their self-esteem had taken root and grown. Participants were astonished at the transformation they had achieved, from the terribly low points when they had been powerless, a "nothing", to now being someone who could influence and have authority over how to act and what to do: "It took me a long time to actually believe that you can get somewhere from nowhere".

At the same time, participants had succeeded in preserving their humanity, meaning that they had not gone down the path of adopting the same values and ways as those people who had not believed them, who had devalued and dehumanised them, who had not given them any help and who had abused and mistreated them. In addition, they found that by refusing to take part in maintaining the existing power structure of society, they had preserved their integrity. Despite all the horrible experiences in their lives and the great struggles they had had to endure, their decency and honesty as human beings had been left intact. They knew that they could be proud of themselves and hold their heads up high. This was possibly their greatest triumph and contributed most to their "sense of inner peace".

Some participants were now ready to go out and do all the things they had wanted to do: "Wanting to do things in life, 'I want to do this, 'I want to do this, I want to do this, I want to do this'. So, I want to make up for lost time". They were now able to engage in pleasurable activities, such as gardening, swimming, bush walking, listening to music, writing literature, painting or doing craft work. Although their life was still far from perfect they could readily

see great improvements and this made them change from being pessimistic about the future to someone who was more hopeful: "I became a glass half full person. Whereas previous to that I had always been a glass half empty person, a pessimist".

Other writers with a mental illness similarly described how they were now at peace with who they were as a person⁵³. Boyer⁴⁴ expressed it thus: "I eventually made peace with the idea that I was who I was ... I decided to just do the best I could with who and what I really was". Others voiced their pleasure when they said that they could "rejoice at my good fortune" despite having gone through many hardships⁶⁰. Brechter⁶¹ declared: "I wouldn't want to go back and change anything in my life as I feel that my mental illness has been a blessing in disguise". This also included people without a mental illness but who had been abused. They described that they also had reached "a point of peace and life satisfaction"³¹.

Only one last aspect of *life is a struggle* remained partially unresolved. Participants in this study knew that *the struggle with staying alive* still lingered and would never go away. With some it remained "at the centre of my being. Somewhere better to go". However, they had now also learnt to live with it: "It's a struggle living but I've got used to it". Although sometimes, when life became hard, committing suicide remained an option because it also brought peace with it, and therefore participants regarded it as the right thing to do on the odd, rare occasion: "I just want to be able to rest and relax and be at peace".

Lakeman and FitzGerald¹⁵ also found in their review of 12 qualitative studies on how people live with suicidality that "struggling against a desire to give in to suicide ... did not diminish in time". Aldridge⁵, in his theory on suicide, cited a person with a mental illness who also thought he could achieve peace through committing suicide: "All I wanted was peace".

Conclusion

Participants in this study went about resolving *life is a struggle* by going through two stages of transformation, which were separated by a *turning point*. In this process of *transforming themselves* participants changed themselves from people who were helpless and powerless to people who were confident and assertive and in charge of who they were and how they ran their lives. They devised real-life solutions as to how to live with a mental illness. How they transformed themselves and thereby resolved each aspect of *life is a struggle* will now be summarised.

With regards to the pivotal aspect of *life is a struggle*, *the struggle to identify any intrinsic value in oneself as a person*, participants initially ignored it. They withdrew physically and mentally because they *did not want to deal with anything*. Those participants who had been abused withdrew mentally to such a degree that they split into two different people, losing a coherent self-identity in the process. This worsened *the struggle to identify any intrinsic value in oneself as a person*. When withdrawal was no longer feasible, participants directed all their attention to *trying to get on top of having a mental disorder*. When they realised that all their efforts in trying to resolve this aspect had come to nothing, their sense of value further plummeted leaving them even more powerless. Their predicament with regards to trying to resolve *the struggle to identify any intrinsic value in oneself as a person* only began to change during the *turning point*. Here participants started to gain some form of power for the first time by deciding to take matters into their own hands. Once in stage 2, they realised that they had to refocus away from *trying to get on top of having a mental disorder* onto *getting better as a person*. Now *the struggle to identify any intrinsic value in oneself as a person* took centre stage. In developing a new, positive identity

participants started to work on identifying any intrinsic value in themselves. They discovered the positive attributes they had, which allowed them to slowly improve their opinion of themselves as valued human beings. This was reinforced during learning new strategies and by taking action until, finally, participants reached the point where they were at peace with whom they were as a person. They now knew that they were human beings in the best sense of the word. They were capable people and had developed good self-esteem. They had also found meaning in their life, mainly by helping others. This fully resolved *the struggle to identify any intrinsic value in oneself as a person*.

Resolving *the struggle with having a mental disorder* followed a similar pattern. Participants were initially unsuccessful in their attempts to resolve this aspect of *life is a struggle* because they did not want to deal with it. They did not want to know about *having a mental disorder* by pretending that it was not there, and by denying and ignoring it. However, they realised that this could not be maintained. Therefore they decided to turn their attention solely on resolving *having a mental disorder*, that is, on their disempowerment to control their mental faculties as covered in chapter 1. They explained that the societal emphasis on *having a mental disorder* was huge and that they wanted nothing more than getting rid of it. However, they found that they could not deal with *having a mental disorder* despite their best efforts. In stage 2, after having gained some power, participants instead redirected their attention to the impact of *having a mental disorder*, explored as *the struggle with having a mental disorder* in chapter 2. In the course of this stage they learnt that they did not have to be helpless. They were now ready to face who they were and de-stigmatised the part of themselves affected by the mental disorder. They went about accepting it, including the necessity for treatment. Not making sense of what was happening that had occurred as part of *the struggle with having a mental disorder* was then overcome by learning new strategies on how to handle signs and symptoms and by having a plan ready as to what to do when facing another episode. In *being at peace*, participants had finally gained enough power to overcome their previously experienced fear and worry.

The struggle with responding to the impact of having been abused was also first dealt with by withdrawing. Participants withdrew by burying the memories of the abuse deeply within their minds under a seemingly secure trapdoor. They also withdrew mentally within themselves into a fantasy world where they imagined that abuse did not occur and where they were loved and cherished. Some participants also encountered imaginary friends in this world who made it possible to *not want to deal with anything*. Some participants withdrew even further behind a protective barrier so that they were cut off from the real world. This necessitated going on automatic to be able to still function in daily life. They created an outside persona that became split off from their inner true selves. Only in stage 2, participants gained sufficient power and mental energy to help them face the fact that the abuse had happened and to accept what could not be changed. In learning new strategies, they learnt to deal with the memories of the abuse and managed to unite the split between an outer persona and an inner true self. They escaped being held emotionally captive. They realised that they were now safe and thereby living in fear was extinguished. They also did not blame themselves any longer for having been abused. In *being at peace*, they could now see a different future where they were able to be happy and enjoy themselves.

The struggle with staying alive was also nearly lost in stage 1 of *transforming oneself*. Participants considered committing suicide as an attractive way of escaping in *not wanting to do anything*. Likewise, in *trying to get on top of having a mental disorder*, they wanted to commit suicide because giving in to not fighting in a seemingly never-ending effort would have been much easier. Only in stage 2 had participants gained enough power to make headway in *the struggle with staying alive*. In developing a new, positive identity, they now

realised that they had a choice over whether they wanted to die. They also gradually gained sufficient mental energy and inner strength to resist the disempowering force of *wanting to be dead*. In learning new strategies, they realised that, by putting problems into perspective, staying alive was more important than *wanting to be dead*. This realisation became convincing when, in taking action, participants wanted to protect other people, particularly those close to them, from getting hurt by a possible suicide. They said that they had also now got used to the disempowering force of *wanting to be dead* and could resist it much more easily. Despite *wanting to be dead* still lingering, participants said they had learnt to live with it. Only on the odd occasion, when life became too hard, did they consider it as an option to also gain peace.

The struggle with establishing credibility was won by the surprisingly simple resolution of not caring about it anymore. Participants had decided that they were content with the fact that they were someone with a mental illness, and that any shame and fear of the expected adverse reaction from others did not concern them any longer. They were also no longer interested in mixing with people who did not like this fact.

The struggle with having been let down by the mental health system was also initially avoided. Participants did not want to contact the health system because they did not want to deal with *having a mental disorder* and did not see the need for treatment. They changed their mind in phase 2. Here they embraced the mental health system and followed all the advice given by health professionals. However, as they realised that this advice, by and large, was not working, they started to despair. Then in stage 2, participants, in gaining sufficient power, realised that they had to protect themselves from *the struggle with having been let down by the mental health system*. They either severed ties with it or decided to take it on by being assertive. In being assertive, they now demanded to be attended to and to get the right treatment. They also no longer tolerated the abuse of power by health professionals and tried to make them accountable for their actions.

The struggle with maintaining normal relationships with individuals was also initially avoided. Participants withdrew physically in order not to have to deal with other people and mentally behind a façade so that they could hide their true feelings from others. Then relationships with other people deteriorated even further when participants engaged in extreme measures in *trying to get on top of having a mental disorder*. Only when participants compared themselves to other normal people in stage 2 did they realise that they were not inferior to other people and were not to blame for relationships failing. They then devised constructive ways of dealing with others. They also noted that help from other people was indeed available and that they could accept it. However, they now attached provisos to what type of help to accept and from whom to accept it. In taking action, they were ready to use their power to protect others and set about helping them. They also learnt to protect themselves from getting hurt by those people who had devalued, dehumanised and mistreated them by not staying in contact with them any longer. In facing other people head on they also sent their perpetrators packing. In *being at peace* with one's place in society, participants had finally become confident in their relationship with others. Some had found loving relationships and others had become reconciled to the fact that they would remain on their own.

Lastly, *the struggle with trying to survive through daily life* was resolved. After initially going on automatic and then using damaging extreme measures, which contributed to their life becoming tumultuous, participants learnt to adjust their lifestyle in stage 2. They recognised that they could be self-reliant, learnt new strategies to deal with study, work and stress and developed new skills to handle the many problems in their lives. They were also no

longer perturbed when they became incapacitated as they realised that this was only temporary.

Importantly, a selection of literature showed that other people who did not have a mental illness but whose life was also a struggle due to a history of abuse or due to a chronic physical health condition were using many similar ways as participants in this study to deal with their lives. This revealed that how participants went about resolving *life is a struggle* was not "maladaptive"¹¹ but was also used by many other people.

However, participants, in having resolved *life is a struggle by transforming themselves*, remained cautious as they were aware that *being at peace* was fragile and that their life could revert to a struggle at any time with the advent of any further disastrous experiences: "I've actually passed the stage where *life is a struggle*. Right now I feel I am sitting on the top of that mountain, but it could go either way. I could be pushed right back down to square one again". Notwithstanding the success of participants in having resolved *life is a struggle by transforming themselves*, this in itself was not enough to counteract *the experience of disempowerment* presented in chapter 1. Participants realised now that it was not under their control to exert influence on the causative *experience of disempowerment* and that other people have to necessarily step in. What society needs to do will be shown in the next chapter.

Chapter 4: Real-life solutions for society

In this chapter participants presented their real-life solutions of what society needs to do to empower people with a mental illness. It is argued that empowering people with a mental illness would directly counter or even prevent *the experience of disempowerment* from chapter 1. In being empowered, their life would not be a struggle and they would be able to live in peace. It is therefore the most important part of this study. It has been identified as the way forward for mental health as it will permanently improve the lives of people with a mental illness. A society thus transformed would result in the creation of a more equitable one, which would be of benefit to everyone.

To briefly recap how this conclusion was reached, it was established in previous chapters that *life is a struggle* was caused by the *experience of disempowerment*. In chapter 1, *the experience of disempowerment* revealed how participants were disempowered to such a degree that they were not able to be in charge of their affairs. The experiences that disempowered participants in their personal sphere were *having a mental disorder, wanting to be dead* and *having been abused in childhood and/or adolescence*. The experiences that disempowered participants in their social sphere were concerned with society's role. Participants stressed that their experiences of being disempowered in their social sphere had a far greater importance than those that disempowered them in their personal sphere. They recounted that society disempowered them by *not believing what people with a mental illness said*, by *devaluing and dehumanising them*, by *not wanting to help* and by *mistreating them*. The last *experience of disempowerment* detailed how society let perpetrators who had abused participants, either as children or adolescents, or had mistreated them as adults, get away with what they had done.

In chapter 2, *life is a struggle* presented participants' account of why they struggled and how they struggled. Participants explained how each aspect of *life is a struggle* was directly brought on by one or more of *the experiences of disempowerment*. This struggle left participants powerless. In the struggle within oneself, they struggled with identifying any intrinsic value of themselves as a person, which was identified as pivotal. They also struggled with *having a mental disorder* and with staying alive. In the struggle with relationships, participants recalled their struggle with responding to the impact of having been abused, *the struggle with establishing credibility*, *the struggle with having been let down by the mental health system* and *the struggle with maintaining normal relationships with individuals*. Both the struggle within oneself and the struggle with relationships ended in the struggle with trying to survive through daily life.

Chapter 3 mapped out the long and arduous journey participants took to resolve *life is a struggle*. This journey, or process, was called *transforming oneself*. Participants explained how they changed themselves from being helpless, powerless, and, in their eyes, worthless individuals, to being confident and assertive persons who knew who they were and what they wanted, and who had the mental energy and strength to achieve what they had set out to do, namely to resolve all aspects of *life is a struggle*.

Participants in this study had undertaken this journey in two stages, which were separated by a *turning point*. In the first stage, entitled trying to deal with life being a struggle, participants started out by *not wanting to deal with anything*. When this became no longer feasible they decided to try to get on top of *having a mental disorder* as this seemed to be the most obvious difficulty in their life. However, despite enormous efforts they could not

get on top of it and were left powerless. This plunged them into an abyss of despair, from which the only viable exit was the *turning point*.

The *turning point* was identified as providing the transition into stage two. It was precipitated either by a distinct crisis or brought on by empowering experiences. These enabled participants to take matters into their own hands and for the first time they felt that they had any power. This was the springboard that catapulted them into stage two.

In stage two, participants decided to start afresh and refocus their attention away from *trying to get on top of having a mental disorder* to what was pivotal to *life is a struggle: the struggle to identify any intrinsic value in oneself as a person*. Participants identified this as getting better as a person. *Getting better as a person* had a personal and a social dimension. Both were attained in three steps: developing a new, positive identity, learning new strategies and taking action. Stage 2 was fulfilled by participants *being at peace*. By *being at peace, life is a struggle* had been resolved.

However, *the disempowering experiences* were still present and could plunge participants' life back into a struggle at any time. Participants realised that *the disempowering experiences* were beyond their control to change. Therefore, of necessity, other people have to step in to alter them by empowering people with a mental illness. This leads us to the current chapter.

Participants outlined their vision of what society needs to do to empower them. They emphasised the importance of seeing people with a mental illness as "equal" in value and social standing to others. This would naturally amount to rearranging the existing power relationship between them and society. Participants maintained that in order to achieve this rearranging, society also has to be transformed, or changed significantly, so that it perceives and treats people with a mental illness as fellow human beings: "That is what it is all about, humanness". Other people with a mental illness concurred. They too wanted to be seen as a "fellow human being"¹. Deegan² pointed out that to achieve this required a change in society.

Participants in this study said that their vast experience, their "career of being mentally ill if you can call it that", put them in the driver's seat for knowing how a *transformation of society* that would empowered them could be accomplished. They identified two requirements as necessary: *treating people with a mental illness with justice* and *providing effective help*. *Treating people with a mental illness with justice* means that they would be treated the same as anyone else, for example in the courts and with regards to new laws. Discrimination at the workplace and with accommodation would also be mitigated. Participants explained that to *treat people with a mental illness with justice* would be brought about most importantly by finding the cause of mental disorders and by changing the attitude of society to them.

In *providing effective help*, participants stated that a medical cure for mental disorders would be the most significant. However, in the absence of a medical cure, they explained that a cure lay in relationships. Governments and individuals could provide effective help if they did their duty towards participants, stood by them, loved them in the case of family members, and showed compassion. Religion would provide solace. These measures would empower participants most.

According to participants, implementing the *transformation of society* would result in the creation of a more equitable society where people with a mental illness would be acknowledged as equal citizens and could take part in all facets of life. Society as a whole would also benefit.

The two ways required to achieve the transformation of society:

Treating people with a mental illness with justice

Providing effective help

The transformation of society would culminate in the creation of a more equitable society.

Treating people with a mental illness with justice

In this first way of accomplishing a *transformation of society*, participants asserted that treating them with justice would empower them by upholding principles of fairness and give them the rights and opportunities to be equal citizens. *Treating people with a mental illness with justice* would particularly address *the experience of disempowerment of society letting the perpetrators getting away with their abuse and mistreatment* from chapter 1. Participants said that they would get justice or "redress" that way. Being treated with justice was so important to participants that they identified it as a basic human need: "Human beings have certain needs and one of them is to be treated with justice".

To participants in this study, *treating people with a mental illness with justice* meant to apply laws equally to everyone so that every person has the same standing in society, irrespective of whether they have a mental illness or not. As an example, participants pointed to the principle of regarding everyone as innocent unless proven guilty. Controversially, they insisted that this principle has to be enforced with regards to people with a mental illness also: "The public should be protected from dangerous people whether they are mentally ill or mentally well, but the law should protect the innocent, and therefore harmless, which many mentally ill suspects are". Participants made the point that it is important to enforce this principle because to them the presence of any illness is irrelevant to whether someone is guilty as charged or not: "Using the state of the person's health, mental or otherwise, to judge [someone in a law court] ... is like using eye colour or length of hair. It's irrelevant". Other writers with a mental illness agreed: "[We] need to be accountable for our behaviour - just like everyone else"³.

Furthermore, participants in this study said that the attitude of judges has to be impartial so that the outcome of trials is fair. They explained that this would largely prevent perpetrators of criminal acts and those who had abused participants as children and/or adolescents getting away with what they had done. In addition, participants emphasised how important it is for any new laws to enshrine equality. They gave the example of a relatively new law in Australia at the time of the interviews that gave both parents equal responsibility for their children after a separation or divorce. The principle of equality portrayed in this law was vital to participants because many had lost custody of their children or felt threatened of losing this custody due to *having a mental disorder*: "To me it [equal responsibility for children guaranteed by this law] should be mandatory".

Beyond the legal system, the concept of justice encompasses social justice. The importance of social justice was stressed by other writers with a mental illness⁴. Social justice in this study is concerned with discrimination or unequal treatment. Participants especially mentioned discrimination with regards to housing, where neighbours often protest if housing for people with a mental illness is to be provided nearby. At the workplace, participants did not want to be discriminated against by being dismissed from their jobs on the basis of *having a mental disorder*. They asked for equal opportunities with regards to being employed and promoted. Some employers indeed gave participants "a fair go", thereby conferring some power onto them.

Both legal and social justice could be fostered by changing society's attitude towards people with a mental illness to counter *society not wanting to believe what people with a mental illness said, society devaluing and dehumanising them and society not willing to help them*, as detailed in chapter 1: "Minds need to be changed here. They need to be. Plenty of minds need to be changed". For instance, participants maintained that if society's mind were changed, discrimination at the workplace would be reduced because employers would gain an understanding of the fact that participants might need to take a few days off work when sick with their mental disorder. Furthermore, employers would become more flexible to accommodate sick days by allowing work to be done at home or by allocating some of it to colleagues. Participants also pointed out that discrimination with regards to housing could be overcome if the community's mind is changed about people with a mental illness moving into their neighbourhood.

Participants proposed ways of how people's minds could be changed. For them, the first and most important way is through a scientific discovery of the cause of mental disorders so that these disorders are seen just like any other medical condition: "That will be the biggest breakthrough ever". They hoped that this scientific breakthrough would include tests, such as blood tests or brain scans that would prove the existence of a mental disorder. Participants explained that only through these scientific discoveries would mental disorders lose the stain of stigma and be acknowledged as legitimate and valid physical illnesses. Moreover, their disorders would no longer be regarded as mere 'mental states' indicating that they were just 'in the head' and made up, as in 'mental state assessment', a term used in the assessment of people with a mental illness: "Then you will get people acknowledging an illness instead of a mental state". Participants believed that by finding the cause or causes of mental disorders, including impartial tests, *society not wanting to believe what people with a mental illness say* from chapter 1 would largely be obliterated.

Another way of changing people's minds is through increasing public awareness. Participants hoped that increasing public awareness would decrease *society devaluing and dehumanising people with a mental illness*, as covered in chapter 1. They said that the general population should be made aware of how many people with a mental illness are living successful lives amongst them. They pointed to prominent people who had come out in public with the fact that they had a mental illness proving that leading a successful life was possible: "They have done more for mental health in that one action than many other people can achieve". Participants argued that even less prominent people who had a mental illness could play a valuable role in increasing public awareness by also telling others about it: "There's doctors, nurses, there's lawyers, I mean, there's people from all walks of life [who have a mental illness], which, perhaps, they should let people know that". Informants in Malins *et al.*'s⁵ study, which was part of the Consumer Evaluation of Mental Health Services project in Australia, agreed with participants in this study in pointing to the usefulness of educating the public on "what it is like to experience a mental illness".

Moreover, participants in this study said that the fact that people with a mental illness are fully able to lead successful lives should be emphasised by the media, for example in documentaries and chat shows: "If they show people [with a mental illness] that are integrated into what everyone perceives as normal, it [living with a the mental illness] won't be seen as such a bad thing". Most importantly, they said that the media has to increase awareness about the fact that people with a mental illness are not dangerous people. This would counteract the deep-seated fear in the general population: "The hysteria often whipped up in the public mind [through the media] should be outlawed. The reporting is false and does enormous damage to people with a mental illness". Participants suggested that guidelines have to be introduced and enforced through anti-defamation laws with attendant penalties to

prohibit the depiction of people with a mental illness as dangerous. They explained that this could be done if, instead of concentrating on the few criminal acts of a small percentage of people with a mental illness, the media put these into perspective and showed the real facts. These real facts are that, although a small number of people with a mental illness have been involved in unlawful actions, they are vastly outnumbered by healthy people who commit crimes: "But the media just don't make that obvious". Furthermore, participants pointed out that, although a few people with a mental illness have committed crimes, all others should not be seen in the same light:

"The public is led to believe that because one mentally ill person murdered someone, all the mentally ill are capable of murder. It is a big mistake to think that there is any connection between one mentally ill person and another [in this respect]. They are as different from each other as the mentally well are."

Participants asserted that as a result of an increase in the general population's awareness, the devastating effects of the public's disempowering views, values and behaviours on people with a mental illness would be revealed. The disempowering force of *wanting to be dead* would then be also taken seriously: "You know the facts yourself that every seven hours someone checks out and they are no different from me because I could have or should have been one of them at any stage". Participants maintained that health professionals would also become aware of their lack of understanding of participants' experiences, of their own misconceptions and of their abuse of power.

The last way of changing people's minds is through education. Participants emphasised that the public, including health professionals, have to be educated on how to interact with people with a mental illness. For example, children in schools should be taught "compassion, fair play and correct treatment of others, and that it is important to be considerate of other people's feelings". In contrast, as participants explained, education on signs and symptoms and how to deal with them is only useful for potential patients and their families so that they can recognise them and seek treatment. Education on signs and symptoms does not change the minds of the general population.

Participants pointed out that in order to educate the general population it is important to engage them on an emotional level by emphasising the "human perspective". They explained that emphasising the human perspective involves both describing their experiences and what they are going through. Giving hypothetical examples of how the public's own family members could be affected if they had a mental illness is also useful: "That's how I do it to them. I say, 'So, tell me, if this is your wife [with a mental illness] and you had children [with a mental illness], would you be saying that?'" Furthermore, participants identified how charismatic leaders had changed the minds of large numbers of people through education by reaching for people's hearts: "Human nature is the first consideration in bringing about change, and wisdom and patience are required in persuading people".

Participants hoped that when the general population became aware and was educated about the experiences of people with a mental illness and what they have gone through, they would be empowered and the violation of human rights would be reduced. They referred here in particular the profoundly *disempowering experience* of being on Community Treatment Orders and residing in locked wards of mental hospitals, as described in *society mistreats people who have a mental illness* in chapter 1. Participants further hoped that the public might then even protest if human rights were not upheld.

The United Nations Children's Fund⁶ statistical analysis of violence against children adds that, most importantly, changing the attitude of the general population to the point of

changing social norms are required to prevent violence and discrimination against children. Violence, or child abuse, was identified as a major contributing factor if not a cause for their mental disorder by participants in this study and *having been abuse in childhood and/or adolescence* was a key reason for the occurrence of *life is a struggle*. The United Nations Children's Fund⁶ states that violence against children can be prevented by "a major shift what society regards as acceptable behaviour". It advocates school and community programmes that target trusted people to become change agents, mass media campaigns, adequate reporting of abuse and making violence against children punishable by law. It relates that when the last item was enacted in Sweden violence against children decreased markedly.

Providing effective help

The second way of bringing about a *transformation of society* so that people with a mental illness are empowered is to identify what type of help is effective and how it can be provided. Participants emphasised that finding a medical cure for mental disorders was the most important way of helping them because they knew this was the only way of combating *having a mental disorder*: "If there was a cure tomorrow, I'll be lining up for it". Repper and Perkins⁷ have also come across people with a mental illness who think the same way: "The continued search for a cure has been a motivating force in the lives of many people". However, in the absence of a medical cure, participants realised that a "cure is only found in society". The ways of finding a cure in society is doing one's duty, standing by people with a mental illness and showing compassion.

Doing one's duty is defined as doing something that ought to be done. Participants explained that they regarded it as a duty to treat every person who needed help equally. If treated equally participants would be valued the same as other people who receive ready help when required. *Society's unwillingness to help* from chapter 1 would thereby be counteracted. Part of doing one's duty, according to participants, lies with governments: "The government has a duty to improve people's lives". They reasoned that governments have a duty to improve people's lives, in this case through *providing effective help*, because they regarded this as a hallmark of a civilised society. Participants insisted that, although everyone has to help themselves as much as possible, as they had done by *transforming themselves*, detailed in chapter 3, anyone who requires help should receive it for the sole reason that they are members of this society. Van der Kolk, McFarlane and Weisaeth⁸ agreed: "People have the right to expect support when their own resources are inadequate".

Participants explained that governments can do their duty by providing effective health services. They called for a transformation of the present health system to one that is "sane, decent, compassionate, a patient friendly system in line with 21st century thinking". Deegan⁹, a writer with a mental illness, affirmed the same call: "We say no to second-class health care". Participants realised that bringing about this improved health service would then tackle *the experience of disempowerment* related to health care, as covered in chapter 1.

Participants explained what they regarded as an effective health service. Firstly, it required making adequate funding available. This is also the view of the Mental Health Economics European Network who insist that adequate funding is at the root of a good mental health system¹⁰. Participants in this study called for extra funding for mental health services so that they would get the same attention as other services: "I mean mental illness is a growth industry. It is just increasing and increasing and increasing but it's just not prioritised for". They said that prioritising mental health services and thereby providing a percentage of funding equal to that of general medical services would allow the tearing down

of the dehumanising and prison-like mental hospitals. Participants recommended building units of the type now found in modern retirement villages in their stead. They suggested that these units should be centrally located with easy access to "transport, shopping centres and natural vegetation" and include libraries and other educational facilities with computers. They should also include amenities for socialisation, opportunities for craft-work and other activities such as holiday camps for younger people with a mental illness. Participants also thought of locating "Centres of Excellence" there to run intensive programmes with a focus on preparing residents for living independently in the community. Participants outlined that the staff of these Centres of Excellence should consist of a dedicated team of specialists: "No one should be considered too insane or impossible to help". A study interviewing people with a mental illness on what they need in crisis added that they wanted mental hospitals to have "homelike surroundings, [be] comfortable ... warm and friendly"¹¹. Participants in Borge and Fagermoen's study¹² on their experiences of hospital treatment expressed their desire for the hospital to be "open and free".

Furthermore, targeting funding to what participants in this study said they require would shift financial and human resources away from the current narrowly based medical services to broad-based services in the community. Participants especially pointed to the provision of accommodation. They explained that having somewhere to stay is especially important for people like them, even if it meant that the equality principle was violated: "Everyone knows how important it is to have a house, but to a mentally ill person it is even more important. It is vital". According to participants, this accommodation should be tailored to their needs. For example, some were happy with hostel accommodation because staff "actually look after you". Others wanted housing where they would live alone so that they could recover from the turmoil of *life is a struggle*. Participants said that, above all, they required accommodation that was affordable and had security of tenure.

The provision of suitable accommodation was also important to other people with a mental illness. A report on housing needs of people affected by mental health problems in Perth, Western Australia, called for accommodation to be "secure and safe"¹³. A study on the nature of recovery as lived in everyday experience quoted participants as wanting accommodation where they could "relax and find peace"¹⁴. Living alone was also mentioned as being important in a study on housing following discharge from hospital¹⁵.

Participants in this study further outlined that broad-based services in the community should include the provision of sufficient numbers of case managers. They said that case managers could help them with *getting better as a person*, explained in chapter 3, by taking up a role similar to that of life coach: "This is what would help me the most". The roles of case managers were listed as watching over participants, ensuring their safety and acting as intermediaries with the health system. Additionally, case managers should be backed up by home help services that would assist with everyday tasks such as collecting medications from the chemist, shopping and cleaning.

Broad-based community services were also seen by participants as important for providing help for families. For example, those participants who had been abused in childhood and/or adolescence emphasised the importance of preventing any similar abuse from occurring by providing help to families at-risk.

Other people with a mental illness had in mind similar roles for case managers as participants in this study, such as being "a guide or facilitator"¹⁶ and a "coach"¹⁷. A call to "invest in families ... at risk"¹⁸ was also made. Furthermore, with regards to health services, a need to inquire routinely and systematically into a history of childhood abuse has been identified in many studies¹⁹⁻²⁶. Education for health professionals^{18,29} with "clear information

on their role in extricating ... [affected patients] from violent circumstances"²⁹ has been seen as important as a basis for pursuing legal action²³ and providing trauma-based treatment³⁰. The United Nations Children's Fund⁶ statistical analysis of violence against children put supporting families at the top of their strategies to prevent abuse against children from occurring. It outlined that this support should be:

"Integrate[d] ... into the everyday lives of families, either through regular visits at home or a community centre or through other local venues staffed by nurses, social workers or other trained professionals. Home visits and parent education classes combine health care, parenting education, child abuse prevention and early intervention services for infants and toddlers."

Participants in this study believed that their suggestions for broad-based community services would be much more cost effective than the current medical services: "It will cost less, especially in the long term, than the present system". They asserted that, by using broad-based community services, the severity of their mental disorder would be reduced and they would be less likely to commit suicide. Therefore, expensive medical services would be used less and access to mental health specialists would be freed up. Adequate communication channels within and between services could be more easily established. Participants thought that these services should then be reasonably priced: "I need help that I can afford".

Participants stated that another way of doing one's duty towards them lies with individuals. For example, participants wanted to be treated with politeness and courteousness just like any other person. In addition, they stressed the importance of following three principles, aimed at counteracting some of *the experiences of disempowerment* from chapter 1, in particular *society did not want to believe what people with a mental illness say* and *society devaluing and dehumanising them*. Participants identified these principles as being listened to, being believed and being told the truth.

Participants explained that other people, but especially health professionals, have to listen and "to look where we've come from". To see where participants had come from would be revealed by asking what had happened to them: "Wouldn't it be nice to say, 'What happened to you? What went wrong?'" Participants stated that finding out what had happened to them and what had gone wrong would then unlock the many events recounted in *the experience of disempowerment*, especially their background of abuse: "I tell you what happened to me. Somebody f***ed my life up". Participants said that omitting to ask what had happened to them and what had gone wrong is "derogatory and makes you feel so to blame". Furthermore, in order not to feel blamed, participants wanted an explanation as to what physical changes had occurred in their brain and they wanted an assurance that these changes were part of a recognised disorder. They said getting a psychiatric diagnosis told them that they were not "mad" after all: "[Getting a diagnosis] was a HUGE relief. Finally I felt there was a reason for what had been going on". Participants explained that not feeling blamed would be deeply "consoling" and would contribute to the realisation that committing suicide was not necessary after all: "Then why do you need to die?"

Participants stated that looking where they had come from would also lead to an increase in other people's understanding. For example, if health professionals were looking where participants had come from they would get an understanding of how manifestations of healthy feelings and behaviour differed from those pertaining to a mental disorder. *Wanting to be dead* as a disempowering force would also be more readily understood.

The second principle participants in this study highlighted as important in doing one's duty towards them was the principle of believing what they said. This would counter *society not wanting to believe what people with a mental illness say* from chapter 1:

"The most important thing to do is to BELIEVE them. The mentally ill tend to be more truthful than other people, not less, and *yet almost everything they say is doubted*. Remember, stranger things tend to happen to the mentally ill than to others. Of course they CAN lie like everybody else, but it should not be assumed that just because something sounds weird, it didn't happen."

Participants pointed out that believing what they said would result in turning the spotlight on *the experience of disempowerment* and the need for addressing this. For example, they explained that if they were believed, health professionals would realise that many mental health signs and symptoms present as superficial manifestations of deeper-seated horrors: "If they discover what was going on internally in you, you might not continue to have these outside symptoms". Furthermore, abusive events would be investigated: "Check out what the people are saying. We are not all paranoid". Then action could be taken, such as providing help with taking abusers to court or, at least, with issuing moving-on orders.

Telling the truth was the third principle participants listed in doing one's duty towards them. For example, participants stated that they wanted to know the truth about the current limited state of psychiatry as a science, about the uncertainty of identifying causes of mental disorders and the inadequacy of treatment methods, such as many medications and electro-convulsive treatment. Participants pointed out that being told the truth was so important because it acknowledged them as someone who was able to think rationally. Moreover, they insisted they had a right to know the truth about what was happening and what was being done to them:

"If there is a reason for all the damaging substances he is making me put into my blood, don't I have a right to know what it is? Shouldn't he discuss it with me? If they know something I don't, why don't they share it with me? I have to suffer the consequences."

Lastly, participants wanted to be told the truth because it constituted the first plank in finding solutions to their problems:

"What is needed to find any solution to anything and particularly to get people to be mentally well again is to be consistently told the truth, and if you don't want to tell something to someone say, 'I don't want to'. Don't make up a lie."

Participants knew that doing one's duty towards them by listening to them, believing what they said and telling the truth would transform many clinical practices into "top quality" care. In addition, the inadequate regulation of professional practices, where health professionals were unaware of the special requirements for looking after people with a mental illness or where they worked outside their level of competence, as covered in *the experience of disempowerment* in chapter 1, would be set right.

Other people with a mental illness also stressed the importance of similar practices. For example, participants in a Norwegian national survey on psychiatric outpatients' experiences with specialised health care delivery asked to be treated with politeness³¹. Furthermore, other writers with a mental illness mentioned the same three principles as participants in this study. They stated they wanted to be listened to^{32,33}, they wanted to be believed^{22,36} and wanted to be told the truth^{16,36}. Participants in a study on their experience of the therapeutic relationship wanted to be asked about what had happened to them¹⁶. Likewise,

getting a diagnosis had provided "tremendous relief" for a writer with a mental illness³⁴ because "finally [I] had an explanation for my unrelenting ... misery".

A second way to finding a cure in society is to stand by people with a mental illness. Repper and Perkins⁷ agreed: "The common denominator of recovery is the presence of someone who 'stands by' you". Participants said that supporting them, giving them solace, genuinely caring and showing love were ways to stand by them. These were actual examples participants had encountered. Participants asserted that in standing by them they were seen as being worth something in the eyes of others. That empowered them.

Participants explained that support did not entail complex acts of practical help or the solving of their life problems. Instead, merely "being there for me" was at its core. Being there showed a readiness to help in simple ways, such as making an effort to understand participants, being concerned about their well-being by ringing them up to see how they were going and by being interested when they wanted to talk about mental health issues. Visiting them in hospital and accompanying them to meetings with health professionals was another way of being there: "Just giving that little bit of leg up. Not much at all. It doesn't take much".

The need for support¹⁴, and in particular being there, was also mentioned as important by other people with a mental illness in other studies^{11,12}. Being there was described as simple acts of "sit[ting] quietly and ... be[ing] with a person who is suffering"⁴, making a phone call³⁷, sending a letter³⁸ or a get-well card³⁹ were specific acts of support identified. A review of studies on how people live with or get over being suicidal⁴⁰ and a theory on this subject by Joiner³⁸ found that even suicidality was reduced with simple support like this.

Some participants in this study stressed that fellow people with a mental illness, or peers, were also effective at supporting them. They regarded this support as so important that they recommended paying peers a wage so that their services could be provided on an ongoing basis. Participants felt that in having the opportunity to listen to their peers' life experiences empowered them. They realised that they were not the only ones whose *life is a struggle* and that they could, indeed, survive it: "If they were able to make it, then maybe I can, too". Furthermore, they found that peers, occupying a unique position, could assist them in getting through *transforming oneself* because they had already gone through the same process themselves: "They are giving you all these tools and tips, championing you, pulling you through".

The importance of peer support was also emphasised in the literature. For example, an Australian study⁴¹ on mental health peer support to avoid hospitalisation and facilitate early discharge, and statements by writers with a mental illness⁴² who run peer-support groups highlighted its importance. Employing people with a mental illness⁴² with appropriate remuneration⁴⁴ to provide peer support was also called for elsewhere^{5,37}.

Another way of standing by people with a mental disorder was to give solace. Some participants in this study found this in religion. They said that they received solace when explanations were forthcoming in religious writings that helped them understand what they were going through: "It doesn't matter what you go through there is something there that'll talk to you". Some participants, especially those who had been abused as children and/or adolescents, found solace through the protective mantle religion provided. They believed that religion had protected them by defending them when they had been helpless, and that many further abusive instances had thus been avoided. They explained that praying had stopped the memories of the abuse from haunting them. They also believed that they had been looked after by religion even in the bad years by, for example, being rescued from becoming as evil as their abusers: "I think it is a spiritual thing when you get abused. Their evilness or their

bad spirit comes into you and goes into your mind. I am so glad that * [divine entity] rescued me from that". Participants also remembered when they had been saved in the act of committing suicide. They said that "some sort of divine intervention or providence" had guided other people to discover them before they had died.

As a result of the solace forthcoming from religion, participants said they had been empowered to better get through the process of *transforming oneself*. They recounted that religion had taught them to be patient when they were suffering and to accept whatever had happened in their life. Religion also kept up their hope for a better future even though their hope had often been sorely tested in the many despairing years. Participants maintained that religion had "the power to make you sane" and, although scars remained from *having a mental disorder*, faith contributed to healing these. Religion also helped with overcoming any fear and with gaining a positive identity. It strongly advised against committing suicide, which further supported them in deciding not to go through with it.

Other people with a mental illness had also found "solace in religion"⁷. Two studies in particular examined its role. Awara and Fasey⁴⁵ asked whether spirituality was worth exploring in psychiatric out-patient clinics and found that religion "provided comfort and hope, [had a] positive impact in improving their [people with a mental illness] coping strategies with life vicissitudes [and] gave them a new meaning to life". Bhui, King, Dein and O'Connor⁴⁶ looked at religious coping with mental distress and identified that people with a mental illness found "strength, knowledge, wisdom and guidance" in religion and that it had "helped ... in a difficult situation". Furthermore, religion also assisted with understanding that "you are not responsible for everything" in a study on views of people with a mental illness of self-help strategies⁴⁷.

A further way of standing by people with a mental illness is to genuinely care. Participants in this study recalled how they had encountered people, for example members of community groups, who showed them how highly valued they were by "genuinely caring". This contributed to their empowerment. Participants explained that genuinely caring involved connecting to other people on an emotional level, making them feel welcome and acknowledging how they felt. Being non-judgmental, tolerant, a "good sounding board" and giving participants roles of responsibility also contributed.

Some health professionals also genuinely cared. Participants explained how these health professionals went "beyond the job kind of thing" and were "dedicated and interested and enthusiastic". Participants remembered how they were treated like special people, feeling empowered: "When I go into hospital, they actually love having me. They do everything to make me want to get better". Furthermore, these health professionals were thorough in their assessment, went out their way to find the right treatment and explained everything they did. Participants recalled being encouraged to the point of having their hidden abilities drawn out: "[The health professional] nurtured the qualities that I had and encouraged me into reaching my potential". Participants remembered some health professionals who even put the needs of participants above their own. They were "not in it just for the cash" and responded even out of office hours because that was what participants required at the time: "He'd come in especially to give [me help]; he'd know what state I was in".

As a consequence of health professionals genuinely caring, participants found that an environment of mutual trust came to the fore. They said that this mutual trust was created when health professionals consulted them about symptoms and about the type of treatment they thought most suitable, including medications: "It becomes a discussion between both sides of what I need". Participants pointed out that in such an environment they felt at ease to talk openly about what concerned them without fear of being condemned.

Other writers with a mental illness had also found health professionals who genuinely cared^{33,48,49}. In a study on the experience of hospital treatment these health professionals were characterised as possessing "both heart and head"¹². Connor and Wilson⁵⁰ quoted people with a mental illness who implicitly trusted these health professionals.

The last way of standing by people with a mental illness was for family members to show their love. This love gave participants a great boost in being empowered. They recalled how family members had shown them their love by giving generously of their time and finances: "They have given me their clothes off their own back". They also went out of their way to help participants with managing the difficult times: "They bend over backwards to help me cope in life". Help ranged from doing the laundry, assisting with choosing a new car or buying a house for them. Others took over roles that participants had previously performed: "My wife said, 'Ok, well, I'll work. You stay at home'".

During episodes of illness, these family members showed participants their love by offering to monitor signs and symptoms in case participants did not notice their recurrence and helped them with adhering to medication regimes. They also went to extraordinary lengths to get them out of locked wards of mental hospitals. Those participants who had been abused in their childhood and/or adolescence said that having been shown love by a spouse and children in later life furthered the healing that took place as part of resolving *the struggle with the impact of having been abused* from chapter 3.

The third way of finding a cure in society, according to participants in this study, is to show compassion. They defined compassion as "REALLY wanting to help, REALLY caring, and showing respect and generosity to a person to whom these things have been missing from their life". The importance of compassion was identified as an essential element for being empowered by *providing effective help*: "This is the key to improvement in the lives of people with a mental illness". Participants explained compassion had to be displayed throughout society, including in health organisations. They pointed out that compassion would become widespread in health organisations if it were made a mandatory theme for all concerned, from Ministers of Health to receptionists. For this reason, participants suggested teaching health professionals how to show compassion during their initial education and for this to be reinforced throughout their working life. Moreover, they advised that it should be made a prerequisite for employment by devising a pre-recruitment test to that end: "They should employ people who have to prove when they apply for a job that they have compassion". Participants recommended that those health professionals who have already been employed and show a lack of compassion should be removed from their positions: "They should be sacked and sacked right now. They shouldn't be allowed another minute near sick people".

A call to show compassion in the health services was also made by other writers with a mental illness⁹ and was present in other studies, for example in Borge and Fagermoen's study¹² on the experiences of people with a mental illness of hospital treatment. A participant in Connor and Wilson's study⁵⁰ said that being shown compassion "lifted me out of the hell".

The creation of a more equitable society

Participants reasoned that the *transformation of society* through *treating people with a mental illness with justice* and *providing effective help*, if achieved, would culminate in the creation of a more equitable society. This would mean that people with a mental illness would have the same power as other people and could assume their place as full citizens. They would be seen as "human beings" who merely had some problems: "Just because we have problems,

nobody should call us crazy. Even schizophrenics or bipolar people, they are still not crazy; they are just like another person". Moreover, in a transformed society, the public would be willing to "show kindness, respect and generosity" towards people with a mental illness and would regard them as the compassionate, trustworthy and honest people that they were. The media would also portray them in a positive light, reducing the fear and stigma of the general population. As a result their reputation would no longer be defamed: "We would not be seen as violent, dangerous people that need to be locked up with no credentials, no trade or skill or anything".

Participants said that in a more equitable society they would also be appreciated as employees who were able to make important contributions. This would give them a chance of reaching their "level of vocational potential" and allow them to gain their "proper social status" through work. Participants explained that they would be included in decision-making and their suggestions would be taken into account: "The true stuff, not this shit token stuff [happening at present]". Moreover, school life would be made tolerable for those children with early signs of a mental disorder: "A better step for them to go into adult life with".

Participants in this study pointed out that in an equitable society there would be little discrimination with regards to housing. Neighbourhoods would be open-minded about people with a mental illness living in their midst, which would allow participants to reside in close proximity to each other if that is what they wanted. Participants explained the advantages of living near each other as it would allow for easy socialisation and engender a feeling of belonging to the same community: "It's not two or three or so people against the world. It is all of us, all of us. Here, this is our place. This is our home. This is our community". Participants called this a "circle of support". They said that they would have the opportunity to devise a common strategy if problems surfaced. Instead of being seen as bad neighbours and "no-hopers" they would be regarded as competent and confident people, which would bring about respect, and even admiration from the public, and further enhance their standing in the community.

According to participants, creating a more equitable society would largely mitigate *the experiences of disempowerment* related to their social sphere, explored in chapter 1, and therefore *life is a struggle* would not be brought on. They explained that, importantly, *the experience of disempowerment* as related to participants' social sphere would be averted because society would not reject them any longer but would value them instead. Being isolated, ostracised and abandoned, experienced in *life is a struggle*, could thus be avoided. Furthermore, by being listened to, any frustration at how they were treated by health professionals with accompanying reprisals would also be prevented: "[Health professionals should] sit them [people with a mental illness] down, talk to them, instead of just jumping and throwing them on the ground and giving them an injection and then putting us in a room somewhere for a few hours".

Participants also pointed to the benefits the *transformation of society* would bring to the general population in that everyone would be empowered. Participants said that the "social capital" of all its members could be utilised. Children would benefit from having two engaged parents: "Your children need you. You can do things that your partner cannot and vice versa". Workplaces would benefit from their work skills. Governments would benefit as they would not have to give as much financial support. Lastly, participants explained that health professionals would benefit by escaping their own dehumanisation. They would join participants in preserving their humanity because they would achieve the highest goal, namely the relief of the suffering of others: "Alleviating suffering is the highest and noblest act".

The empowerment of the general population due to the creation of a more equitable society was also noted by others, for example by Koenig⁵¹, the recipient of the 2003 UN Human Rights Award: "Living in a world of human dignity, freedom, and social and economic justice ... [will] empower us all".

Participants' vision of a transformed society as explored in this chapter, was hopeful, positive and optimistic. However, some participants remarked on feedback that they thought some of it "utopian". Nonetheless, a comparison with the achievements of other groups of people to attain equal status in society in the next chapter will show that the real-life solutions for society provided by participants in this study are entirely feasible and can be implemented.

Conclusion

In this chapter, participants outlined their vision of how a *transformation of society* would give them sufficient power, and equal value and social standing to everyone else. They identified two ways that were necessary to achieve this transformation: *treating people with a mental illness with justice* and *providing effective help*. It was found that implementing these two ways would address all of *the experiences of disempowerment* from chapter 1. How these ways specifically countered each one will now be briefly summarised.

Having a mental disorder would be alleviated if a cause for the occurrence of mental disorders was identified through scientific research and a cure was found. *Having been abused in childhood and/or adolescence* could be prevented by supporting families at risk.

Society devaluing and dehumanising people who have a mental illness and society mistreating them could be lessened if the public's mind was changed through increasing public awareness backed up by the media. Participants hoped for education, including through school programmes, on the experiences of people with a mental illness and what they have gone through, on how to interact with them and by engaging people on an emotional level. Reducing discrimination at the workplace and in accommodation would also forestall mistreatment.

Society not wanting to believe what people with a mental illness say could be counteracted by listening to them and believing what they say. *Society is not willing to help* would be mitigated by other people doing their duty, standing by people with a mental illness and showing compassion.

Lastly, *society letting perpetrators get away with their abuse and mistreatment* would not happen if people with a mental illness were treated with justice, existing laws were applied equally to everyone, new laws were created along the same lines, and the justice system was impartial and fair.

The only *experience of disempowerment* for which participants had found no antidote was *wanting to be dead*.

According to participants, implementing the *transformation of society* would culminate in the creation of a more equitable society where people with a mental illness were accepted as equal citizens. Society as a whole would also be empowered and thus benefit. As the *transformation of society* addresses the causative *experience of disempowerment* and has the capacity to ameliorate or even prevent *life is a struggle* from occurring, it has been identified as the most important real-life solution for mental health.

Chapter 5: Why a mental health rights movement is the overarching solution

This chapter is important to read because it puts the real-life solutions developed up to now into a broader context. It was established that disempowerment is at the core of the real issues behind mental illness and empowerment fundamental to its resolution. The underlying philosophy of the disease model, psychological models and theories, the disability model, socio-political models and theories, and the study of psychological trauma are compared with how they treat power. Surprisingly, and contrary to the expectations of both the participants and me, it is concluded that a mental health rights movement, examined as part of the socio-political models, is the most suitable one to serve people with a mental illness. Although this will challenge the existing power arrangements in society in the short-term, and resistance of established powerbrokers will be evident, it will be realised that in the long-term it will be to the best of everyone.

In order to be able to carry out this comparison, a brief reminder of the most important topics, cardinal to the theory developed in this book, are given first: The concept of power was central. It was established that society's views, attitude and behaviour were the most important factors in *the experience of disempowerment* weighing on participants who had been diagnosed with major depression, bipolar disorder or schizophrenia. This brought on *life is a struggle*, where the pivotal aspect was the existential struggle with who participants were as a person and what their place was in society. Although participants tried their best to devise a process by which they could resolve *life is a struggle* by empowering themselves with good results, they had no control over *the experiences of disempowerment* that had brought on *life is a struggle* in the first place. Therefore, the most effective way to lift this disempowerment permanently is for society to transform itself also to view and treat people with a mental illness as equals. This is the way forward in mental health.

To elaborate a bit further, in chapter 1, participants' disempowerment in their personal sphere, by *having a mental disorder*, by *having been abused in childhood and/or adolescence* and by the disempowering force of *wanting to be dead*, was towered over by those in their social sphere, where *society did not believe what they said*, *society devaluated and dehumanised them*, *society not wanting to help them*, *society mistreating them* and *society let the perpetrators get away with what they had done*.

Chapter 2 detailed the impact of *the experience of disempowerment* on participants. They explained that this impact had turned their life into a struggle. This struggle was so overwhelming that it left them powerless. Pivotal to *life is a struggle* was the existential *struggle with identifying any intrinsic value of oneself as a person*. In addition, participants also struggled with *having a mental disorder* and with *staying alive*. Again, these aspects were overshadowed by the struggle with relationships, which consisted of *the struggle with responding to the impact of having been abused*, *the struggle with establishing credibility*, *the struggle with having been let down by the mental health system* and *the struggle with maintaining normal relationships with individuals*. The last aspect, *the struggle with trying to survive through daily life*, dealt with the mundane of work, study and stress.

Chapter 3 traced the difficult and long process of how participants managed to gain power on a personal level. The change from being powerless to gaining power was so great that it was tantamount to a transformation. In going through the whole process of *transforming oneself*, consisting of two stages separated by a *turning point*, participants were

successful at resolving *life is a struggle* when they felt at peace. However, *the experience of disempowerment* from chapter 1, which were beyond participants' capacity to prevail over, were still present and were threatening participants' hard-won resolution of *life is a struggle* at any time. Therefore, other people had to be summoned to change society to such a degree that it reigned in *the experience of disempowerment*. This *transformation of society*, detailed in chapter 4, would then empower people with a mental illness on a permanent footing so that they would be seen as having the same value as others and be treated as equal citizens. In order to achieve this, participants asked to treat people with a mental illness with justice and provide effective help. This, they concluded, would result in the creation of a more equitable society, which would empower not only them but everyone else as well. The *transformation of society* is therefore the most important part of the study as it can counteract *the disempowering experiences* from chapter 1 and prevent life from being a struggle for people with a mental illness.

In this chapter, the disease model, psychological models and theories, the disability model, socio-political models and theories, and the study of psychological trauma are chosen for comparison because they are relevant. The selected models and theories address major topics from those at the beginning of the theory presented in this book, that is, *the experience of disempowerment*, explored in chapter 1, through *life is a struggle* in chapter 2, and *transforming oneself* from chapter 3, to those at its end, which detail the *transformation of society* in chapter 4. The theoretical underpinnings and the practice of mental health care attached to each theory or model will be included. It will be concluded that the most appropriate theory for people with a mental illness is the social movement theory, examined as part of the socio-political theories. The social movement theory delineates how social movements can achieve political empowerment for their members through broad social change by the establishment of a civil rights movement. This addresses the most important part of this study, how to gain empowerment through the *transformation of society* that participants advocate. It can provide a wider framework of how to achieve this transformation, and serves therefore as the best framework to permanently improve the lives of people with a mental illness.

This chapter contains:

- A comparison with the disease model
- A comparison with psychological models and theories
- A comparison with the disability model
- A comparison with socio-political models and theories
- A comparison with the study of psychological trauma

A comparison with the disease model

Taber, Quay, Mark and Nealey¹ explain that the disease model, also referred to as the medical model² or the biomedical model by participants in this study, is "a belief system basic to the practice of medicine". Taber *et al.*¹ ascribe to it four main features. The first is a belief that diseased and non-diseased states are qualitatively different and can be identified through "a unique set of observable signs and 'symptoms'". The second feature consists of a belief that an abnormality of a physical organ exists, or a pathology, which is "inimical to normal functions". The third feature refers to a belief in a specific "pernicious" cause. The fourth

feature, according to Taber *et al.*¹, concerns treatment, or "the belief that how the patient is treated makes a difference".

The advantage of a belief in the disease model is that it is able to explain and treat many diseases successfully. In these cases, a belief in the disease model can pinpoint the cause of an abnormality, assign a diagnosis according to a unique set of observable signs and symptoms, and prescribe effective treatment. However, with many diseases there are grey areas. Medical discoveries are ongoing and not all causes of diseases, their diagnoses and treatments have been confirmed³. In addition, not all diseased and non-diseased states are qualitatively different. For example, the debate on the cut-off point between normal blood pressure and hypertension is continuing³. In another example, type II diabetes, the causes and the exact biological abnormalities are still being discovered and further differentiation into more refined disease categories is being developed⁴.

The differentiation between physical diseases and psychiatric disorders is also in flux in some instances. For example, some diseases are classed as psychiatric when it is difficult to group signs and symptoms, a cause has not been found and no effective treatment is available. Once these requirements have been established, the disease is then reclassified away from the field of psychiatry. This occurred with syphilis⁵ and Gulf War Syndrome⁶. Epilepsy is still included in a report on mental health by the World Health Organisation⁷ but not in the Diagnostic and Statistical Manual of Mental Disorders (DSM)⁸. Exceptions are the dementias and substance use disorders, for which both physical pathologies and/or aetiologies have been identified but which remain under the aegis of psychiatry. In addition, the demarcation between, for example, normal grieving and minor depression⁹, and minor depression and major depression is also not entirely clear⁸.

Despite the grey areas in a belief in the disease model, contemporary mental health care is largely defined by it¹⁰. Participants in this study also wanted it to be successful. They hoped that applying the disease model to mental disorders would lead to an explanation of their signs and symptoms and that it could, with further scientific research, elucidate a cause. They also fervently clung to the possibility that by applying the disease model a cure could be discovered, which would free them from their mental disorder. Large organisations in the USA, such as the National Mental Health Association and the National Alliance on Mental Illness, also promote the application of the disease model to mental disorders¹¹.

In line with the first feature of a belief in the disease model, the belief that diseased and non-diseased states are qualitatively different and can be identified through a unique set of observable signs and symptoms, psychiatry has defined signs and symptoms and grouped them into categories⁸. These categories aim to describe the difference between how healthy people think, feel and behave and how people with a mental illness think, feel and behave. However, instead of these signs and symptoms being clearly demarcated between diseased and non-diseased states, as a belief in the disease model indicates, threshold problems have surfaced. Bebbington, Fowler, Garety, Freeman and Kuipers¹² explain that the threshold between the signs and symptoms belonging to a mental disorder and healthy thoughts, feelings and behaviours is difficult to locate. For example, Verdoux and van Os¹³, in referring to studies from Europe and the USA, found that 5 to 28.5% of non-clinical populations report phenomena that cannot be distinguished from delusions and hallucinations.

From the difficulties with locating a threshold between what constitute signs and symptoms of a mental disorder and what are healthy thoughts, feelings and behaviour it can be postulated that the allocation of signs and symptoms into disease and non-disease categories depends on interpretation. For example, Bebbington *et al.*¹² highlight the difficulty in distinguishing belief from delusion by pointing to the many "impossible, incredible or

false" beliefs that are, like delusions, so strongly held that people cannot give them up even in the face of contrary evidence or counter-arguments. Bebbington *et al.*¹² give examples of beliefs in "astrology, alien beings, telepathy or ghosts [and some strongly held] political beliefs ... even though they may be untried, or indeed tried and found wanting". The psychiatrist Szasz⁵ states that what perhaps is one person's belief, is another person's delusion. He adds that some beliefs are defined as belonging to a mental disorder particularly if society regards them as "illegitimate" or "wrongheaded". However, as the psychologist Aldridge¹⁴ points out, wrongheaded or "illogical" beliefs cannot be used as evidence of a mental disorder just because they are not understandable to other people or do not conform to the norm. Participants in this study also relayed that others regarded them as irrational cases beyond comprehension in chapter 1 under society devaluing and dehumanising people who have a mental illness. This was especially the case when the reason for their behaviour was not obvious or understandable to the observer.

Another difficulty with a belief in the disease model as applied to mental disorders is the boundary problem. Bebbington *et al.*¹² explain that the boundary problem refers to the hard to define line between different diagnostic categories, such as between bipolar disorder and schizophrenia. Participants in this study also alluded to the boundary problem when they voiced their fears about their mental disorder's capacity to progress to other, to them, even more serious disorders in *the struggle with having a mental disorder* in chapter 2: "Some of the fears for me are things like my bipolar disorder going on to schizophrenia".

There are also difficulties with applying the second and third features of a belief in the disease model to mental disorders, that is, a belief in an abnormality of a physical organ and a belief in a specific cause. Over the last 100 years¹⁵ studies on family histories, including twin studies and adoption studies, have given strong indications of a physical abnormality existing in many mental disorders due to their heritability¹⁵. This was also attested to by many participants in this study in *the experience of disempowerment of having a mental disorder* in chapter 1 when they listed the many family members who had a mental illness, indicating a genetic origin. In addition, researchers have examined structures of the brain¹⁶, tentatively identified some genes¹⁷, and implicated immune¹⁸ and hormonal systems¹⁹⁻²¹ in the pursuit of finding an abnormality and a cause. However, despite a huge investment of intellectual energy and monetary resources¹², the discovery of specific causes of mental disorders based on a specific abnormality has been elusive to date^{22-24,27}. Even magnetic resonance imaging that purports to show the amount of blood rushing to an active area of the brain and which has been used to associate supposedly structural abnormalities with, for example, depression, has been found to be largely incorrect²⁵.

Due to the difficulty in applying the first three features of a belief in the disease model to mental disorders, psychiatric practice has been presented with problems. Assessment depends on identifying signs and symptoms that are solely based on personal accounts of patients and on visual observation²⁶. No laboratory tests or scans are available³. Therefore, instead of diagnostic categories of mental disorders depending on discovering⁵ naturally occurring² diseases, they reflect concepts of illness formulated by committees using broad professional consensus³.

Treatment, or the belief that how the patient is treated makes a difference, also has been found to be problematic in applying the belief in the disease model to mental disorders. Mechanic³ points out that problems with discovering an abnormality and a cause are not so important if treatment at least makes a difference. In psychiatry, treatments try to make a difference mainly through the use of biological agents such as medications²⁹ and electroconvulsive therapy³⁰. According to Repper and Perkins³¹, the initial intent of curing mental

disorders with medications has not been achieved and the aim of treatment has been scaled back to alleviating signs and symptoms. Although some success in alleviating signs and symptoms by using the right medication and even by electro-convulsive therapy was reported by some participants in this study, as well as by other writers with a mental illness, for example Steele³², participants said in *the experience of disempowerment* in chapter 1 that many medications and electro-convulsive therapy resulted in not helping them and damaging them instead. Morgan, McKenzie and Fearon³³ note that "responsiveness to ... medications is not uniform, and there is a sizable minority of subjects [patients] who remain resistant to most common forms of treatment". Rose, Fleischmann, Wykes, Leese and Bindman³⁰ add in their systematic review of 16 studies that patient satisfaction with electro-convulsive treatment is variable and depends on the type of research method used.

The lack of success in applying the disease model to mental disorders is further illustrated by the fact that the number of people with a psychiatric diagnosis has inexorably risen despite treatments being hailed as successful. In Australia, the 2007 National Survey of Mental Health and Wellbeing found that the lifetime prevalence of mental disorders covered 45.5% of the general population³⁴. Similarly, based on a variety of sources³⁵, the one year prevalence was 38.2% in 30 European countries in 2010.

In the USA, studies cited by Whitacker³⁶ revealed that the number of people disabled by a mental disorder has likewise soared. One in every sixteen young adults has now been classed as seriously mentally ill. The number of children disabled by a mental disorder rose thirty-five fold. Whitacker³⁶ has come up with an explanation for this "epidemic". He noticed that the rise coincided with the introduction of mental health medications. Already by 1967 one third of Americans were taking these medications. By examining academic research articles from prior to and post introduction of mental health medication, Whitacker³⁶ correlated the two events. For example, prior to the introduction of mental health medications in the 1950s and 1960s, schizophrenia was rare. Moreover, some three quarters of people admitted to hospital with such a diagnosis managed to live productively in the community after discharge with few symptoms remaining. Today, one in 125 Americans is thus affected and most are on disability benefits with high relapse rates. Depression also used to be rare 50 years ago and largely self-limiting. Today, one in ten Americans suffers from it, with their illness taking an often lifelong and debilitating course. Likewise, the once rare bipolar disorder has struck up to 25% of adults - "almost as frequently as the common cold", according to Whitacker³⁶.

Whitaker³⁶ provides an explanation of how this large increase in numbers of people diagnosed with a mental disorder might have happened. He says that mental health medications were discovered by chance during research on other diseases. No pathological brain function amongst the 100 billion neurons and 150 trillion synapses in the human brain had been identified beforehand. Nevertheless, citing many research studies, Whitacker³⁶ points out the medications seem to dampen signs and symptoms initially for a short period of time. They then become less effectual. Nonetheless, ceasing the medication worsens signs and symptoms and even brings on new ones, including physical ailments. These then abate again with the recommencement of their administration. Such observations convinced treating doctors that the medication was correcting faulty neurotransmitters in the patient's brain. However, Whitacker³⁶ shows that it is the medications that "perturb a neurotransmitter system" in the initially healthy brains. "In response [to the neurotransmitter system having been perturbed]", Whitacker³⁶ found, by carefully examining many research studies, that "the brain undergoes compensatory adaptations, and as a result of this change, the person becomes vulnerable to relapse upon drug withdrawal". The signs and symptoms during relapse are caused by changes that had occurred in the brain as a response to the medications, and not by

the original disease. He concludes that the use of mental health medications constitutes a "trap". Once they are started it is very hard to stop them as often lasting changes have occurred in the brain in response to their use. Instead of curing the disease, or at least decreasing signs and symptoms, and improving the life chances of affected people, their continued use leads to chronic illness, a decline in functioning and often permanent disability.

Despite the mental health medications having been largely unsuccessful, and, in fact, often damaging to patients was also found by participants in this study, their prescribing continues unabated. Whitacker³⁶ also has an explanation for this. In citing examples, he shows that pharmaceutical companies throw millions of dollars at promoting their products and co-opt psychiatrists into their distribution, and prominent advocacy groups into supporting medication-taking with payments and perks. According to the British Medical Journal²⁸, not quoted by Whitacker³⁶, 75% of experts who determine definitions of mental disorders had links to pharmaceutical companies. At the same time, Whitacker³⁶ came across actual instances where those health professionals not acquiescing to the pharmaceutical companies were sacked from their jobs, funding was withdrawn from their programmes and their alternative research was silenced. In addition, as Whitacker³⁶ points out, the criteria of what signs and symptoms belong to a mental health diagnosis are increasingly widened to draw in larger and larger sections of the population. For example, using different sources to Whitacker³⁶, the Statistical Manual for the Use of Institutions for the Insane from 1917 listed only 22 diagnostic categories³⁷, whereas the Diagnostic and Statistical Manual-IV-R from 2000 contains 408³⁸. Continuing with Whitacker³⁶, all the while, a public relations campaign on the benefits of these "wonder drugs" is unleashed on the general population to deceive them as to their benefits and convince them of their necessity. Whitacker³⁶ explained that the corruption of mental health care occurred for the sake of prestige and greed.

Participants in this study, despite a professed belief in the disease model, pointed to another type of corruption, this one ideological. They noted, in chapter 1, that "the very theories that psychiatrists base their treatments on are false". Participants recalled that health professionals could not understand them because they had been blinded by the psychiatric model. They said that they could not link in-your-face abuse to the occurrence of mental disorders. They could not assess signs and symptoms accurately, make correct diagnoses or prescribe the right medications. They explained that health professionals developed a distorted and wrong view of people with a mental illness. Naturally, in chapter 2, participants were struggling with having been let down by the mental health system. In chapter 3, they found empowerment only when they relegated the importance of *trying to get on top of having a mental disorder* to *getting better as a person*. They explained that they were only successful in dealing with the mental health system when they decided to either not use it at all or when they became assertive, demanding better service. In chapter 4, they asked to be provided with effective help. As the psychiatric system could not come up with a cause nor a cure for their mental disorder they realised that a "cure is only found in society". They pointed out that this cure consisted of other people doing their duty, standing by people with a mental illness and showing compassion. These solutions are not in the field of vision of contemporary psychiatry.

However, despite the failures in the medical field, applying the disease model to mental disorders promised to have at least some socially advantageous implications, and participants in this study wanted very much to benefit from these. These socially advantageous implications come about because the public believes that the disease model provides an "objective understanding of a universal reality" and is "rational and measurable"²⁶. Therefore any moral judgment of the sick person is out of place because no personal motive can be attributed to the occurrence of the abnormality⁵. The lack of a

personal motive then precludes responsibility, blame³⁹ and moral condemnation¹⁴. The National Mental Health Association and National Alliance on Mental Illness, both from the USA, promote a belief in the disease model for these reasons with messages of "broken brain/nobody's fault"¹¹. Participants in this study were well aware of this potentially socially advantageous implication of a belief in the disease model. As recounted in the *transformation of society* in chapter 4, they hoped that if their mental disorder were acknowledged scientifically as a disease by the identification of a physical cause, thereby moving their mental disorder firmly into the orbit of the disease model, their condition would be viewed as value-free and they would no longer be blamed and condemned.

In order to capture the potentially socially advantageous implications of a belief in the disease model, participants in this study attempted to invoke a comparison of their mental disorder with physical diseases in *the struggle with establishing credibility*, from chapter 2. They thought that if they could convince other people of the value of their mental disorder by comparing it with the value of other general medical conditions, they could reduce stigma and prejudice. They hoped that they would then be believed and would be able to establish their credibility as trustworthy and honest citizens. However, Read, Haslam, Sayce and Davies⁴⁰, researchers from Australia, New Zealand and the United Kingdom, disappoint this hope. They looked at the 'mental illness is an illness like any other' use in countering prejudice with regards to schizophrenia in 58 studies from 17 countries spanning over 50 years. They found that this catchphrase, contrary to received wisdom, increased negative stereotypes, produced harsh and punitive behaviour and worsened prejudice and discrimination. Furthermore, they found in the reviewed studies that although the public accepted that a sick person has no control when faced with a general medical condition, this did not apply to mental disorders. Despite the public linking these disorders to abnormalities in the brain, people with a mental illness were viewed as incapable of judgement, reason and autonomy, all of which negated their person-hood. Therefore people with mental illness were seen as categorically different from others and as not sharing a common humanity.

A second negative effect of the 'mental illness is an illness like any other' approach to countering prejudice, identified by Read *et al.*'s⁴⁰ literature review, was that it produced a patronising attitude as in "They must be shown how to do things and where they have erred". This mirrored participants' account of how other people treated them in society mistreating people who have a mental illness in chapter 1, when participants relayed how other people thought they were superior and had the right to tell participants what to do, what participants' needs were and how they should conduct their life. Lauber, Nordt, Falcato and Rossler⁴¹ backed this up in a survey of the opinions of a representative population sample of 594 people in Switzerland. They found that a disease orientated understanding of mental disorders such as schizophrenia may indeed increase stigma. They concluded that this would have important implications for anti-stigma campaigns in that such campaigns would be ineffective or even damaging to the reputation of people with a mental illness.

Participants in this study came across other socially disadvantageous implications of a belief in the disease model, such as *society devaluing and dehumanising people with a mental illness*, as explained in chapter 1. Participants said they were devalued because society saw them as failures, and as stupid and helpless creatures just because they were unable to control their mental faculties despite their best efforts. They also reported being dehumanised because they were only seen as "a bunch of symptoms". In the experience of Coleman⁴², a writer with a mental illness, the dehumanising aspect of a belief in the disease model comes about because people with a mental illness are regarded as "somehow biologically flawed" and because their mind is seen as being reduced to a "by-product of the brain". Coleman⁴²

maintains that it further adds to no longer seeing people with a mental illness as human beings.

Another disadvantage of a belief in the disease model is that it leads to depicting patients as entities who are acted upon by disease and merely respond to it passively⁴³. The Division of Clinical Psychology of the British Psychological Society⁴⁴ elaborates that people with a mental illness are disempowered by psychiatry because they are seen "as necessarily dependent on expert advice and treatment, which may have the effect of discouraging them from making active choices about their recovery and the best means of achieving it". This passivity is then reinforced by disempowering treatment methods. Being passive and disempowered is not usually a problem for patients when treatment results in a cure. However, when no cure is available, disempowering treatment methods become significant also in patients afflicted by general medical conditions. For example, patients suffering from chronic pain⁴⁵ and incapacitating conditions associated with asthma, heart disease, multiple sclerosis and diabetes⁴⁶ complained about being disempowered.

A further disadvantage of a belief in the disease model is its focus on biological origins of diseases and the subsequent de-emphasis of psychological and socio-political factors. This is termed decontextualising⁴⁷. Participants in this study reported that *the experience of disempowerment* from chapter 1, with the exception of *having a mental disorder*, was excised from psychiatric knowledge. Salter and Byrne⁴⁸ add that stigma is not mentioned in any main psychiatric text. Along with participants in this study, as explained in *society devaluing and dehumanising people who have a mental illness* in chapter 1, other writers with a mental illness also report the segregation of psychological and socio-political factors in the decontextualising of their mental disorder: "We ... are forced to understand our problems as solely a biological matter"⁴⁹. Due to major life events being largely ignored they feel alienated from their own experiences⁵⁰. They also found that the gulf between what they experience and what health professionals tell them is so large that they develop a mistrust in the mental health system³¹. This also occurred to participants in this study in *the struggle with having been let down by the mental health system* in chapter 2.

Another consequence of decontextualising in this study led to mental health care concentrating exclusively on *having a mental disorder*. This is a mistake that participants in this study eventually discovered in stage 2 of *transforming oneself*. In addition, the necessity for a *transformation of society*, as outlined by participants in chapter 4, is not recognised.

The disappointment with the disease model as applied to mental disorders leads some authors to conclude that psychiatry is, in fact, not a branch of biomedical science⁵¹. They regard mental disorders not as real biological diseases but categorise them under human difficulties⁵. The Division of Clinical Psychology of the British Psychological Association⁴⁴ goes as far as calling for a "paradigm shift ... towards a conceptual system [in mental health] not based on a 'disease' model". Some writers with a mental illness, such as Coleman⁴², renounce a belief in the disease model outright and have sought out other non-biologically based ways of dealing with their symptoms to their satisfaction.

In conclusion, a comparison of the theory in this study with the disease model shows that the disease model with regards to mental disorders has not been successful despite its usefulness in explaining and treating many general medical conditions. However, participants in this study, along with other people with a mental illness, clung to a belief in its validity because they were convinced that their signs and symptoms, as explored in *having a mental disorder* in chapter 1, had a physical basis. They hoped that a cause and a cure for their mental disorder could be discovered through its application. They also hoped that mental health services operating within this model would help them and that it would grant them a

better life. As the evidence presented by participants themselves and the literature cited in this chapter show, these hopes cannot be fulfilled. Instead participants found that a belief in the disease model further fostered their disempowerment.

A comparison with psychological models and theories

Psychology is the "scientific study of the behaviour of individuals and their mental processes"⁵². Psychological models and theories seek to explain both abnormal and normal behaviours and their associated mental processes.

Psychological models and theories explaining abnormal behaviour and abnormal mental processes

Psychological models and theories concerned with explaining abnormal behaviour and abnormal mental processes concentrate on how behaviour has become abnormal, also called psychopathology, and how this abnormal behaviour can be corrected through intervention⁵³. The demarcation between psychopathology and normal behaviour is not as definite as in the belief in the disease model because psychological models and theories presume that the same psychological mechanisms are at the root of both of them⁵³. The four models chosen for comparison are the psychoanalytical model, the cognitive-behavioural model, the phenomenological-existential-humanistic model and the model employed by the Network of Voice Hearers.

The psychoanalytical model has been selected for inclusion in the comparison because it was the first modern psychological model developed. Created by Freud in the early part of the 20th century, it sees the nature of behaviour as being determined by a conflict between drives and defences, with the latter trying to keep drives in check⁵³. Examples of drives are sexuality and aggression⁵⁴, and examples of defences are repression and denial⁵⁵. The development of multiple personalities is also described as a defence against intolerable abuse⁵³. The psychoanalytical model states that drives and defences, and the conflict between them, often occur in an unconscious part of the mind⁵⁵. A balance in the conflict between drives and defences is achieved by applying the right amount of psychological energy on each. Psychological energy originates with innate drives⁵³.

Psychopathology is produced according to the psychoanalytical model if too much psychological energy is expended either on drives or on defences⁵³. It is corrected by revealing to the patient why the imbalance between the drives and defences has occurred. Teaching the patient to apply the right amount of psychological energy to each restores the balance. Intervention depends on gaining insight, which is obtained through free association⁵⁴ and dream interpretations⁵⁶. These help with bringing the presence of the drives and defences into the conscious realm. Intervention also aims to recreate the patient's past relational difficulties by enacting these between the patient and the emotionally neutral therapist⁵⁶. It is hoped that re-enactment will help the patient learn how to cope with any further problems in the future.

With regards to the theory of this study, the psychoanalytical model can be compared with how participants resolved *life is a struggle* by *transforming themselves* in chapter 3. In stage 1, there are similarities between the psychoanalytical model and participants' description of how they denied that they had a mental disorder. Participants' withdrawal behind a façade and a mental brick wall can be construed to be equivalent to the repression of unconscious material in the psychoanalytical model. How participants in this study felt split

between an outer persona and an inner true self is similar to the development of multiple personalities as a defence against intolerable abuse in the psychoanalytical model.

There are also similarities between the psychoanalytical model and of *transforming oneself* in this study. Participants spoke of the role of mental energy. Whilst going through stage 1, they made reference to how their unsuccessful attempts at *trying to get on top of having a mental disorder* had sapped their mental energy. When in stage 2, participants mentioned how their mental energy was built up when they gained inner strength during *getting better as a person*. This can be equated with psychological energy in the psychoanalytical model. Furthermore, in stage 2, participants consciously remodelled their view of themselves and their place in society when they developed a new, positive identity. In learning new strategies they started to redirect their feelings, thoughts and behaviour, analogous to learning how to cope with future problems in the psychoanalytical model.

The psychoanalytical model and this study are also comparable in how they view suicide. The psychoanalytical model sees suicide as an innate drive associated with aggression, called the death drive⁵⁵. The death drive "represents the innate tendency towards giving up the struggle" with the life drive, or life 'instinct'⁵⁵. In the psychoanalytical model carrying out suicide then means a failure to control the death drive, which triumphs over the life drive. Participants in this study also ascribed innate or "in me anyway" feelings for *wanting to be dead*, explored in chapter 1. As in the psychoanalytical model, they described their struggle between the contrasting forces of *wanting to be dead* and staying alive. However, in contrast with the psychoanalytical model on suicide, participants in this study asserted that they were disempowered with regards to *wanting to be dead*, which was a passive stance and not an active one associated with aggression. Participants found that they could not control their feelings of *wanting to be dead* and learning otherwise was not possible. They also did not regard going through with suicide as a failure but as an act that required determination and courage despite its passive stance. This last point is also brought up by Joiner¹⁵ whose theory on suicide emphasises the courage and competence required for carrying it out. Portraying participants as failures if they could not control *wanting to be dead*, or their death drive, as the psychoanalytical model implies, has the added disadvantage of putting the blame on the patient and increasing the struggle to identify any intrinsic value of oneself as a person, as explored in chapter 2 of this study.

The second psychological model seeking to explain abnormal behaviour and abnormal mental processes is the cognitive-behavioural model. It was selected for inclusion in the comparison because it is regarded as first line treatment in psychology. Heavy emphasis is placed on the cognitive-behavioural model's validity and effectiveness in contemporary psychology, even as an intervention for schizophrenia⁵⁷. Originally developed by Beck and colleagues⁵⁸ in the 1970s⁵⁹, this model's focus is on learning through cognitive, or thinking, processes⁴⁷. It states that people learn, for example, by associating emotional reactions with stimuli, also called classical conditioning. They learn by responding to the consequences of their actions, as in operant conditioning. They also learn by observing and imitating the behaviour of others, as in modelling. The cognitive-behavioural model further teaches that the correct thinking produces the correct behaviour⁵³.

In the cognitive-behavioural model, a psychopathology occurs when people learn the wrong thing, either by being placed in the wrong learning environment or by being "ignorant, confused or mistaken"⁵³. Free⁵⁹ explains that affected people develop "cognitive distortions", also referred to as logical errors, which are "errors in the processes of reasoning, such that a distorted conclusion or inference is drawn from the facts". These logical errors are then reflected in wrong ways of how the person sees the world and organises their behaviour⁵⁹.

Intervention, called cognitive-behavioural therapy, concentrates on correcting the faulty learning by providing education that instructs patients to "relearn" what they think⁵³. Peterson⁵³ explains that the aim of relearning is to see the world more "accurately" and to re-evaluate one's "'reality' of ... beliefs". According to cognitive-behavioural therapy, this relearning will result in producing the correct behaviour. Which worldview is accurate, what reality of beliefs should be adopted and what is the correct behaviour is not elaborated on. How the wrong learning environment consisting of other people's actions can be altered is also not mentioned.

The cognitive-behavioural model is applied to depression in the following way. Individuals with depression are said to have thoughts with an overwhelmingly negative content⁵⁸ because they have learnt these thoughts through either "negative interpretations ... of the cause of events" or "logical errors"⁵⁹. According to the cognitive-behavioural model, the person with depression also develops comprehensive and deep-rooted views about how they see themselves, the world and the future⁵⁸ that are largely negative⁵⁹. One consequence of the negative view is that the affected person applies it to everything and blames himself for anything that has gone wrong⁵⁸.

Intervention with the cognitive-behavioural model in depression consists of challenging the negative views so that they are changed to "thoughts that are more consistent with objective reality" and in line with "appropriate logic"⁵⁹. Who determines what objective reality and appropriate logic is, is not explained. In addition, if the objective reality of the patient is negative, cognitive-behavioural therapy may be futile.

Many participants in this study also talked about negative thoughts that had become, in some instances, overwhelming. They reported seeing themselves, the world and the future as negative, as elaborated in *the struggle to identify any intrinsic value in oneself as a person* and in subsequent aspects of *life is a struggle* in chapter 2. They also affirmed that thoughts influenced behaviour in developing new skills in stage 2 of *transforming oneself* in chapter 3.

However, with the exception of linking having been abused to the occurrence of their mental disorder in chapter 1, participants in this study gave no indication that their thoughts and behaviour had been learnt through either classical conditioning, operant conditioning or modelling. They were also aware that their worldview and how they saw reality differed markedly from those of other people, including health professionals. They said that the reasons lay in *the experience of disempowerment* as explored in chapter 1. This experience, particularly having been abused, was not common to other people and was therefore not seen by them. Instead of being accurate and logical, participants considered other people's views concerning participants, including health professionals', as distorted. The reason participants gave was that other people did not want to know and understand where participants had come from. They also gave detailed explanations as to why their thoughts and views were negative that justified their perspective.

Participants also stressed that positive thinking had no influence over whether they got an episode of illness in *the struggle with having a mental disorder* from chapter 2. They pointed out that merely changing negative thoughts to positive ones would not help because negative thoughts were not at the root of their disorders but emotions, as they explained in *the struggle with establishing credibility*. Emotions are not dealt with in the cognitive-behavioural model.

Despite being aware of these differences to the cognitive-behavioural model, participants in this study spared no effort in trying to change their thought patterns, as described in stage 1 of *transforming oneself* in chapter 3. However, they were unsuccessful.

When they were finally able to deal with their negative thoughts it was the last new skill they learnt in stage 2. There they succeeded only because they had already gained sufficient power in other areas. Moreover, instead of relearning and turning their negative thoughts into positive ones they simply countered or opposed their negative thoughts. They managed to gradually decrease the number of negative thoughts and increase the number of positive ones so that the number of positive thoughts eventually outweighed the negative ones.

The third psychological model explaining abnormal behaviour and abnormal mental processes chosen for comparison with the theory of this study is the phenomenological-existential-humanistic model. This model is regarded as just outside of current mainstream psychology and is seen as an "alternative" or "third force"⁶⁰. It views behaviour as freely chosen and not as subject to unconscious drives or cause and effect as in the psychoanalytical and the cognitive-behavioral models⁶⁰.

The phenomenological aspect in the phenomenological-existential-humanistic model, originating with Husserl in the early part of the 20th century, delves into understanding the subjective meaning of the patient's experiences, or the "essences of things"⁶⁰. The existential aspect, developed by Kierkegaard, Heidegger and Sartre in the first half of the 20th century, emphasises the need to understand the person's "individual existence"⁶⁰. The humanistic aspect, espoused by Maslow, amongst others, from the 1950s onwards, stresses the importance of needs and values and sees people as rational beings who want to do their best in life⁵³. According to Misiak and Staudt Sexton⁶⁰, the humanistic aspect contrasts with some other psychological models, which portray people as "mechanistic ... reductionistic" or as "dehumanised".

Psychopathology in the phenomenological-existential-humanistic model comes about when personal choices or circumstances do not allow the individual to achieve their potential. Problems are seen as "derailments along the way to self-actualisations"⁵³ where the patient has "lost, erred [in] ... or twisted [his/her] mode of existence"⁶⁰. The aim of therapy is to help the patient achieve his/her "authentic self ... [and] a degree of self-realisation"⁶⁰.

One type of intervention in the phenomenological-existential-humanistic model follows Rogers' client-centred approach, where the therapist, through warmth, concern, genuineness, empathy and a non-judgmental attitude, tries to help the individual find their own solutions to the problems they face⁵³. However, if the patient does not acknowledge that his 'problematic' behaviour is linked to free choice then he is seen as either deceiving him/herself or as acting in "bad faith"⁶¹. It is then up to the therapist to confront the patient with "what his choice had been and also the fact of his being in 'bad faith'"⁶⁰.

The phenomenological-existential-humanistic model resonates with much of *life is a struggle*, from chapter 2 in this study, where participants struggled with existential problems such as who they were as a person and what their place was in society. Participants also described elements akin to Rogers' client-centred approach as beneficial in *providing effective help* in chapter 4. They said how much they valued being supported and genuinely cared for. This included being made to feel welcome, having their feelings acknowledged and not being judged. Moreover, they expressed the wish that their life experiences be taken into account and they be shown compassion, as envisaged in the *transformation of society* in chapter 4.

Other writers with a mental illness also like aspects of the phenomenological-existential-humanistic model. For example, Coleman⁵⁰ points out that strange behaviours and experiences, known in psychiatry as symptoms, can become understandable and can be seen as rational when the meaning of this behaviour is elucidated in the context of the person's life events. According to Peterson⁵³, the interventions of the phenomenological-existential-

humanistic model also work well with individuals who have difficulties with self-esteem and self-perception, which played a pivotal role in *life is a struggle*, as explained in chapter 2 of this study.

The disadvantage of the phenomenological-existential-humanistic model is the belief that behaviour is freely chosen. Participants in this study emphasised that they had not chosen to have a mental disorder and that any behaviour derived from it was not under their control. How social circumstances can be changed to reduce problems from arising or how they could be changed from causing further problems is also not covered in the phenomenological-existential-humanistic model.

The fourth and last psychological model explaining abnormal behaviour and abnormal mental processes chosen for comparison is the model used by the Network of Voice Hearers. Although this model is not part of mainstream psychology and addresses only a small part of the experience of some of the participants in this study, its popularity is growing. The Network of Voice Hearers is now established in over 10 countries⁶² and includes a branch in Perth, Western Australia⁶³ where this study was conducted. It illustrates how the seemingly intractable hearing of voices can be managed and is therefore useful to those participants in this study who were subject to this experience.

The model used by the Network of Voice Hearers provides a new approach to the phenomenon of hearing voices, identified as hallucinations in psychiatry and attributed to the disease category of schizophrenia. The Dutch psychiatrist Romme⁶² describes how he and Escher gained a different insight into the phenomenon of hearing voices in the late 1980s, based on interviews with large numbers of voice-hearers.

Romme and Escher⁶² establish that hearing voices is not mental disorder specific. They furthermore conclude that it is not a symptom but a reaction to highly disruptive and often traumatic life experiences, which the voice hearer is powerless to deal with. They postulate that hearing voices is part of a survival strategy, which ensures that memories of the highly disruptive and often traumatic life experiences are kept hidden: "The voices emerge instead of the memories"⁶². However, Romme and Escher⁶² go further and take the phenomenon of hearing voices out of the realm of pathology and place it into the context of the voice hearer's life-problems, how they interpret these problems and how they deal with them.

Romme and Escher⁶² further researched what type of intervention is useful. Based on interviews with voice hearers, including those not diagnosed with a mental disorder, they formulated some general guidelines on how voice hearers cope with their voices. They found that the voices have to be accepted as real experiences and understood as being linked to the voice hearer's life history. The content of what the voices say and how they say it must be listened to because each can reveal why the voices first appear and what their function is. As Coleman⁵⁰ explains: "The important question ... becomes what were the circumstances in which you had this experience and why did you feel so unable to cope with it. These are the building blocks of recovery (or healing) - it is a power taking process".

This interpretation then leads to exploring strategies the voice hearer already finds useful, along with incorporating strategies discovered by other voice hearers. One strategy, according to Romme and Escher⁶², is to increase the control the voice hearer has over their voices. Some of these control strategies include dismissing the voices, designating a set time and duration for allowing the voices to appear and challenging them to the truth of what they say, particularly when they are derogatory. Medication also has a role to play in reducing anxiety associated with the hearing of voices.

Another strategy, described by Romme and Escher⁶², deals with making sense of the meaning and function of voices as being an understandable reaction to specific life experiences. A third strategy is to "restore ... [the voice hearer's] honour by acknowledging their real pain and trauma" and to work with them through "relinquishing the events of the past"⁶². They maintain that the voice hearer will then be able to make choices for their future life within society.

Participants in this study also utilised some of the same strategies identified by Romme and Escher⁶² and found them very useful. Participants finally recognised the connection between the abuse and their mental health symptoms, which contributed to the healing that took place as part of resolving *the struggle with the impact of having been abused* in chapter 3. They also learnt to counter or oppose troublesome thoughts, such as voices in their head, by sternly talking back at them. However, the recognition of the connection between the abuse and their mental health symptoms and also the acquisition of the skill of dealing with their voices occurred very late in the process of *transforming oneself*.

The model of the Network of Voice Hearers has advantages in that it formally recognises the causative link between often highly disruptive and often traumatic life experiences and the hearing of voices. Not recognising a causative link between the abuse occurring in childhood and/or adolescence and mental health symptoms was one of the main complaints participants in this study had with regards to their current health care. The model of the Network of Voice Hearers goes further in identifying a detailed set of strategies to deal with the hearing of voices, some of which go beyond those strategies participants in this study had used. Participants could probably have benefited from knowing about them. However, the model of the Network of Voice Hearers does not mention that society also needs to be changed and how this can be achieved in order to prevent any further highly disruptive and often traumatic life experiences from taking place.

Psychological models and theories explaining normal behaviour and normal mental processes

Two psychological models, being attribution theory and positive psychology, have been chosen to further clarify the reasons for some of the behaviour and mental processes recorded in this study. Attribution theory is a core theory in psychology. It seeks to understand some of the mental processes that organise behaviour⁶⁴. Attribution theory is particularly helpful in further explaining some of the attitudes and behaviours displayed by members of the general population towards participants in this study, as recorded in *the experience of disempowerment* in chapter 1.

Attribution theory postulates that people attribute a cause for the occurrence of the behaviour of others. This cause can be ascribed to either a personal disposition or to situational circumstances⁶⁵. Ross⁶⁴ gives examples of personal dispositions, such as abilities, traits, feelings or motives. Examples of situational circumstances are social pressures, forces or constraints, such as incentives, peer pressure, financial need, alcohol consumption, or a spouse's threat of abandonment. Attributing the cause to either category allows people to then infer the future behaviour of others. As Ross⁶⁴ points out the advantage of attributing either a personal disposition or situational circumstances as causing behaviour is that it becomes possible to predict how 'people in general' respond in relationships. Social chaos is thus avoided in the interaction with others.

Attribution theory goes further in identifying errors in attribution, called fundamental attribution errors. According to Ross⁶⁴, one fundamental attribution error overestimates

personal dispositions as causative factors of behaviour and underestimates situational circumstances. One reason for this error is that attributing the cause of behaviour to personal dispositions is much easier than to analyse complex situational circumstances.

Ross⁶⁴ further explains that this fundamental attribution error leads to others. For example, one's own attributes are often believed to be more valid than those of others, especially those that are different from one's own. Furthermore, ignoring or overlooking situational circumstances leads to reaching hasty conclusions. Both of these errors underlie biased and erroneous judgments of the behaviour of others and result in the misinterpretation of why other people do what they do.

Ross⁶⁴ points out that these fundamental attribution errors form deep convictions in people and are therefore difficult to invalidate or reverse even in the face of contrary evidence. As a consequence, a change in social attitudes and behaviour is very hard to achieve. Attribution theory also explains why a distortion of judgment and the resulting misinterpretation of the behaviour of others can lead to "personally maladaptive, socially pernicious, and often puzzling" behaviour in the holder of these fundamental attribution errors.

Attribution theory is highly relevant to the theory of this study. It explains many of the beliefs, values and behaviours of members of society that were puzzling to participants, as detailed in *the experience of disempowerment* in chapter 1. For example, attribution theory can explain why participants were not believed in *society does not believe what people with a mental illness say* as participants' accounts were outside the experience of the general population and therefore regarded as unbelievable. As a consequence, participants were held responsible and blamed for what they insisted they had no control over. Furthermore, attribution theory can highlight why participants were devalued and dehumanised in *society devaluing and dehumanising people who have a mental illness*, also in chapter 1. Other people felt superior to participants and used this as justification for mistreating and not helping them. Attribution theory also explains why the views, values and behaviours of society including those of health professionals, would be very hard to change, as envisaged by participants in this study in the *transformation of society* in chapter 4. However, attribution theory does not suggest how this can be remedied.

A second psychological model explaining normal behaviour and normal mental processes belongs to the study of positive psychology. As Seligman⁴³ explains, there are three pillars of positive psychology. The first pillar deals with positive emotions such as confidence, hope and trust. The second pillar consists of positive traits such as strengths, integrity, loyalty, future-mindedness, leadership, kindness, originality and wisdom. The third pillar describes positive institutions, which, in turn, support the first two pillars. Examples of positive institutions are democracy, strong families and free inquiry or a free press.

Keyes and Haidt⁶⁶ further describe individuals who possess positive emotions and positive traits as "flourishing". Flourishing individuals are healthy, productive and happy. They know what makes life worth living, are filled with emotional vitality, function positively in their private and public lives and are said to be "truly living rather than merely existing"⁶⁶. Furthermore, they reach out to others and engage positively with their social environment. Most of all, flourishing individuals are free from mental illness.

Clausen⁶⁷ also described the lives of flourishing individuals in two longitudinal studies of 300 Americans, using intensive interviews and questionnaires, which commenced in 1928 and 1932 and spanned 60 years. In these studies, flourishing individuals are found to be able to maintain equilibrium through a good understanding of themselves, cope well

through deprived times, have good self-esteem, a firm sense of self-identity and are confident that they can do whatever needs to be done.

The purpose of studying positive psychology, according to Seligman⁴³, is to prepare oneself for troubled and difficult times. By possessing positive emotions, nurturing positive traits and shoring up positive institutions, strengths and virtues that would "effectively staunch wounds"⁴³ are built up. How individuals have gained these positive emotions and traits and how they can use them in hard times is not discussed. Furthermore, how the third pillar, positive institutions, helps is not mentioned.

The positive emotions and positive traits described in positive psychology are similar to the emotions and traits exhibited by those participants who had gone through the whole process of *transforming oneself* from chapter 3 and were at peace. They described how they had become content, how they had gained strengths and capabilities, especially with regards to their helping ability. They said they had gained a positive identity with good self-esteem and had found meaning in life. It is interesting to note that participants had succeeded in reaching these positive emotions and positive traits despite the continuing presence of their mental disorder, albeit after overcoming enormous hardships in enduring and then resolving *life is a struggle*. The similarities between the study of positive psychology and *transforming oneself*, stage 2 in particular, therefore raises the question whether the process uncovered in this study may be useful to other people whose *life is a struggle* but who do not have a mental disorder as already shown in chapter 3.

Advantages of psychological models, both those explaining abnormal and normal behaviour, and abnormal and normal mental processes, lie in their ability to further illuminate many parts of the theory in this study. They also outline interventions, some of which would be useful to participants.

However, none of the psychological models compared here encompass participants' entire experience. A major disadvantage was an absence of the role of power in initiating or resolving *life is a struggle*. In this study, the role power played and the recognition of who held this power at different times was crucial.

Another disadvantage of the psychological models presented for comparison is that many do not acknowledge the impact of social influences and none show how to address these. Yet social influences were identified both as bringing on and having the ability to reduce or even prevent *life is a struggle* from occurring. As Aldridge¹⁴, a psychologist, points out, "individuals are treated [by psychology] to promote their accommodation within society". He states that this stance absolves society from taking any responsibility for the causation, correction and prevention of patients' problems. He concludes that psychological intervention, by regarding the social context as not being in its remit and concentrating on the "individualistic perspective" only, may thus become part of the problem and contribute to further damaging the patient.

Moreover, Aldridge¹⁴ found in his study on suicide that the psychoanalytical and the cognitive-behavioural models in particular largely lack any explanatory power and intervention methods with regard to suffering and distress. Thus Aldridge's¹⁴ study, as well as this study, clarifies why patients consider many psychological models of limited help.

The psychological models and theories have gained responses within mental health care. Mental health care, although downplaying psychological phenomena⁶³, does acknowledge the presence of psychological problems in patients³³. According to Szasz⁵, in mental health care, problems of behaviour identified in psychology are reinterpreted as diseases, complete with psychiatric diagnoses attached. These diagnoses included

masturbation and homosexuality until recently⁵, and currently contain diagnostic categories for caffeine withdrawal, sleep apnoea and stuttering⁸. Once identified as diseases, psychiatric treatment can be advocated for "all manner of human problems"⁵. Szasz⁵ calls the medicalisation of human problems the "institutionalised denial of the tragic nature of life".

Moreover, mental health care views problems of behaviour narrowly as an "inability to function"⁴², referring to the purely practical aspects of a patient's life. Success of treatment is then measured as an increase in the ability to function⁶⁹. Participants in this study described how they 'functioned' in *the struggle with trying to survive through daily life* in chapter 2. They referred to 'functioning' in their ability to studying, to working, in regard to stress and how they had become incapacitated. However, they regarded 'functioning' as the least important aspect of *life is a struggle*. The other aspects, concerned with existential matters of who participants were as a person and what their place was in society, were dominant in this study but are largely ignored within the psychological framework of mental health care. Therefore, mental health care again focuses on matters that are not the most important in the eyes of participants. This is backed up by Connor and Wilson⁷⁰ who explain that not focusing on what most matters for people with a mental illness fits in with psychiatry's mechanistic way: "We are seen as machines which have somehow developed some obscure fault". By focusing on functioning, mental health care does not take into account what is the main concern of patients, how they can resolve it and whether the patient has been truly helped.

In conclusion, the psychological models and theories compared here reflect many parts of the theory in this study. However, the disadvantage of psychological models and theories in not taking into account the importance of social determinants and a need for social change remains. In light of the strong emphasis placed on the need for social change by participants in this study in the *transformation of society* in chapter 4, this disadvantage may offset the advantages. Stroman⁶⁶ speculates that in psychology "maybe this [social change] was not seen as necessary".

A comparison with the disability model

In contrast to the disease model and psychological models and theories, the disability model is not concerned with the past but with the future. It does not look at where the disability has come from⁴⁰ or even what indicators of disability there are⁴². Identifying and categorising signs and symptoms, locating a particular cause, whether biological or psychological, or finding a 'cure' are considered unimportant³¹. The disability model instead looks to the future, to how the affected person can go about "getting on with your life"⁴². Its goals are to "see people beyond their problems - their abilities, possibilities, interests and dreams - and recovering the social roles and relationships that give life value and meaning"²⁹.

People with a mental illness who adhere to the disability model prefer to describe themselves as people with a psychiatric disability⁷². According to them, this term confers a very different outlook on life: "It is well known that many individuals with disabilities cope successfully with the difficulties they experience; therefore, as a person with a [psychiatric] disability, I can ... achieve great things"⁷³.

Inherent in the disability model are two interconnected aims: devising personal ways of improving one's life despite an ongoing disability, and changing society so that people with disabilities regain their rights and are not discriminated against²⁹. Within mental health, the disability model has been translated into the recovery model²⁹.

As Deegan⁷⁴, a writer with a mental illness, explains, the recovery model is "an attitude, a stance, and a way of approaching the day's challenges". It encapsulates a "process

of emancipation⁵⁰ and records how people with a psychiatric disability have "triumphed" in their struggle⁷⁵. The recovery model was created and developed by people with a mental illness⁷⁶: "Hit and miss, out of need and invention, we were building an alternative system of our own: by mental health consumers and for mental health consumers"³². The term mental health consumer is used in some countries to denote someone with a mental illness. The recovery model therefore sees the subjective experience of people with a psychiatric disability as central. It argues that this experience is different from the knowledge and experience of other people, including health professionals⁷⁷.

A central element of the recovery model is gaining personal power^{72,78-80}. Gaining personal power means to take an "active stance"⁷⁴, to be "in the driver's seat of my life"⁷² and to "taking back control over one's life"³¹. It means making one's own decisions³¹ and creating the life of one's own choice⁸¹. It also means insisting on being seen as a human being who has the right to be heard and to be regarded as an expert on one's own life⁷⁴. Gaining power in the recovery model also means to be actively involved in all facets of treatment⁵⁰ including the freedom to choose not to have any⁹. Medications are used as tools, as the following person with a mental illness, quoted by Romme and Escher⁶², explains: "It is of critical importance that we don't allow drugs [medications] to oppress us. We use drugs; we won't be used by them".

The first and most important element in the recovery process as described in the recovery model is having a sense of hope^{75,80-84}. Other important elements are "self-discovery, self-renewal and transformation"³¹. Self-discovery means gaining a positive self-identity⁴⁴ by redefining who one is⁸¹. It also involves integrating what has happened and moving beyond the 'illness'³¹. Overcoming the stigma of *having a mental disorder*⁷⁹, coming to terms with it and gaining confidence in managing it⁷⁸ are also essential. Additionally, in recovery, a new perspective on the relationship with others is gained⁸⁵ and a new lifestyle conducive to living with a mental disorder developed⁷⁹. People with psychiatric disabilities are not disturbed by mental health signs and symptoms remaining⁴² because they have achieved new meaning and value in life that does not require their disappearance^{31,84}.

The recovery model contains many elements also present in the theory of this study. The role of power is central to both. The recovery model closely resembles many parts of *transforming oneself*, explicated in chapter 3, especially stage 2. Hope, the first element in the recovery process, was also kindled in participants of this study during their transition through the *turning point*. However, they did not emphasise it to the same degree.

The greatest advantage of the recovery model is that it leaves behind the passive stance expected of patients in the disease model and in some psychological models and theories. People with psychiatric disabilities are accepted as they are and are not expected to change what they cannot change. They are also not required to comply with treatment or interventions that are damaging. The literature in this area does not identify that they are blamed, nor are they urged to "fit in" with the rest of society³¹.

The greatest disadvantage of the recovery model is the invisibility of what is stage 1 of *transforming oneself* in chapter 3. In fact, people in the equivalent of stage 1 seem to be purposefully excluded from some recovery programmes because they are considered as being "not ready"⁴². People who are in the equivalent of stage 1 could therefore get the impression that they have been rejected and feel excluded, although this seems far from the intention of the recovery model. They get no guidance on how to proceed through the *turning point* into stage 2. Yet proponents of the recovery model describe the equivalent of stage 1 in their autobiographical writings^{32,50,72,86}. It is also present in other studies. For example, Andresen *et al.*⁸⁴ call it "moratorium", Spaniol *et al.*⁷⁸ identify it as being "overwhelmed by the

disability" and Baxter and Diehl⁸⁷ describe it as crisis characterised by dependence, denial, confusion, despair and anger.

Turning points are also either mentioned only incidentally in the recovery model literature⁷² or not at all³¹. Some exceptions, however, exist, for example, in Coleman's⁴⁴ steps of recovery, where identifying a *turning point* is the first step. Rakfeldt and Strauss⁸⁵ describe a *turning point* as "catastrophic plummeting" and "a bottoming-out experience", which perhaps involves a crisis. Baxter and Diehl's⁸⁷ description of their stage 2 matches closely the description of the *turning point* in this study. They detail how people with a psychiatric disability make a decision "to get going" that helps them in starting to rebuild their independence. Smith's⁸⁸ study highlights a *turning point* occurring when her participants accept their psychiatric disability.

Another disadvantage with the recovery model is the near non-existence of ways to change society. Although this is a prominent feature of the disability model and the most important part of the theory of this study, it is either not mentioned at all in the reviewed recovery literature, or relegated to an add-on position³¹. The exception is Jacobson and Greenley⁸⁰ who give external conditions such as human rights, equity, equal opportunities and a positive culture of healing to be enacted in both the general population and among health professionals equal weight to the internal conditions happening within people with a mental illness in the recovery process.

With regards to the disability model and mental health care, both have adopted the term recovery. However, mental health care harks back to the disease model and psychological models and theories in defining recovery as "remission of symptoms and restoration of functioning"⁸⁹. Neither of these has much relevance in the recovery model. As Coleman⁴² points out, recovery as seen by mental health care remains impersonal: "Within this [psychiatric] scenario recovery is objective not subjective and the [affected] person is no longer a real factor in the process". According to Glover⁷⁵, mental health care, although voicing that it is recovery oriented, remains focused on a technical application of treatment and on "maintenance, monitoring, symptom management and relapse prevention". This has been called the "'old wine in new bottles' approach" by Pilgrim and Rogers⁹⁰. Therefore, the adoption and redefinition of recovery by mental health care can be construed as a distortion of the meaning of recovery as used in the recovery model. As this redefinition of recovery by mental health care does not equate with *transforming oneself* as described by participants in this study in chapter 3 it could contribute to *the struggle with having been let down by the mental health system*.

In conclusion, the disability model as applied to mental health is very useful to those people with a mental illness who are in the equivalent of stage 2 of *transforming oneself* in this study. However, the recovery model leaves the many people who are in the equivalent of stage 1 out in limbo without recognition and guidance. It also does not adequately address the *transformation of society*, which this study found is necessary to gain empowerment and allows for lasting gains to be made in the recovery process.

A comparison with socio-political models and theories

Socio-political models and theories try to explain the behaviour of groups of people⁹¹. According to Giddens⁹², behaving as a group means being able to act in such a way that that action is able "to make a difference to a pre-existing state of affairs or course of events". Therefore it involves the use of power. Issues of power and control are political issues⁶².

Power, the lack of it and how to gain it, was a central topic in this study and therefore comparing socio-political models and theories is important.

Oliga⁹² refers to power as not being inherently "noxious, oppressive, and exploitative" and says that how it is exercised determines whether it has a positive or negative impact.

The negative impact of power

The negative impact of power manifests itself through the exercise of social domination by one group over another². This domination is achieved through ideology and social control⁹². Ideology is defined by Edwards² as "meaning a biased and often false representation of social reality but one consistent with the selective interests of a particular, and typically dominant, section of society". Ideology is usually concealed and most groups in society, even the dominant group, are often not aware that the representation of social reality is biased and false⁹². Yet, according to Oliga⁹², domination is legitimised by declarations that the existing power structure is "natural, eternal, unalterable" and that it is "unproblematic". Oliga⁹² maintains that science can also be used to bolster ideology as a biased and false representation of reality "in order to conceal its [referring to science] distortions and legitimate itself in the pretentious name of rationality".

Ideology, through its biased and false representation of social reality, is inculcated through education⁹³ to such an extent that it becomes part of a highly pervasive and internalised "social consciousness"⁹⁴. As Oliga⁹² explains, powerless groups, by having internalised the highly pervasive social consciousness, may acquiesce in the power structure that disadvantages them. They may think of it as inevitable. They may feel that they need to be resigned to it, accommodate it, defer to it, obey it or even fear it. This fear may be in response to physical force and violence or it may consist of a moral fear of being ostracised. A social fear of losing one's job or social position may also be present⁹². As Kieffer⁹⁵ points out, the acquiescence in the power structure may lead to "an attitude of self-blame, a sense of generalised distrust, a feeling of alienation from resources for social influence, an experience of disenfranchisement and economic vulnerability, and a sense of hopelessness in gaining social and political influence".

Participants in this study reported that they experienced these influences of ideology, such as self-blame and a feeling of disenfranchisement and economic vulnerability. They said they were also ostracised, and some experienced physical force and violence as adults. Others said they had lost their job and social position. However, they did not seem to be enraged enough to take definitive steps to tackle the ideology enshrined in the power structure directly. It is possible that the pervasive and internalised social consciousness had impacted on them to such a degree that they felt they had to be acquiescent. Alternatively, maybe their anger had been "absorbed by depression"⁹⁶. Participants in this study also suspected that many members of the dominant group were not fully aware of the impact of what they were doing.

The negative influence of power is then enacted through social control¹. Social control is the "regulation of ... behaviour in accordance with some dominant interests"⁹². It has been argued that social control is essential to maintaining social order: "It ... [is] impossible to contemplate social life without social control"⁹⁷. This is especially so in times of perceived conflicts⁹². Furthermore, it has been maintained that social control is beneficial for society and this has been used to justify its continuation⁵. However, studies on social control found that it is not always beneficial because the dominant group doing the social

controlling does not necessarily act in the best interests of the common good but seeks to only bolster its own position⁹⁷.

In the health field, the enactment of social control also has two sides. It is deemed beneficial if it protects the public, and seen as harmful, and therefore not justifiable, if it interferes with private matters and violates human rights⁵. For example, according to Richard and Rathbun, cited by Szasz⁵, protecting the public against drunk drivers, infectious diseases and contaminated food can be seen as beneficial and needs to be under social control. However, the same authors regard the wearing of seatbelts, taking medication against hypertension and eating a healthy diet as a private matter that should be voluntary. In mental health, discussions are ongoing about where the line falls between the need to protect the public through the social control of people with a mental illness and the need to respect their private interests and human rights³⁹. Oliga⁹² maintains that when social control crosses the line between being beneficial in protecting the public and being harmful by interfering with private interests and violating human rights it becomes exploitative and should be seen as "sociopathology". Similarly, participants in this study also referred to the world being crazy in *the struggle with establishing credibility* in chapter 2 because other people mistreated them and in so doing violated ethical standards and criminal laws and got away with it.

Social control is achieved, according to Edwards², by deciding which values, norms and beliefs are right and should be adopted society-wide, and which are wrong. Making these decisions is referred to as rule making and is carried out by the dominant group⁹⁸. Rulemaking is not arbitrary because the rules decided on "defend and reinforce entrenched power positions and interests ... [and thereby] help to maintain ... [the] social order"².

Rules are then enforced by designated control agents². Control agents are individuals⁹⁷, such as neighbours and employers³³, and social institutions, such as families and schools⁹³. The state as a control agent uses its medical, welfare and justice systems to enforce rules². Participants in this study were highly aware of the functions of control agents such as family members, employers, teachers, health professionals and welfare employees, as they recounted in *the experience of disempowerment* related to their social sphere in chapter 1.

Rules also shape "moral and social judgements about human beings and their behaviour, and how to deal with them"². In order to make these judgements, control agents need to be able to distinguish between themselves, that is, the dominant group in society who set the rules, and those whom they are tasked to control. This distinction again is defined by the dominant group in that they have the power to determine who is "them and [who is] us"³¹. They do this by deciding that the 'them', that is, the powerless, display "undesirable and problematic" behaviour². This undesirable and problematic behaviour is referred to in sociology as deviancy, or as rule breaking⁹⁸. As the rules and therefore deviancy are defined by the dominant group, "deviance is determined not by the nature of the deviant acts, but by societal responses to those acts"³³.

Participants in this study recalled how they were battling in *the struggle with having a mental disorder*, in chapter 5. They were highly dismayed that they felt powerless to control it and prevail over its impact. In sociological parlance they acted with deviancy, as they were unable to stick to certain socially agreed on rules due to *having a mental disorder*. This is backed up by Scheff³³ who extended the general sociological research on deviancy to people with a mental illness. He reframed mental health symptoms as "rule ... violations". Mental health symptoms are viewed as rule violations because people with a mental illness are seen as not wanting to conform to how society expects one should behave⁹⁹. Behaviour thus becomes misbehaviour⁵. The psychiatric profession is then given monopolistic control⁵ by the

state⁴² to define what is normal, or healthy and natural, behaviour, and what is misbehaviour⁹⁷. In its "preoccupation with norms and normalisation"⁹⁷ the psychiatric profession thereby co-opts both a belief in the disease model and psychological models and theories into the realm of social control.

The literature on social control elaborates how people who display so-called deviant behaviour can be identified. They are identified by "naming" them as deviant⁹⁸. Naming is done through labelling. Phelan and Link¹⁰⁰ explain that "a label is a definition that is applied to a person and specifies what type of person that individual is". Again, these labels are applied by the dominant group to the powerless. Therefore labelling is a political act⁹⁸. In mental health, the value-free diagnoses dispensed under the disease model have become value-laden labels attached to unwanted behaviours⁵. This turns psychiatric diagnosing also into a political act⁹⁸ and psychiatry into a political entity⁵.

In this study, participants told in *the experience of disempowerment*, in chapter 1, how they were labelled by society as irrational cases beyond comprehension. Their behaviour was seen as unbelievable and was to be condemned. They were labelled as having a condition that was demonised by psychiatric diagnoses. Through these labels they said that they were marked permanently as non-persons who were not part of the human family.

The label that was the most offensive to participants in this study was that people with a mental illness were dangerous. Monahan and Arnold¹⁰¹ confirm that the linking of mental disorders with dangerousness is the most damaging label the public use. In fact, studies have shown that more people now view those with a mental illness as violent and dangerous than a few decades ago. In the USA, Phelan, Link, Stueve and Pescosolido¹⁰² found that 7.2% of people surveyed mentioned violence in relation to mental disorders in 1950. This had increased to 12.1% in 1996. Likewise, surveys in the United Kingdom by the Department of Health¹⁰³ showed that in 1993, 14% of a representative sample of the population expressed fear of someone with a mental illness moving into their neighbourhood; this had increased to 25% in 1997.

Evidence that the label of being dangerous was made up and not based on fact, as participants in this study also asserted, came from a number of extensive studies. For example, in England and Wales The Confidential Inquiry into Homicides and Suicides by Mentally Ill People chaired by Dr William Boyd¹⁰⁴, also called the Boyd Inquiry, found that of 2000 homicides in the three-year reporting period only 34 were committed by people who had been in contact with mental health services. Nine percent of these or only three cases involved killing a person unknown to them. Most of the perpetrators with a mental illness had taken their medication and had received adequate mental health care. The Boyd Inquiry concluded that it was therefore unclear whether the homicides were due to a mental disorder or due to other causes.

In the media, the view that people with a mental illness are dangerous is enhanced, as participants in this study also pointed out. For example, Williams and Taylor¹⁰⁵, in analysing 83 Australian newspaper articles with a subject matter of mental health, found that people with a mental illness were stereotypically perceived as violent. Likewise, the Glasgow Media Group¹⁰⁶, which examined how the British media routinely associated mental disorders with violence, systematically established that reporting concentrated on a tiny number of cases of violence. A distorted image was thus created of those with a mental illness.

Also in line with what participants in this study reported, the Glasgow Media Group¹⁰⁷ showed that 40% of the general public had been influenced by the media to believe that schizophrenia was associated with violence. The influence of the media was even

overriding belief systems gained from direct experience with non-violent patients. Sayce¹⁰³ added that the increase in the 1990s of fear of people with a mental illness in the United Kingdom was due to a moral panic linking violence with mental disorders after the widespread publication of some high profile crimes.

In addition, facts are distorted and sensationalised in the media¹⁰⁸ by exaggerating the violence angle, further backing up what participants said in this study. Crepaz-Keay¹⁰⁴, also of the Glasgow Media Group, describes how the findings of the above mentioned Boyd Inquiry were altered even in quality newspapers. For example, the 1.7 % of murders carried out by people with a mental illness changed to: "Mental patients kill 34 people in 18 months" (citing The Times, 17 August, 1994), "One murder a fortnight by mentally ill" (citing the Daily Telegraph, 17 August, 1994), and "Free to kill" (citing The Sun, 18 August, 1994). One newspaper (citing the Daily Telegraph, 17 August, 1994) called for compulsory administration of medications for people with a mental illness although most of the offenders had been on medication. In addition, more than three-quarters of offenders had received adequate professional care in the community, according to health professionals. This was reported as: "All of them had ... missed medical appointments before they killed" (citing The Times, 17th August, 1996). Crepaz-Keay¹⁰⁴ concluded that not only was the damage increased in being labelled dangerous but also the value of community care associated with people with a mental illness was attacked. He concluded that the media missed a chance to even-handedly report on a valid inquiry and instead focused exclusively on dangerousness "for the sake of a good story". The same stereotype was also evident in other factual and fictional representations on television and in magazines, where "violence to others"¹⁰⁹ was the most common feature depicting someone with a mental illness.

However, research into the dangerousness of people with a mental illness drew a different picture. Only a small subset was found to be violent¹¹⁰. On closer inspection only those subject to certain psychotic symptoms were thus identified¹¹¹. For example, some people with a mental illness felt so threatened by other people, due to their psychosis, that they thought it was justified to defend themselves in a violent manner. Others had been prevented by their psychotic thinking from applying internal controls over any violent behaviour. For example, they believed that God had commanded them to kill someone. Based only on a small subset of people with a mental illness being violent, Link, Monahan, Stueve and Cullen¹¹¹ conclude that the public's fear of people with a mental illness remains unjustified, and that the stereotype of dangerousness is not based on fact. They point out that if society wants to exclude people on the grounds of dangerousness they should be looking to exclude men, teenagers and people with low educational levels. Rosenman¹¹² writes most poignantly that "argumentative drunks, sedative-abusing adolescents and wife-beating men pose greater risks and dangers than the average mentally ill person".

Once so-called deviant people are labelled, social control springs into action to eradicate, correct or contain the behaviour deemed deviant⁹⁷. Again, this is carried out by the dominant group against the powerless. Social control is therefore also a political act¹⁴. It is achieved through regulatory interventions that seek compliance and conformity with the rules⁹⁷. Regulatory interventions are called sanctions⁹². Sanctions can be restricted to the ethical realm with measures that put pressure on the so-called deviant person. Some of these measures include blaming the individual and not the context of their lives¹⁴, restricting choices⁹⁵ including political decision making, and monopolising resources, together with knowledge⁹².

The participants in this study reported that they were exposed to all these measures, as explored in *the experience of disempowerment* in chapter 1. They were blamed for *having a*

mental disorder. Their choices were restricted when issues they brought up were brushed aside. Their interests were disregarded and decisions were taken by others on vital matters directly affecting them without taking into account what they wanted. Their political decision-making was restricted when their comments at government-sponsored meetings were ignored. Their feelings concerning *wanting to be dead* were also not given any credence by families and health professionals. Furthermore, their choices were restricted to access to services, including education on mental disorders, and accommodation. Speed¹¹³ adds that even the term mental health consumer, used as a term for a person with a mental illness in some countries and denoting having opportunities to make a selection amongst several service models, is a misnomer as there is little choice in a psychiatry-dominated health system.

Social control is then enacted as sanctions in the form of discrimination. Discrimination consists of the unfair treatment of the stigmatised¹⁰³ and is practiced by creating a social distance between society and the stigmatised person^{41,114}. Discrimination in the mental health field occurs as a consequence of the fear of dangerousness in particular¹¹⁵. For example, people with a mental illness are denied work opportunities because they are seen to be potentially dangerous at work, or they are refused housing because they are presumed to damage rental property¹¹⁶. Repper and Perkins³¹ write about the British 'nimby' (not in my backyard) campaigns against letting people with a mental illness move into the neighbourhood because residents were afraid of them. Participants in this study also reported how people cut off contact with them and wanted nothing to do with them, in *the experience of disempowerment* in chapter 1.

Social control is also used in the clinical treatment of mental disorders. As now 45.5% of the Australian³⁴ and 38.2% of European³⁵ populations are estimated to have a mental disorder, as mentioned above, nearly half the population has been put under the social control of mental health. How this was enacted was attested to by participants in this study, also in *the experience of disempowerment*.

The clinical treatment of mental disorders is used to enforce the rules in order to "eliminate, modify, isolate or regulate ... a deviant pathology within the individual"¹⁴. The deviant pathology is corrected through compliance⁹⁷. Non-compliance with treatment, even if this treatment is damaging, is "seen as further evidence of deviance and recalcitrance by a resistant manipulative patient"¹⁴. As Repper and Perkins³¹ point out, non-compliance with treatment is often interpreted as 'lack of insight'. It is seen as a sign of the mental disorder, as being irrational, and not as a challenge to "accepted psychiatric wisdom". Thus it is a "very powerful way of minimalising the impact of any challenge that an oppressed group might make to the way in which its members are defined and treated"³¹.

Participants in this study related, in *the experience of disempowerment* in chapter 1, how, in its most blatant form, social control was applied when people with a mental illness did not agree with clinical treatment. They were put under Community Treatment Orders or placed in locked wards of mental hospitals. According to participants, this was achieved through taking away their decision-making power by violating their human rights. Adam¹¹⁷ adds that the state sees the violation and removal of human rights of people with a mental illness as easy because of their devaluation and dehumanisation: "What rights could a psychopathology have?" He explains that the state further justifies the removal of human rights because it "had a duty to stamp them [diseased people] out by isolating them in ... hospitals [and] excluding them from [daily life]".

As with participants in this study, the removal of human rights of people with a mental illness is carried out through legally authorised coercion using psychiatry. In order to

understand how this coercion became legally authorised, Szasz⁵ writes that it is critical to go back to the origin of psychiatry and to contrast this to the origins of general medical services, both of which were "radically different": "The fatal weakness of most psychiatric ... [histories] lies in the historians' failure to give sufficient weight to the role of coercion in psychiatry ... [Something] never to be lost sight of".

Szasz⁵ recounts that general medical services were sought out voluntarily by sick people to relieve their suffering. In contrast, psychiatry began with family members searching for a way to get relief from the embarrassment and distress their "unwanted, troublesome" relatives caused them. This started in 17th century England with the advent of a new social outlook, which favoured the rule of law, cooperation and compromise to settle disputes. Therefore it was no longer acceptable for family members, all belonging to the "dominant classes", to coerce those relatives they regarded as displaying unwanted or troublesome behaviour and who were either not willing or unable to follow the rule of law, to cooperate and compromise. Evicting them from the home also often proved difficult without help. Moreover, providing that laws had been broken, it would have resulted in the relative's death in 17th century England. Therefore, as Szasz⁵ explains, a new socially acceptable and legal way needed to be found that ensured control over these people. This control was obtained by creating a new concept, the concept of mental illness. Szasz⁵ explains that this is the reason that the concept of mental illness differs so much from general medical concepts: "The point is that the physically ill person can be cared for without requiring coercive social control, but the so-called mentally ill person cannot be cared for in this way because he or she (rightly) rejects the patient role". Szasz⁵ concludes that due to this radically different origin of psychiatry "mad-doctoring had nothing to do with healing".

Szasz⁵ further explains how the practices of legal coercion of people with a mental illness continue to this day. Their rights as self-determining people are reduced to that of children. He refers to this as a political reframing of the status of the person with a mental illness. Furthermore, special laws, called Mental Health Acts, have been established, separating people with a mental illness from patients with general medical conditions. Under these Mental Health Acts people with a mental illness are not held legally responsible for their actions. This further adds to their powerlessness by taking away what, according to Szasz⁵, makes them human: "Being responsible for our actions is what renders us fully human".

Moreover, the coercive power of mental health services thus created suffuses every encounter people with a mental illness have with them because the threat of coercion and involuntary treatment is always present in the background even when agreement to treatment is given voluntarily^{31,118}. Furthermore, coercive treatment will never be able to foster recovery as understood in the recovery model⁴² and as documented in this study in *transforming oneself* in chapter 3. Szasz⁵ adds that in his opinion, such "nonconsensual 'treatment' is assault, even if it cures the patient of his disease".

Szasz⁵ further points out the no-win situation people with a mental illness find themselves in with regards to the twin medico-legal procedures of the insanity defence in court and involuntary admission to a mental hospital:

"In one case, the idea of mental illness is used to excuse a guilty person of his crime and incarcerate him in a mental hospital; in the other, the idea of mental illness is used to incriminate an innocent person as 'dangerously ill' and incarcerate him in a mental hospital."

Szasz⁵ is of the opinion that "psychiatry rests on these two procedures and would disappear in their absence". He writes that in not distinguishing between the need to heal the suffering patient who has the right to refuse treatment if dissatisfied and the so-called deviance of people with a mental illness punishable through involuntary incarceration leads to a "moral catastrophe". To muddy the legal-medical waters even further, the risk to the public from the person with a mental illness has been fused with a risk to the self, "hence the view of the insane person as 'dangerous to himself or others'. For centuries, this ... formula justified involuntary mental hospitalisation"⁵.

For these reasons, Szasz⁵ thinks that "psychiatry is not a medical but a moral and political enterprise". Aldridge¹⁴ concurs in finding that any claims that psychiatry has an "independent scientifically justified status" can be regarded as false. However, according to Szasz⁵, the public still regards psychiatry as humane because it remains "bedazzled by the myth of mental illness" and because it remains useful for society in "disposing of unwanted persons". The public therefore "recoils in confronting the irreconcilable conflict between the political ideals of a free society and the coercive practices of psychiatry"⁵.

As participants in this study presumed, most health professionals were not aware of the social control they performed in the name of mental health care, resulting in the abuse of their power, as documented in *society mistreating people who have a mental illness* in chapter 1. Participants speculated that health professionals instead interpreted the abuse of power as the right thing to do and as beneficial. However, as Vassilev and Pilgrim²⁹ note, "the principles of trust ... about autonomy, beneficence and non-maleficence are lawfully undermined" and therefore many people with a mental illness, along with the participants in this study, feel betrayed and do not trust mental health services.

Another type of coercion of people with a mental illness is carried out by the judicial system. Here the so-called deviant behaviour becomes punishable by criminal law. That many people with a mental illness have become embroiled in the judicial system is reflected in the number incarcerated in prison¹¹⁹. For example, the Treatment Advocacy Centre¹²⁰ in the USA found that there are ten times as many people with a severe mental illness in prisons as in mental hospitals. In Australia, 38% of prisoners have been told that they have a mental illness¹²¹. In addition, according to Vassilev and Pilgrim²⁹, "no other group of people in society (other than suspected terrorists) can be detained without trial". In this study, participants' fear of becoming entangled with the justice system was therefore justified. However, in line with social control and in contrast to sanctions, punishment in the justice system does not seek "to reform the guilty person or deter others but to maintain social cohesion by sustaining the collective consciousness"⁹⁷.

Lastly, social control also answers the question why *society lets perpetrators get away with their abuse and mistreatment*, as described by participants in chapter 1. According to Roach Anleu⁹⁷, perpetrators are allowed to get away with their abuse and mistreatment because they do not offend the collective consciousness. They do not disturb social cohesion, which can be maintained or even enhanced by their actions against the devalued and dehumanised sections of the population.

In conclusion, well-established socio-political explanations of the negative impact of power put the experience of participants in this study into a broader social context by explaining how the negative impact of power is exercised in general and how this exercise is applied to other social groups not connected to mental health. The disadvantage of the socio-political models and theories on the negative impact of power is that they do not have a remedy.

The positive impact of power

One socio-political theory explaining what to do about the negative impact of power and how to turn power into a positive force is the social movement theory¹²². The social movement theory describes how the actions of individuals and small groups can be transformed into a widespread collective social and political movement¹²³. The central goal of these social movements is to achieve broad social change through reforming society¹²⁴. Adherents seek to change a system that deprives them of power to one in which they gain sufficient power to be accepted as equal citizens, or, as Adam *et al.*¹²² put it, where they go from "repression to liberation". Having sufficient power to free oneself from being repressed, or from being disempowered as it is referred to in this study, means to seek equal amounts of power to that of other groups, and not to be dominated, in contrast to the negative impact of power.

According to the social movement theory, powerless social groups gain power by "challenging the structural arrangement of society and the prevailing ideologies, social expectations and moral codes which they see as resulting in their own marginalisation and devaluation"². Social movement theory thereby takes on what the disability model and socio-political models and theories on the negative impact of power leave unfulfilled, and what participants in this study were seeking, in chapter 4, when they called for the *transformation of society*. Social movement theory therefore confirms participants' aspirations for a transformed society as a legitimate goal. Examples of other groups of people who have achieved some measure of power show that participants' wish for a transformed society is achievable. In addition, social movement theory gives participants guidance as to how to go about attaining the *transformation of society*.

In social movement theory, two prerequisites have been found to be necessary for success. The first prerequisite is being grounded in a well-researched theory¹²⁴ that describes²⁹ and integrates the group's personal, health and socio-political experiences¹²⁴. These theories give strength to individual-based experiences and provide clear guidelines for what needs to be changed. Furthermore, these theories unmask how power is controlled in society⁹² and how this impacts on the group concerned. Feminism¹²⁵ and Queer Theory¹²⁶, which deal with the experiences of women and gay and lesbians respectively in the context of the social movement theory, are two such examples.

The second prerequisite is a favourable political climate¹²⁷. For example, despite the Women Rights Movement, disability rights and gay and lesbians rights groups starting in the 19th century, they did not gain traction until the 1970s^{71,122,123}. This was due to a favourable political climate being produced by the creation of the New Left, which followed on from anti-colonial movements in the Third World and the civil rights movement in the USA¹²². Producing a favourable political climate, however, is beyond the influence of any one social movement.

Social movement theory marks out four areas for change. Although these areas are intertwined and happen at the same time, change occurs in some before others. The first area of change, taking place earliest¹²⁸, concerns the change taking place in powerless individuals. Powerless individuals are changed by becoming aware of "previously unrecognised societal forces that shape their roles and limit their opportunities"¹²⁴. By sharing and analysing their life experiences within a group of similarly affected people they come to recognise that there are commonalities between them¹¹⁶. These commonalities tell them that it is external, societal factors that predominantly contribute to their predicament¹²⁸ and that they, as individuals, are

not at fault for what has happened to them. This realisation leads to a reinterpretation of what needs to be changed, pointing to society and not to the affected individual¹²⁴.

Coleman⁴² refers to this realisation and reinterpretation as "the politicisation of the self within wider society". According to Adam¹¹⁶, this realisation leads initially to "immense anger". However, the subsequent reinterpretation about the causes of what has happened then turns into "joy, pride and a boiling over of new ideas"¹¹⁶. It also results in "an enormous sense of relief, connection and healing"¹²⁴. Stroman⁷¹ states that this realisation and reinterpretation resulting in a "dramatically new and positive valuation of [oneself]" amounts to "a personal transformation". Increasing self-confidence and self-esteem⁹⁵ and a sense that one can determine what one wants to do⁷¹ become evident.

Once the politicisation of the self through personal transformation has been achieved, actions by both individuals and small groups follow. Actions by individuals can make great contributions in the early stages of a movement. For example, as Stroman⁷¹ describes, a young man called Edward Roberts, paralysed from the neck down by polio, went from being placed into a nursing home with no hope of a meaningful future to gaining his Master's degree at university and to starting the Independent Living Movement in the USA, a precursor to the Disability Rights Movement.

Actions by small groups may result in the creation of their own social spaces¹²⁴. These social spaces can foster the development of a culture unique to the group, as has happened in the Deaf Culture Movement and in the Gay and Lesbian Movement. People of the Deaf Culture Movement recorded their own history and heritage and established their own language, schools and university¹²⁹. The initially self-contained culture of the Gay and Lesbian Movement blossomed into "images of homosexuality in movies, books, theatre and popular music, as well as in newspapers and on television programs"¹²². It culminated in the Mardi Gras, a politically motivated demonstration of sexual diversity, which has gained public recognition and has become a mass celebration of this diversity.

As part of the ongoing change occurring in individuals and small groups, they also start to assert their human rights¹³⁰. Human rights are set down in the Universal Declaration of Human Rights, passed by the United Nations in 1948. These rights insist on "dignity, autonomy, privacy and equity in all contexts" for all people¹³⁰. Asserting one's human rights is achieved by fighting discrimination¹²². This fight entails challenging interpersonal discrimination, institutional discrimination, employment discrimination and housing discrimination⁷¹ in areas ranging from sports¹³¹ to the armed forces¹²² and marriage¹³². Joining up with other "sibling" movements also engaged in the fight against discrimination¹²² can lead to further creating an atmosphere where discrimination becomes politically unacceptable. In coupling with mass demonstrations and the lobbying of politicians, even becoming politicians themselves, a degree of political legitimacy, now backed by the media, is attained¹²². This reinforces the process of emancipation¹²². In this way, the social movement concerned has moved from being a stigmatised, pathologised and even criminalised group residing in seclusion¹²² to becoming a legitimised group getting diversity acknowledged as a source of strength¹²⁹. It has moved towards becoming accepted as part of mainstream¹²⁶ in being a "recognisable political and societal actor"¹²².

The second area of change advocated by the social movement theory concerns the judicial system. Affected people demand "basic [legal] rights and [legal] equality as citizens"¹²². The United Nations Children's Fund¹³³ statistical analysis of violence against children calls for children to be also included as persons with rights equal to adults. Acknowledging the rights of children will thus afford them the same legal protections against violence as adults enjoy.

Responding to international human rights, particularly to the International Bill of Human Rights of the United Nations and two important international treaties, the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights, many governments formulated anti-discrimination laws¹³⁰. For example, in Australia about 100 laws were amended to ensure legal equality between the general population and gays and lesbians "relating to superannuation, tax, care for the aged, health, social security, benefits for veterans as well as workers' compensation and discrimination in the workplace"¹³⁰. Disability Acts were written into law in countries such as Britain³¹, the USA⁷¹ and Australia¹³⁴. Anti-discrimination legislation is further strengthened by "constraining derogatory representations in television series and inflammatory media coverage"³¹.

Participants in this study also called for being *treated with justice* in the *transformation of society* in chapter 4. They wanted to have equal rights and wished not to be discriminated against. They advocated for anti-defamation laws with regards to people with a mental illness. In order to assert human rights and strengthen the fight against discrimination even further, Thornicroft and Kassam³⁹ have urged mental health anti-stigma campaigns to focus on discrimination, on who is involved and how it is carried out. This contrasts with anti-stigma campaigns based on a belief in the disease model, which, according to Thornicroft and Kassam³⁹, do not decrease stigma but merely perpetuate stigmatising labels.

The third area of change in the social movement theory concerns the change in public attitude towards the affected group¹²⁶, as participants in this study also emphasised. The reviewed literature found that attitude changes often lag behind legal changes^{130,135}. The social marketing approach has been found to be effective in changing public attitudes^{136,137}. The aim of the social marketing approach is in line with the social movement theory as it seeks to empower those groups of people it serves¹³⁷. Each particular campaign is designed "by the people it is about" together with experts in this approach¹³⁷.

Three ways are used in the social marketing approach: protest, education and interpersonal contact. As Corrigan and Gelb¹³⁶ explain, protest seeks to portray the attitude of the public as a moral injustice and advises them not to act in "this socially inappropriate way". It has been used to call for boycotts of businesses and in convincing the media not to present stigmatising images. Protest can also achieve a level of public attention that the other two tactics do not attain⁷¹. The second tactic, education, challenges inaccurate stereotypes and seeks to replace them with factual information¹³⁷. The third tactic, interpersonal contact between affected people and the public, has been found to make the greatest difference to a change in attitude¹¹⁰, especially if the affected person is perceived to be of equal status^{138,139}. However, a disadvantage of interpersonal contact is that a much smaller audience is reached¹³⁶.

The fourth and last area of change addressed by the social movement theory concerns a change in health care. With some social movements this involves demedicalising their 'condition'⁷¹. For example, the Gay and Lesbian Rights Movement "mounted ... [an] assault against American psychiatry, which resulted in the 1973-1974 removal of homosexuality from the APA [American Psychiatric Association] official diagnostic manual"¹¹⁶. Szasz⁵ adds that this removal of homosexuality from the APA manual due to political pressure from the affected group reveals that inclusion in the classification of mental disorders is based on ideology and not on the supposedly objective disease model.

Some proponents of the Disability Rights Movement also do not see themselves as sick and in need of treatment, such as the deaf¹⁴⁰. However, those in the Disability Rights Movement who are in need of medical treatment demand a transfer of power and authority

for decision-making from health professionals to themselves⁷¹. They want to determine the planning, budgeting, selection and evaluation of services⁷¹.

In order to affect change in the four areas of a social movement, that is, change of the affected individual, the justice system, public attitudes and the health system, support from like-minded advocates is also required⁷¹. This support comes from forming alliances with lay, academic and/or professional groups¹²⁴.

However, within mental health, a rights movement for people with a mental illness remains embryonic and isolated³¹. Although protests by people with a mental illness also started to be made in the 19th century^{31,141}, and some campaign groups were founded in the 1970s such as the British Networks for Alternatives to Psychiatry and the Campaign Against Psychiatric Oppression³¹, no comprehensive theory pertaining to the personal, health and socio-political experience of people with a mental illness was found in the literature review for this study. Although a favourable political context exists in democratic Australia with the progressive National Mental Health Strategy¹⁴², especially with its emphasis on human rights and its focus on the person with a mental illness, they have not suffused to many grass-roots health services, as attested to by participants in this study. Beyondblue¹⁴³, the premier mental health promotion organisation in Australia, remains disease focused and does not emphasise the need for a *transformation of society*. A selection from its website contains symptom checklists and outlines its strategic direction as "providing a national focus and community leadership to increase the capacity of the Australian community to prevent and respond effectively to depression". Some of its research topics centred on perinatal depression, pets and animal therapy, depression and related issues in gay, lesbian and bisexual people and in elite athletes.

Psychiatry, with its emphasis on a belief in the disease model and its social control function, has only made indirect contributions to the social movement theory. For example, it highlighted the widespread prevalence of mental disorders through surveys. Moreover, none of the participants in this study was in contact with any groups who had political emancipation as their core activity. Those people who stood by them could only support them on an individual level around local issues without being able to provide the kind of advocacy occurring as described in the social movement theory.

In conclusion, the social movement theory backs up the calls made by participants in this study in the *transformation of society* in chapter 4. It gives credibility to participants' aspirations. It also shows them that these aspirations can be realised and that their vision of such a society constitutes the real-life solution to permanently improve their situation.

A comparison with the study of psychological trauma

The study of psychological trauma has pulled together most of the theories and models discussed in this chapter and has shown how they can work together in order to change the lives of traumatised people. Having been abused and its sequelae played a central part for many participants in this study. Therefore it is important to discuss the study of psychological trauma and how it has helped other people. The study of psychological trauma has arisen out of years of research with a wide-range of traumatised people, including children, women, soldiers and holocaust survivors, following their experiences of child abuse, domestic violence, rape, captivity, natural disasters, accidents or wars¹²⁷. It defines trauma as following an "inescapable stressful event that overwhelms people's [everyday] coping mechanism"¹⁴⁴.

The study of psychological trauma has recognised the need to develop a theory that encapsulates "a new way of thinking about human experience, human tragedy, and the

universal human response to that tragic experience"¹⁴⁵. The theory behind the study of psychological trauma seeks to include a "comprehensive, cohesive, and compassionate cognitive framework that provides us with a direction and process for strategising about meaningful and effective social change"¹⁴⁵. The psychiatrist Judith Herman¹²⁷ formulated such a theory in her book *Trauma and Recovery*. This seminal work was the basis for other prominent research conducted by, for example, the psychiatrists Bloom¹⁴⁵ and Van der Kolk and colleagues^{47,144,146-152}.

Psychiatry has made valuable contributions here. It has recognised the role of psychological trauma in the development of mental disorders, albeit belatedly after a delay of nearly 100 years^{127,151}. The creation of a new disease category in its classification system, named post-traumatic stress disorder, has given legitimacy to the suffering of trauma victims and allowed resources to be assigned to its management¹⁵³. Research funding has also been forthcoming for extensive quantitative studies, some of which are cited in *the experience of disempowerment* from chapter 1 herein.

Experiences described in the study of psychological trauma closely mirror the experiences of having been abused described by participants in this study. As participants also claimed, the study of psychological trauma links trauma with the development of a variety of mental disorders including all those that participants were diagnosed with, namely major depression, bipolar disorder and schizophrenia^{127,154}. The study of psychological trauma also concurs with participants in this study in asserting that "symptoms may reflect permanent damage and change ... in the brain structure"¹⁵⁵. Incorporating the disease model, it postulates that various biological mechanisms might be involved that permanently change the brain structure following traumatic experiences. For example, changes in neurodevelopment¹⁵⁶, the hypothalamic-pituitary-adrenal axis involved in regulating stress, and various neurotransmitter dysregulations, such as dopamine¹⁵⁷ and serotonin, have been implicated¹⁵¹.

The study of psychological trauma also hypothesises, by using psychological models and theories, that delusions and hallucinations can result from a response to trauma in that the world is seen as an "essentially hostile source of threatening experiences over which the individual has little personal control ... and for which he or she has to remain on perpetual alert"¹⁵⁷.

Most importantly, and in line with socio-political models and theories and agreeing with this study, the study of psychological trauma acknowledges the centrality of power:

"The methods of establishing control over another person are based upon the systematic, repetitive techniques of psychological trauma. They are the organised techniques of disempowerment and disconnection. Methods of psychological control are designed to instil terror and helplessness and to destroy the victim's sense of self in relation to others."¹²⁷

The study of psychological trauma regards the use of power in traumatising others as not being accidental or incidental but as "a central organising principle in the formation, development, and maintenance of human society as a whole"¹⁴⁵. It further documents how trauma victims are seen society-wide as "mendacious, greedy and vengeful"¹⁵² and in need of social control. For example, reports by trauma victims are discredited and not believed¹⁵⁸, as also happened to participants in this study whose reports of abuse were not believed: "Despite the vast literature documenting the phenomena of psychological trauma, debate still centres on the basic question of whether these phenomena are credible and real"¹²⁷.

The study of psychological trauma concludes that trauma victims are not believed because their experiences are regarded as either uncommon or as "unthinkable"¹²⁷. They are regarded as unthinkable because they challenge the view of a just world¹⁴⁵. As also happened with participants in this study, people do not want to know about them and do not want to support them¹²⁷. Trauma victims are also blamed for what has happened to them, including being made a scapegoat, even when it is obvious that the trauma could not have been avoided¹⁴⁵. As DeVries¹⁵³ postulates this "social extrusion and stigmatisation" rests on "a cultural defence reaction to the unwanted information or behaviour". O'Gorman¹⁵⁹, who was abused by an Irish priest for many years and was highly traumatised through these acts, adds that "abuse is only possible in a silent world ... The silencing of truths ... allows us to continue to pretend that everything is fine, even when it is definitely not". In fact, as Erdmans and Black¹⁵⁸ write: "The silence that accompanies the abuse intensifies the devastation of the crime".

The study of psychological trauma also examines the response of the health system to the trauma victim. It finds that the health system denies or even furthers the abuse^{127,145}. The decontextualisation occurring as part of the disease model regards the "idea [of abuse as] ... simply unacceptable"¹²⁷. In addition, many psychological models and theories, also in thrall to decontextualisation, ignore the source of the abuse: "The exploitative social context in which ... [abusive] relations actually occur ... [become] utterly invisible. [For example,] psychoanalysis became a study of the internal vicissitudes of fantasy and desire, dissociated from the reality of experience"¹²⁷. For these reasons, and as has happened to participants in this study, a history of abuse is not linked up to the signs and symptoms of a disorder and misdiagnoses occur¹²⁷.

The resulting lack of progress in the patients' conditions due to not addressing the underlying issues of trauma¹²⁷ then causes health professionals to exhibit "coercive behaviour"¹⁴⁵. Health professionals' abuse of power, therefore, continues the abuse previously encountered elsewhere¹²⁷. This is referred to "iatrogenic re-traumatisation"¹⁶⁰. These responses of health professionals were all experienced by participants in this study and explored in *the experience of disempowerment* in chapter 1.

Furthermore, participants in this study reported, also in chapter 1, how *society was not willing to help them* and thereby *let perpetrators get away with it*. They particularly singled out the mental health system as standing by and not being responsive when criminal acts were committed against them. This is interpreted by the study on psychological trauma as exhibiting the behaviour of a bystander. Herman¹²⁷ explains what this involves:

"When traumatic events are of human design, those who bear witness are caught in the conflict between victim and perpetrator. It is morally impossible to remain neutral in this conflict. The bystander is forced to take sides. It is very tempting to take the sides of the perpetrator. All the perpetrator asks is that the bystander do nothing. He appeals to the universal desire to see, hear, and speak no evil. The victim, on the contrary, asks the bystander to share the burden of pain. The victim demands action, engagement, and remembering."

The reason why bystanders, whether the public or health professionals, do not want to share the victim's burden of pain and do not want to act, become engaged and remember is that they do not wish to be "disturbed by the raw emotions of injured people"¹⁵². The study of psychological trauma also found that trauma victims are even angrier with the passive bystander than with the perpetrator¹²⁷, as was also reflected in this study when participants described their anger with the mental health system in *the struggle with having been let down by the mental health system* in chapter 2. The response of the justice system is then to often

further traumatise the victims due to a hostile environment that an adversarial legal system produces for them¹²⁷.

The study of psychological trauma also confirms what abused participants went through in other aspects of *life is a struggle*, as explored in chapter 2. *The struggle to identify any intrinsic value in oneself as a person* is documented, complete with feelings of having no self-worth, no self-esteem and of being completely inadequate^{127,145}. Likewise, *the struggle with responding to the impact of having been abused* is present, including living in fear and self-blame^{127,145}. Stockholm Syndrome is renamed "traumatic bonding"¹²⁷. As participants in this study reported, traumatised people get to the point of being suicidal. The study of psychological trauma explains that being suicidal is due to feeling "utterly abandoned, utterly alone, cast out"¹²⁷ and "outside the bounds of the normal human community"¹⁴⁵.

With regards to *transforming oneself*, as explained in chapter 3, the study of psychological trauma also describes what trauma victims do. For example, withdrawal is acknowledged as a common reaction¹²⁷. Dissociation is identified as a "hallmark of trauma"¹⁴⁵ and seen as an "ordinary response to ... unspeakable ... atrocities"¹²⁷. However, a *turning point* is only mentioned incidentally^{127,145} whereas in this study the *turning point* was crucial.

Herman¹²⁷, in her book *Trauma and Recovery*, conceptualises three stages in the process in which trauma victims engage. As with this study, Herman¹²⁷ presents empowerment as an overarching fundamental component. Her first stage is concerned with the central task of establishing psychological safety. Her second stage involves remembrance and mourning, where trauma victims tell of their experiences. She writes that by remembering and mourning they transform the memory of the trauma so that it becomes integrated into their life story. Herman's¹²⁷ third stage deals with the reconnection to ordinary life. This involves taking power in real-life situations, developing the ability to choose whether to remember the traumatic events, rebuilding a valid sense of self, engaging in social action and helping other people. It culminates in trauma victims "feel[ing] calmer and better able to face ... life with equanimity"¹²⁷. According to McFarlane and Van der Kolk¹⁵¹, in this last stage, trauma victims have "transcended rage ... in the face of suffering and oppression" and have instead "transformed [it] into issues of social justice".

In common with the recovery process discussed under the disability model, Herman's¹²⁷ process of recovery starts with the equivalent of stage 2 of the basic social psychological process of *transforming oneself*, as explored in chapter 3. Many of the same elements were present as in this study, with the only difference being the timing of establishing a sense of safety. In this study, a sense of safety was not reached until after participants had gained a lot of power at the end of step 1 in stage 2. The equivalent of transforming rage in the face of suffering and oppression into issues of social justice was presented in the *transformation of society* in chapter 4.

Both participants in this study and the study of psychological trauma emphasise the importance of other people's support to counteract disempowerment. Herman¹²⁷ describes how this type of support facilitates healing. She writes that healing is achieved by being a witness and ally, by "detoxifying ... [the] sense of shame, stigma, and defilement" and by employing fairness and showing compassion. DeVries¹⁵³ adds that society can also support trauma victims and facilitate healing by providing "important mechanisms that allow individuals to reorganise their often catastrophic reactions ... [through] stories, rituals and legends highlighting the mastery ... [over] communal trauma". In addition, a relationship to the spiritual realm and religion can provide support and healing¹⁵³. The health professional becomes an assistant, a trainer and coach who gives expertise and moral support in what

Herman¹²⁷ calls a "cooperative therapeutic alliance". The role of support groups has also been highlighted in providing an environment for a "widespread, if not universal, mode of healing"¹⁵³.

The study of psychological trauma also calls for a *transformation of society* with regards to how to treat trauma victims. Bloom¹⁴⁵ points out that, as psychological trauma is a "social disease", the "mechanism for healing is [also] ... social". She proclaims that "it is not the traumatised person who is ... sick. It is those people who fail to understand [him/her]". This reflects statements made by participants in this study in that they saw the cure in society as explained in chapter 4. They also pointed to the need for society to change, in particular for the perpetrators, in chapter 2.

Herman¹²⁷ sees society as being transformed when its members take responsibility. This responsibility lies in two areas: recognition and restitution. Recognition means to fully reveal the extent and complicity of society in perpetrating violence. This revealing involves "public truth-telling"¹²⁷. Thorough official reports such as those into the abuse of children by the Catholic Church in Ireland¹⁶¹ and the Royal Commission¹⁶² into child abuse that had occurred in institutions such as schools and care homes in Australia have been set up to facilitate public truth telling. Public truth telling then becomes the factor that allows for social action¹²⁷. O'Gorman¹⁵⁹ backs this up by explaining that revealing the truth "demands action while secrets and lies allow us to avoid taking action". This action involves repairing the harm done through society's second responsibility, restitution. The justice system is the arena for this¹²⁷.

According to McFarlane and Van der Kolk¹⁵², the media, in being "prime purveyors of traumatic news", can also play an important role in assuring that trauma victims are treated with compassion and understanding. In addition, the media can influence public awareness by highlighting the social cost of trauma and violence. This includes educating and motivating the public, including politicians, to "develop sophisticated interventions to change these behaviours"¹⁵². An example of the positive role of the media was given by O'Gorman¹⁵⁹ who described how a media organisation was instrumental in helping him expose the abusive practices of the powerful institution that allowed him to become abused.

McFarlane and Van der Kolk¹⁵² conclude that unless society deals with victims of psychological trauma the consequences can be "disastrous". These consequences lie in "the costs of the re-enactment of trauma in society, in the form of child abuse, continued violence, and the lack of productivity, [which] are staggering".

In conclusion, the study of psychological trauma rests on the study of many diverse groups of trauma victims. It confirms the reports of those participants in this study who had been abused. The study of psychological trauma also illustrates how aspects of the disease model, psychological models and theories, the disability model, and socio-political models and theories, including psychiatry, can work together to help trauma victims.

In summary to this chapter, the models and theories selected for comparison brought with them further illuminations of the experiences reported by participants in this study. The one theory giving practical guidance as to how to accomplish a permanent change in the lives of participants in this study, as outlined in the *transformation of society* in chapter 4, is the social movement theory. This underscores this theory's assertion that this is the most important real-life solution.

Chapter 6: What you can do

Participants in this study laid out their *experience of disempowerment*, which brought on *life is a struggle*. They recounted how they resolved *life is a struggle* through *transforming oneself*. Most importantly, they wanted society to be transformed so that *the experience of disempowerment* that brought on *life is a struggle* in the first place would be ameliorated or even prevented from occurring. This last chapter will summarise what you can do to help people with a mental illness. You are a person with a mental illness, a health professional, a government or health service and a member of the general population. What you can do is based on the real-life solutions participants provided in chapters 3 and 4, coupled with further literature. What you can do revolves around how you can empower people with a mental illness both on a person-to-person level and a society-wide level. It is found you can indeed implement the real-life solutions devised by participants.

This remaining chapter covers what you can do:

As a person with a mental illness

As a health professional

As a government and health service

As a member of the general population

An example of a successful implementation of the real-life solutions from this chapter in a health service is given.

What you can do as a person with a mental illness

You may want to consider tracing the footsteps of participants in this study because, as participants pointed out, you are a person "like me". If you chose to shut yourself off from society as a wise measure after long and careful deliberation, as some participants in this study did, your decision has to be fully respected. Or you can chose to get together with other people with a mental illness, share your experiences, validate each other and provide support to each other for your long and arduous journey towards fully resolving *life is a struggle*.

With this theory now to hand you will know that you are not at fault and not to blame. You would also know that you can make your own decisions and take ownership over your life in spite of any ongoing *experience of disempowerment*. This will give you sufficient power and strength to learn new strategies and take action, particularly in protecting others and yourself, and in helping others. It will result in *transforming yourself* and attaining *being at peace*. You will seek to *get better as a person* instead of trying to *get on top of the mental disorder* by recognising your positive attributes in order to build a positive identity. You may also know that the dehumanisation occurring through being disempowered, as Freire¹ put it, "although a concrete historical fact, is not a given destiny but the result of an unjust order" and that being disempowered should not be seen as a "closed world from which there is no exit, but as a limiting situation, which ... can [be] transform[ed]".

Yet you may want to join those participants in this study who wanted to take political action but did not know how to at the time of the interviews. They may choose to engage in a different struggle, a struggle that tackles disempowerment politically. Oliga² urges people on

in this "long term, arduously uphill struggle" by issuing a "battle cry ... against entrenched and often unwitting forces of social domination, oppression and exploitation".

This different struggle then involves changing *the disempowering experiences* of society according to participants' vision in the *transformation of society*, as presented in chapter 4, and as elaborated on in the social movement theory in chapter 5. Deegan³, a writer with a mental illness, proclaims that in order to move towards this vision it is necessary "to organise our movement, raise our consciousness, develop our own lived philosophy, and discover and develop services that we need in order to live independently".

What you can do as a health professional

As a health professionals you can implement tasks that support people with a mental illness to gain power. These tasks should be carried out on a personal, professional and societal front. On a personal front, a major cultural change is required: "There needs to be a change of ethos overall"⁴. This involves altering the balance of power between people with a mental illness and you⁵. Coleman⁶ calls for a "deconstruction of the power of the psychiatric system and [a] reconstruction [of] power as a personal commodity [belonging to people with a mental illness]". The psychiatrist Bloom⁷ adds that this requires health professionals to "lay aside the brute power of our authority and to try other methods instead". These other methods, according to Høyer⁸ "would 'coerce' psychiatrists and other mental health professionals to develop non-coercive alternatives". To help with the implementation of empowering measures, a participant in Brody's⁹ study suggests that "rather than measure individual 'outcomes', why don't we measure consumers' empowerment as a whole?"

Guidelines for measuring empowerment of people with a mental illness can be obtained from this study. The level of empowerment could be measured by how many decisions people with a mental illness make themselves, as participants did during *transforming oneself* in chapter 3. Their empowerment would then be recognised if their decisions were respected by others, especially if they expressed alternative viewpoints. For example, respecting the decision not to use abusive health services and damaging treatments, as some participants in this study decided to do when they took action to protect themselves, also in stage 2 of *transforming oneself*, would recognise empowerment.

On the professional front, your task involves resolving the contradictions inherent in the dual roles of psychiatry as a 'curing' agency and as a control agency. Many mainstream authors assert that these two roles cannot exist together^{7,10-13}. All that participants in this study wanted was effective help. They found that neither the absent medical cure nor control fulfilled this request. Jacobson and Greenley¹¹ emphasise that control through coercion in particular has no place in mental health care, and consent has to be "the bedrock of daily practice".

However, psychiatry can help people with a mental illness by transforming itself into a healing agency. This healing, as found both in this study and in the literature presented in the comparison with other models and theories in the last chapter, has to occur with regards to the wounds that opened up in *having a mental disorder* and with respect to *having been abused*, both explored in *the experience of disempowerment* in chapter 1. Healing does not promise an elusive cure at some time in the future but can be achieved at the present time. As was explained in chapter 4, healing can be achieved by *providing effective help* through doing one's duty, standing by people with a mental illness and showing compassion. This would empower people with a mental illness by recognising them as equal human beings:

"What exists, in the truly existential sense, is not an illness or disease. What exists is a human being and wisdom demands that we see and reverence this human being before all else. Wisdom demands that we wholeheartedly enter into a relationship with human beings in order to understand them and their experience. Only then are we able to help in a way that is experienced as helpful."¹⁴

On the societal front, your task has to be directed towards engaging in social and political reform with the aim of *transforming society*. Bloom⁷ asks: "Should we be helping them [people with a mental illness] 'adjust' to a sick society, or should we be doing something to make society less sick?" Some health professionals have already taken on this task and see their role as "radical social activists, proselytising for changes in our society to make it more supportive, less dehumanised"⁷. They have come to realise that many concerns of people with a mental illness are "resolved not by therapeutic strategies but by political moves and revolutionary changes. The therapist or practitioner must become, in this view, revolutionary"¹⁵. The psychiatrists Salter and Byrne¹⁶ urge health professionals to "stand up and be counted".

You are tasked with recognising that empowerment of people with a mental illness is central to your role. You can help bring about this empowerment through engaging in the *transformation of society* by lobbying politically for justice and *providing effective help*, as outlined by participants in this study in chapter 4. You would then carry out as a human being what participants termed as the highest and noblest act, namely the alleviation of the suffering of others.

What you can do as a government and health service

Your job as a government is *to treat people with a mental illness with justice and provide effective help* through institutions such as health services. Participants in this study said that these two measures would empower them most. They saw justice as being treated equally in law. They wanted governments to reform laws to ensure they had equal status with the rest of society. Court judgements should be impartial and fair so that *perpetrators do not get away with their abuse and mistreatment* but are brought to task. Moreover, anti-discrimination legislation should be enforced, and anti-defamation laws created with regards to people with a mental illness.

Contentiously, participants insisted that all those individuals who are a danger to others should be dealt with under the justice system, irrespective of whether they have a mental disorder. This study therefore calls on governments to re-examine the line between protecting the public, including people with mental illnesses, and human rights laws that recognise all people, including those with a mental illness, as being capable of knowing the difference between right and wrong. As Szasz¹⁷ puts it: "The [mental] illness limits their [people with a mental illness] freedom of action but not their status as moral agents". Participants in this study provided ample proof that they were capable of being moral agents, for example in *transforming oneself* in chapter 3. However, governments sanction compulsory treatment of people with a mental illness before any crime has been committed which violates their human rights.

Participants in this study also called for governments to transform health services. Health services should resist the disempowering practices that cling to an institution-like department¹⁸ and engage in those practices that affirm the humanisation of their patients and their own¹⁹. Participants called for the old-style mental health hospitals to be redesigned into modern village type units with suitable amenities and Centres of Excellence to run intensive

programmes. Affordable accommodation with security of tenure should be made available in the community. Broad-based community services should be provided with a sufficient number of caseworkers and home help workers. This would then free up access to specialised mental health services, and allow for adequate communication channels between and within services.

Health services should listen to people with a mental illness, believe what they say, and tell them the truth. They should also ask what had happened so that *the experience of disempowerment* is uncovered and addressed. Being there for them, genuinely caring and showing compassion should also be routinely practiced. The search for the right medication must be persisted with. Support for families-at-risk would prevent or at least reduce further abuse from occurring. These ways of *providing effective help* should be enshrined in education programmes, including in best practice guidelines and policy documents.

You as a government also have to allocate adequate and appropriate financial resources so that health services can implement these recommendations. It may be necessary to transfer mental health to the disability services sector as a first step because their philosophy is based on empowerment already.

What you can do as a member of the general population

Your task is the empowerment of people with a mental illness through positive relationships, as set out by participants in this study in chapter 4. At the heart of these relationships is valuing people with a mental illness as equal human beings.

In order for positive relationships to occur, participants in this study explained that a change of mind has to take place in the general population. In the *transformation of society*, as laid out in chapter 4, participants suggested using persuasion and education to affect change. They also advocated using a personal approach that would try and influence those people whose minds have to be changed using emotions. The social marketing approach, described as part of the social movement theory from chapter 5, adds that protest is also useful when the public are urged to practice moral justice and act accordingly.

A second way for you to empower people with a mental illness is to stop pointing the finger at them, blaming them for *having a mental disorder* and ignoring or dismissing *the experience of disempowerment*, elaborated on in chapter 1. As other authors point out, the general population should reflect "upon the society that we have produced"¹⁴. When reflecting upon what society has been produced, according to Van der Kolk and McFarlane²⁰, the public will "inevitably [be] confronted with issues of man's inhumanity to man, with carelessness and callousness ... with manipulation and with failures to protect". In sociological parlance²¹, society should shift its focus from labelling the powerless, in this case people with a mental illness, as so-called deviants, towards challenging the rules, particularly the rules underlying the discriminatory behaviour of the dominant group: "This means sharpening our sights on human rights, on injustice and on discrimination as actually experienced by people with mental illness"²². This backs up calls by participants in this study, made in chapter 4.

As part of challenging the rules, the "shuffling out of our own responsibilities"¹⁴ for creating them has to be addressed. These responsibilities come in five forms. In the first form, you are called upon to take responsibility for your views, values and behaviour towards people with a mental illness:

"Taking responsibility means to uncover what society has done to 'cause the person to be mad'. When someone goes mad in our culture it is off to the hospital with him or her. It is not a gathering of the local community that gets together to decide what is wrong with the community."⁶

As a result of you taking responsibility for you views, values and behaviour, people with a mental illness would not be seen as the perpetrators of violence but as the victims²³.

The second form of taking responsibility, in Bloom's⁷ words, lies in caring for others. She states that this responsibility is "fundamental ... [and] not just an abstract concept". She explains that taking responsibility to care for others involves "making peace and eschewing violence, to create an atmosphere of kindness, respect, mutual regards, and tolerance rather than one of hostility, fear, disrespect, shame, or intolerance".

In the third form, responsibility entails deciding what to do when one is confronted with situations where injustice and the mistreatment of others is played out: "Every day, in virtually every situation in which there is a power imbalance, an injustice, a hurt person or hurt feeling, we are offered the opportunity to play one of three parts: the victim, the perpetrator, or the bystander"⁷. Bloom⁷ urges people to decide to take the side of the victim because this can make a crucial difference: "All it takes is for one bystander in a group to take some sort of positive action against perpetration and others will follow". She refers to widespread research, which shows that "the behaviour of the bystander determined how far the perpetrators went in carrying out their behavior". Marshall *et al.*²¹ also apply this responsibility to take the side of the victim to social scientists: "It is important for [social scientists] to understand 'which side they are on', and to be clear that they cannot ever be detached observers giving only 'the facts'". So-called detached scientific objectivity should not be applied in this context.

In the fourth form, taking responsibility refers to speaking out about the actions of perpetrators and making it known that they are not acceptable. This gives legitimacy to the disempowered by "counteracting the ordinary social processes of silencing and denial"²⁴. Speaking out then leads to the containment of mistreatment: "This containment can happen ... only if bystanders choose to become witnesses and rescuers, instead of silently colluding with the perpetrators"⁷. According to Bloom⁷, the actions of bystanders can then create physically and ethically safe environments, or what she calls a "sane society".

In the fifth and last form, responsibility is "confronting and addressing explicitly ... the existing social order"² that enshrines unequal power relationships. Oliga² calls for a "radical transformation of that social order". The necessity for this radical transformation is demonstrated throughout this study.

An example of a successful implementation of the real-life solutions from this chapter in a health service is given.

The mental health services in Trieste, Italy, are an example of how the struggle against disempowerment and the humanisation of treatment for people with a mental illness through its converse can be implemented. At the centre of the mental health services in Trieste is the assertion of the humanity of the patient²⁵. Its theoretical underpinnings were formulated by the Italian psychiatrist Basaglia in the 1960s, as summarised by Kendall²⁵:

"The psychiatric patients' real problem was not their mental illness but rather the way we treated them and how we viewed them; in particular our substitution of the illness

for the patient and the subsequent incarceration of the patient in the mental hospital, excluded from the rest of society."

As in this study, Basaglia²⁶ recognised the central importance of power in the relationship between society and people with a mental illness. For example, he acknowledged that the only difference between a psychiatrist and the patient is force. He stated that mental health care must not be used as social control. He set about to "dismantle what has been done" and advocated to "confront the world of terror, the world of violence, the world of exclusion" for people with a mental illness. He realised that in order to effect this radical change, which would turn psychiatry "upside down", health professionals themselves had to become politicised. He pursued this politicisation, along with colleagues, and a substantial part of the Italian society that had joined a popular struggle as part of an anti-authoritarian movement in the late 1960s²⁷, by creating a "radical movement for the liberation of psychiatry"²⁵. Basaglia²⁸ explained that the liberation of psychiatry depended on health professionals freeing themselves from seeing patients as objects, which he described as an "alienated relationship of slave towards lord". Instead, Basaglia²⁶ emphasised that health professionals should establish "a real relationship" based on a subjective understanding of "anguish and suffering"²⁹ that went beyond the "cultural schemes that imprison us". He wrote that health professionals "must grasp the world of needs from which suffering emerges, restoring it to the history from which it was banished in the very moment it was defined as an illness"²⁹.

Basaglia's movement in Italy in 1978 succeeded in enacting a law, called Law 180, which prohibited the construction of new mental hospitals and facilitated the gradual closure of existing ones²⁹. Law 180 also abrogated the use of the judicial concept of dangerousness so that psychiatry had to "confront those who suffer from psychic disturbances without protecting itself behind the screen of dangerousness and custody"²⁹. If hospitalisation was required, it was due to a lack of capacity in the community to respond to the "needs and rights of the citizen, in sickness and in health"²⁹. The onus was therefore put on the community to set this right. Another facet of Law 180 was to prevent the ideology practiced in mental hospitals with its "persistence of social marginalisation [of people with a mental illness], justified by the alibi of illness and treatment" to be carried over into services provided in the community²⁹.

Reflecting this study, respect for patients' decision-making power was at the heart of the humanisation of the treatment in Trieste¹⁸. Health worker-patient co-operatives were established²⁷ where people with a mental illness were not only directly involved in creating their own personalised treatment programmes but also in strategies aimed at restoring their rights and integrating them back into society. Mezzina *et al.*¹⁸ argued that this overcame the "separation between 'the illness' and the clients' comprehensive existence in society". Patients discussing and analysing their relationships with the community, "in particular the process of exclusion/marginalisation", was the aim of restoring the "opportunity to have access to these rights"¹⁸.

By 2006, a report on the mental health services in Trieste by Australian Senator Lyn Allison, then chair of the Senate Select Committee on Mental Health, found that no electroconvulsive treatment was used, no homelessness had occurred, only one person was in a forensic ward, suicide rates had dropped by 30%, and many patients, even those with psychosis, were employed in competitive industries on award wages³⁰. Despite its success, the humanisation of the treatment of people with a mental illness through empowerment as practiced in Trieste has not been implemented in many other places. Basaglia²⁹ gave as one reason for this "the fear of the mad overcoming every logical and humanitarian

comprehension". A second reason is "medicine's defence against any increasingly urgent attack on the old way of understanding medicine and its ability to translate into natural phenomena even that which is an explicit social product"³¹. This is still the case today as documented by participants in this study and elaborated on further in the comparison with other theories and models.

The success in Trieste also shows that the real-life solutions from this chapter are not fanciful but can be translated into reality. People with a mental illness in Trieste welcomed the effort undertaken by Basaglia and his colleagues as illustrated by a graffiti painted in large letters on the wall of a closed mental hospital: "Liberty is Therapy"²⁵. Participants in this study would also surely welcome such a health service.

Concluding statement

This study put forward a theory that explored and explained the experience of people with a mental illness. It is hoped that it will contribute to the increasing literature emanating from the community of people with a mental illness so that their power is strengthened through theoretical research that will highlight their concerns and their solutions. It is also hoped that this theory will provide guidance towards a mental health rights movement for both people with a mental illness and society in order to make practical differences to lives so that no one must struggle.

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Appendix: The grounded theory method and its application to this study

The appendix describes the methodology used in this study. It is useful for those readers who want to know more about the grounded theory method based on Glaser and Strauss¹ and Glaser²⁻⁸, and how it was applied in this study. It describes how the raw data from the interviews of participants resulted in the above theory.

General overview of the grounded theory method

Data collection

Data analysis

Criteria for evaluating a grounded theory study

Ethical considerations

Limitations of the study and future research

General overview of the grounded theory method

The grounded theory method is a systematic approach to generating theory from data by following clearly set out procedural steps. The grounded theory method is based on the implicit assumption that human societies are socially organised and that latent but recurrent patterns in this organisation can be uncovered. It asserts that these patterns "drive and organise behaviour and its social psychological aspects"⁵. The grounded theory method aims to identify and explain these latent patterns, especially in how people resolve their main concern, called the core category. It organises the complex, and possibly confusing, nature of the pattern of behaviour around this core category to "reduce the confusion to an integrated complexity"⁶. In addition, factors or conditions that vary the pattern of behaviour are identified whereby the pattern may be maximised, minimised or otherwise changed. In this study, the main concern was identified as *life is a struggle* (chapter 2). Participants resolved *life is a struggle* by *transforming themselves* (chapter 3). The condition that brought on *life is a struggle* was *the experience of disempowerment* (chapter 1), and the condition helping with its resolving and having the capacity to prevent its occurrence, was the *transformation of society* (chapter 4).

Two features are central to the grounded theory method: induction and conceptualisation. The inductive feature of the theory ensures that the research focuses on the concerns of participants and on trying to understand the patterns of behaviour from their perspective. The resulting theory is, therefore, not based on any pre-existing or preconceived theories, models or frameworks. It develops its own abstract model or framework based on the analysis of the data alone. Glaser⁷ argued that applying preconceived ideas to the analysis is "diametrically opposed to the goal of grounded theory". He explained that preconceived ideas would distort or bypass the participants' main concern and instead merely confirm the researcher's own perspective, which is often not the real problem relevant to participants⁴. The method is therefore called grounded, that is, the generated theory corresponds to or is grounded in the experience of participants, and not in the ideas of others⁶. Once the theory has been inductively developed it is set into the context of existing scientific literature.

The second essential feature of the grounded theory method requires that the fundamental pattern of behaviour be explained conceptually and not descriptively⁶. Conceptualisation means identifying concepts involved in the pattern of behaviour, which elevates the theory to an abstract level, that is, abstract of time, place and people. The grounded theory method, thereby, does not record the particularistic voices of participants but identifies their common shared pattern of behaviour and explains the reasons behind this behaviour⁶. It "transcended the boundaries"² of describing specific people in a specific place at a specific time. The resulting theory, which arises from a substantive area of research, can then be "fully generalisable as abstract processes"² and applied to other research fields¹.

The origins of the grounded theory method

The two essential features of the grounded theory method identified above were already evident in Glaser and Strauss¹ first book, entitled *The Discovery of Grounded Theory: Strategies for Qualitative Research*. In this work they described how they "discovered"¹ the grounded theory method while doing research on dying patients in hospitals^{9,10}. They believed that their new method would be more relevant and applicable than other research methods because it was able to interpret, explain and predict behaviour relevant to real life. It would give affected people, whether laymen or professionals, an increased understanding on what is going on in their social sphere and subsequently allow them some control over their situation. In addition, theories could be formulated where none previously existed or when a new perspective was called for. They claimed that basing theory formulation inductively on data gave it credibility and endurance over time.

To ensure the generation of a theory from any type of data, qualitative or quantitative, Glaser and Strauss¹ devised a set of systematic analytical procedures, which were further explained by Glaser in two other books: *Advances in the Methodology of Grounded Theory: Theoretical Sensitivity* in 1978², and *Doing Grounded Theory: Issues and Discussions* in 1998⁴. Glaser stated that some of the analytical procedures formulated in these books were based on other research methods. For example, Glaser^{2,7} explained how he took the procedure of how to generate concepts from data from Lazarsfeld's model in survey research analysis, a quantitative method on the conceptual coding of a set of indicators. This yields concepts that are linked to data and therefore produce an inductive theory. Glaser² mentioned that Merton supplied his idea of substantive and theoretical coding-conceptualisation to grounded theory's coding procedures.

While Glaser's background was in quantitative research, Strauss had been trained in qualitative methods, particularly in symbolic interactionism⁷. The term symbolic interactionism was first coined by Blumer¹¹ and was based on the work of Mead¹². According to Blumer¹¹, the term symbolic interactionism signifies that human beings attach meanings not only to objects in their daily life but also to their social interaction with other people. Individuals interpret these meanings and shape their behaviour on the basis of this interpretation.

However, although symbolic interactionism played an important part in the formulation of the grounded theory method, there are important differences. As Glaser⁷ pointed out, unlike the grounded theory method, symbolic interactionism tends to use only one type of data; data dealing with the interaction between people. It often uses preconceived interview guides and manages data restricted to only one type of framework, namely the meaning in overt interactions between people. In contrast, the grounded theory method uses any type of data, including simple facts, concepts not directly expressed by participants,

documents, or factors dealing with social organisation and social structures. The grounded theory method does not use preconceived interview guides. It does not search only for overt patterns but seeks to identify any underlying latent patterns, which explain behaviour. Glaser⁷ acknowledged that the theoretical perspective of symbolic interactionism could be useful in many studies but that it was paramount to stay open to other viewpoints so as to avoid using a preconceived framework, which was anathema to the grounded theory method. Therefore symbolic interactionism, according to Glaser⁷, should not be seen as dominating the grounded theory method's origins to the exclusion of other inspirations.

The arrival of the grounded theory method 40 years ago was described as turning traditional research methods upside down in that it advocated using data to create theory instead of testing it¹³. Since its inception it has become very popular in many fields of research and has now been described as a global phenomenon¹⁴. It was postulated that this was due to its track record of impressive studies¹⁵, its originality¹⁶, its powerful explanations of behaviour and its relevance to stakeholders⁵. It has been heralded as ground breaking¹⁴ and revolutionary¹⁷, and is used in a wide field of research, such as in nursing¹⁸, social science¹⁵, anthropology, business and management, history, economics, political science, biochemistry, philosophy and organisational theory⁵. The success of the grounded theory method has been marred, however, by the divergence in the writings of its originators in the 1990s.

The divergence in the writings of Glaser, and Strauss and Corbin

In 1990 Strauss, with his co-researcher Corbin, published a new book, entitled *Basics of Qualitative Research: Grounded Theory Procedures and Techniques*¹⁹, which sought to present the procedural steps in the grounded theory method in an easier to understand format for the beginning researcher. In this book, Strauss and Corbin introduced a new framework or model, called conditional matrix, to integrate the core category with specified conditions, actions, interactions and consequences. They stated that "the researcher needs to fill in the specific conditional features" (bold font in the original version) such as time and place. To emphasise the necessity of using their model, they warned: "Unless you [the researcher] make use of this model, your grounded theory analysis will lack density and precision". In order to accommodate their model, Strauss and Corbin introduced an additional step in the analysis, which they named axial coding. In axial coding the specified conditions, actions, interactions and consequences were to be explicated¹⁵ by directing predetermined questions at all concepts and categories in the data²⁰. Strauss and Corbin¹⁹ told readers: "With such category relating questions in mind, we then return to our data and look for evidence, incidents, and events that support or refute our questions". This statement indicated that their version of the grounded theory method model was deductive, not inductive. They insisted that all studies had to verify their model.

Glaser wrote a reply to Strauss and Corbin in 1992³, in a book called *Emergence Versus Forcing: Basics of Grounded Theory Analysis*, in which he explained in detail that Strauss and Corbin's method forced their preconceived model onto the analysis, whether relevant or not. In contrast, Glaser^{2,4,7} only gave examples of theoretical frameworks in order to sensitise the researcher to a palette of possible models. He insisted that these were not prescriptive. In fact, he encouraged researchers to devise their own, new theoretical framework if the analysis called for this. The original grounded theory method is purely inductive with data only used to illustrate the theory, whereas Strauss and Corbin¹⁹ made verification of their framework from the data an explicit goal²¹.

Glaser³ called Strauss and Corbin's¹⁹ model conceptually descriptive and denied that it was compatible with the original and, according to his judgement, only true grounded theory method. Glaser⁵ explained that conceptual description consisted of identifying a concept and then describing it fully. In contrast, concepts in the original grounded theory method are generated to identify patterns that are abstract of time, place and person. Strauss and Corbin did not directly reply to Glaser's stance but mellowed their assertion that their theoretical model "needed" to be used¹⁹ and instead went over to suggesting its use²².

The divergence in the writings of Glaser, and Strauss and Corbin divided grounded theory researchers into Glaserian and Straussian schools²⁰. Although this divergence has complicated the choice for an appropriate research method, this choice hinged on whether an inductive or deductive theory is sought. An inductive theory can contribute to uncovering new phenomena, whereas the deductive version verifies Strauss and Corbin's^{19,22} model. As this study aimed to generate an inductive theory, the original or Glaserian approach was chosen.

The differences between the grounded theory method and other research methods

Exploring the differences between the original method, from now on called the grounded theory method only, and other research methods further helped in understanding its essential feature of conceptualisation. Many researchers criticised the grounded theory method for not producing accurate or objective findings, a traditional science concern⁶. They wanted a careful and detailed description⁶, which reflected reality²¹. Glaser addressed their concerns in his 2003 book entitled *The Grounded Theory Perspective II: Description's Remodelling of Grounded Theory Methodology*⁶. He countered that the grounded theory method was not another quantitative or qualitative method but in a category of its own because the goal of the grounded theory method was abstract conceptualisation and not description. He stated that a grounded theory presented probability statements between categories and their properties, and not facts. The grounded theory method aimed to produce a theory that corresponded to reality and not one that represented it accurately.

Glaser⁶ pointed out the difficulties and drawbacks in accurately describing reality and explained how the grounded theory method addressed these. He said that accuracy was largely unattainable in many studies because "there is no adequate objective standard of reality, truth, hence accurate description". Very few data in everyday life were based on accurate descriptions, especially with qualitative data, where much was vague, interpreted or properline data. Properline data consists of participants stating what they think is suitable and appropriate for researchers to hear. It is not based on facts. Properline data were therefore distortions of reality and biased.

Glaser⁶ maintained that the grounded theorist has no problems handling different types of data, as they are important indicators of what is going on. Accuracy is just another variable to be considered in the analysis. He added that much of social life is built on "vested fictions" and that accurate descriptions are not able to capture these. For example, "half-truths, falsehoods ... lies ... and deception" can be useful data because they may reveal organisational cover-ups or explain strategies for selling cars.

Glaser⁶ stressed that descriptive studies, quantitative or qualitative, are not inferior or superior to grounded theory studies but are different in nature and serve different aims. Descriptive studies, with their aim for accuracy, reveal important information about the study population²³ but are less suited to revealing patterns of behaviour⁴. Glaser⁶ maintained that the purpose of the grounded theory method is to "produce concepts related to each other, not

... facts". The grounded theory method explains latent patterns that are easily generalisable and endure over time. In addition, to achieve accuracy, quite different methodological steps have to be adhered to, which would corrupt the grounded theory method if applied to it.

The difference in methodological steps between descriptive studies and the grounded theory method are therefore pronounced⁶. Descriptive studies determine the model to focus the study on, the study population and the data collection method, including the questions, before commencement. Vast quantities of data have to be collected to gain a full description, which is expensive in time and money. The analysis of descriptive data occurs after the completion of data collection and can therefore not respond to unanticipated findings.

The grounded theory method's approach is to use a wide range of sometimes unanticipated data instead, which are sampled according to theoretical relevance, avoiding standardised questions. It performs the data collection and analysis in tandem so that data collection can be varied according to what emerges as important. It delimits the large amount of data and is, therefore, resource efficient. It is able to handle complex data by focusing on a core category, and any outlying concepts are integrated into the theory by constant comparisons. Glaser⁶ concluded that due to these very different methodological approaches between descriptive studies and the conceptual grounded theory method, they cannot be mixed together, as both would lose credibility. They, therefore, have to be judged or evaluated in different ways according to different criteria.

Rationale for choosing the grounded theory method for this study

The grounded theory method was chosen for this study because it enabled the objectives to be achieved. Objective 1 was to explore the experience of people with a mental illness and to identify conditions or factors that influenced this experience. The grounded theory method was especially suitable for exploring participants' concerns from their perspective. Adherence to the procedural steps in the grounded theory method resulted in the formulation of an inductive, conceptual substantive theory, the second objective.

Other reasons for choosing the grounded theory method for this study were its suitability to manage qualitative data², its promised relevancy⁶ and immediate applicability²⁰, in this case to other people with a mental illness, their families, the general population, governments and health professionals. In addition, the theory could be generalised to other substantive areas.

Explaining the grounded theory method in detail by examining how its two essential features, induction and conceptualisation, were applied to the data collection and data analysis in this study will now be proceeded with.

Data collection

Induction in this study was achieved in the way data were collected, how data were sampled, how participants were recruited for the study, how interviews were conducted and how literature was selected. Qualitative data were used. Qualitative data are those data that are not experimentally measured²⁴ or analysed using statistical methods³. Qualitative data were chosen because they were most suited to inductively accessing participants' own accounts to learn about their experiences¹⁶. In addition, qualitative data were suitable for explaining the complexity of participants' real life situations²⁵. Tanenbaum²⁶ asserted that through qualitative data the researcher is able to seek "a deeper and more complex truth about how ... [participants] make sense of illness".

How data were sampled

The sampling method used in the grounded theory method is called theoretical sampling. According to Glaser and Strauss¹, theoretical sampling searches for concepts that address the theoretical purpose and relevance of the study. Glaser² explained that "the initial decisions in theoretical sampling are based only on a general sociological perspective about a substantive area within a population". The data for this study came from interviews with people who had experience with the phenomenon under study, that is, what it was like to be a person with a mental illness. They had identified themselves as having a diagnosis of major depression, bipolar disorder or schizophrenia, and were using or had been using mental health services. Participants with these diagnostic labels were chosen because of the high personal and social costs associated with these illnesses. For legal and convenience purposes participants had to be over 18 years of age and speak English as a first language so that no formal interpreters were needed. They were living in the Perth metropolitan area in Western Australia. This data was suited to produce concepts necessary for developing a substantive theory.

A central characteristic of theoretical sampling is induction. Induction is achieved through the application of the constant comparative method. The constant comparative method consists of continuously comparing new data with concepts that have already emerged from previously collected data, and which have been found to be important to the evolving theory. Glaser² described the constant comparative method as the joint collection of data, concept identification and analysis. Further data are then collected based on these concepts and the developing analysis. This ensures that "data collection is controlled by the emerging theory"² indicating its inductiveness.

Induction through the use of the constant comparative method during data collection was achieved in the following way in this study. Participants were invited to tell anything they liked, usually by me opening the interview with the following open-ended statement: "Tell me about yourself" to prompt them to talk. Some participants did not even need this prompting and started to talk about what was important to them straight-away.

In order to be able to encourage participants to talk freely it was important to establish rapport and an atmosphere of trust. This was achieved by me listening to what participants had to say with genuine interest and by emphasising the importance of their contribution. The rapport and trust gained also helped to "capture the nuances and meanings"⁵ of what participants were saying, enabling the identification of initial concepts. These concepts, and an early discovery of relationships between them, were then used in the following interviews as the basis for follow up questions after participants had exhausted what they had wanted to say. These concepts directed me to what type of further data to sample in subsequent interviews². To further ensure induction, interviews were later reviewed to see whether all follow up questions had been open-ended and whether any leading questions had been present, which might have unduly influenced the response of later participants. Glaser² pointed out that any topics that were not mentioned by participants were deemed unimportant and had to be left out of the evolving theory.

A description of the characteristics of participants

Thirty-five people who were or had been using mental health services participated in this study. Their ages ranged from 22 to 77 years, with a nearly equal number of participants being in the thirties, forties, fifties and sixties age groups. Two thirds were female. Fifty one percent had worked in the past in well-regarded jobs, two were studying, one at postgraduate

level, and one was working full-time when interviewed. Twenty percent were working part-time and 9% were doing voluntary work. Fourteen percent had been retired early against their wishes. Most (93%) had never used illicit drugs. Thirty eight percent of participants were members of support groups or daycentre organisations.

All participants identified that they had been diagnosed with a mental disorder. Twenty six percent had been diagnosed with major depression, 46% with bipolar disorder, 17% with schizophrenia and 12% with a combination of a mood disorder and psychosis. At the time of the interview, none were in an acute stage of their illness, 94% were on medication for their mental disorder, and the same number was using mental health services.

Fifty seven percent of participants volunteered that they had been subjected to some form of abuse in childhood and/or adolescence; two thirds of the abuse they characterised as severe. Twenty percent mentioned a happy childhood, and the remainder did not comment on their upbringing. Eighty three percent had thought about suicide with one third reporting actual attempts.

How participants were recruited

Recruitment occurred through advertisements placed in 16 community newspapers, through invitations at support groups and a drop in centre as well as through announcements about the study on a community radio station. Two participants were recruited following the introduction by a third person.

How interviews were conducted

When a potential participant was identified the researcher initially contacted that person to arrange a time to meet up, usually by telephone. The most common meeting place was in the participants' home, with the remainder taking place in public places such as cafes, parks and community centres. All participants were interviewed separately. Privacy was assured during all interviews by making certain that no one else was close enough to understand what was talked about.

Interviews were conducted between November 2006 and February 2007. The most common length was about one hour, with the shortest being 13 minutes and the longest five hours, the latter split into two sessions. Interviews were audio-recorded with each participant's permission.

How field notes were written

In addition to interviews, data were generated through the use of field notes² where the researcher noted down what she observed and her early analytical thoughts, complementing the data obtained in the interviews. The field notes contained information on the environmental setting and the ambiance during the interview. The following is an excerpt from a field note:

"Excellent interview! I think I have identified the main concern as struggling. I need to explore from now on in other interviews whether this is correct. The participant said prior to the voice recorder starting that she wants to do further education in social studies to help other people affected by a mental illness. She was teary twice during the interview but recovered from that within a short time. Just before I left she said

that the interview had inspired her to do some more advocacy work, meaning that she felt better and the interview had helped her. "

How literature was selected

Literature was not reviewed prior to the completion of the theory to avoid influencing the analysis and ensuring induction. Glaser⁴ emphasised that the researcher needs to be "as free and as open as possible to discovery and to emergence of concepts, problems and interpretations from the data" so that the use of any preconceived ideas emanating from the literature that does not fit or is irrelevant to the theory is avoided.

The literature review, carried out once the analysis was complete, concentrated on what was relevant to the developed theory⁵. This literature was "woven into the theory as more data"⁴ by comparing it to the concepts and patterns identified in the analysis. Therefore it is grounded to concepts sourced from the original data and thus inductive. In this study, both technical and non-technical literature was used as both played an important role¹. Technical literature, or refereed literature, consists of reports of other research studies and theoretical writings, and non-technical is comprised of non-refereed writings, such as autobiographical writings. Literature can also be chosen from other population groups. This choice contributes to the density and scope of the theory and facilitates its integration with existing literature².

How data saturation was reached

Saturation means that no additional data are found to add new concepts¹, and the same concepts are detected indicating a recurrent pattern in behaviour⁵. Glaser and Strauss¹ explained that saturation does not depend on the number of participants or how often a concept occurs but on how many diverse concepts are identified. They explained that the diversity of concepts determines the density of the emerging theory. Interviewing is therefore stopped when saturation is reached and this occurred after 35 interviews in this study.

How data were prepared

In this study, all interviews were audio-taped and transcribed verbatim. Although Glaser⁴ strongly advised against taping and transcribing interviews because of the time involved, I found it useful as it allowed her to go back over the exact statements given by participants and extract the correct concepts. For example, it had first appeared that education about mental disorders would be useful for the general population. However, by reading over the transcripts again carefully it emerged that this type of education was only beneficial for prospective people with a mental illness so that they could recognise what was happening to them. As was shown, education about mental disorders does not change the attitude of the general population but only furthers the stigmatisation of people with a mental illness.

Data were prepared by placing the text of the transcripts into one column, and the concepts into a second column. The concepts were then collated into categories. Further sorting was done until initial relationships between these concepts and the categories were fully explored. Concepts were then combined under higher order categories, which were further related to one another and finally assembled into the theory.

In conclusion, data collection in this study abided by the essential feature of induction in the grounded theory method. It was based on sampling participants who were exposed to

the experience of living with a mental illness. The concepts identified from the interviews then directed further concept identification in the following interviews. Field notes and literature were included only if relevant and after the theory had been developed. Obtaining deductive data that were not based on concepts obtained from the interviews was thereby avoided, and the inductive nature of the grounded theory method ensured.

Data analysis

Data analysis is based on the second essential feature of the grounded theory method, conceptualisation. Conceptualisation is achieved through the application of the constant comparative method at all levels of data analysis⁶. In contrast to the application of the constant comparative method during data collection, where induction is the aim, its use during data analysis facilitates conceptualisation. The constant comparative method here allows conceptualisation by constantly comparing differences and similarities between theoretical concepts and the data at each step of the analysis. How the steps in the data analysis, also called coding procedures, arrived at the final integrated substantive theory from the raw data through the application of the constant comparative method will now be described.

Coding procedures

Glaser⁴ defined coding as assigning concepts to incidents in the data. He explained that incidents are noticed in a phrase or a sentence in interviews. These concepts are then grouped as categories at a higher level of abstraction. Coding is carried out in two steps: substantive coding and theoretical coding.

Substantive coding

Substantive coding deals with concepts close to the substantive data or the actual behaviour of participants¹ and these codes are regarded as hypotheses or "probability statements about the relationship between concepts"⁴. Substantive coding is divided into open and selective coding.

Open coding is ascribing concepts to all incidences in the data¹. Glaser¹ used the term "open" in open coding to refer to "running the data open" or coding incidents into as many categories as possible. Open coding lifts the data from a descriptive level to a conceptual level. It concludes with the selection of a core category, which is how participants resolved their main concern. This core category is easily recognised because participants constantly talk about it, as it is "the prime mover of behaviour"⁵. The core category in this study was found to be *transforming oneself to resolve life is a struggle*. The identification of the core category marks the end of open coding and the start of selective coding².

In selective coding, the coding focuses only on the core category. This process is called delimiting². In delimiting, the large number of categories and their properties are reduced into a smaller set of those related to the core category only¹.

In line with the constant comparative method, incidents are compared with other incidents, followed on by comparing concepts with incidents. These concepts are then compared with emerging categories and their properties and then to the core category². This process results in theoretical completeness⁴. Theoretical completeness is defined as covering as much variation in the behaviour with as few concepts and categories as possible, also

referred to as scope and parsimony². All conceptual thoughts on the analysis are recorded in memos and then placed into a memo fund ready for sorting in the last stage of the coding procedure, theoretical coding².

Theoretical coding

Theoretical coding refers to how the substantive codes are organised or related to each other^{2,6} in an overall abstract model or framework, called the theoretical code⁷. While in open coding the data are taken apart, in theoretical coding "the fractured story is weaved back together again"². This weaving back together is achieved by fusing all substantive codes together using one theoretical framework, resulting "in a unified whole"². The integration of the core category with the theoretical code constitutes the theory⁷.

In conclusion to the data analysis, the identification of concepts at ever-higher levels of abstraction, and the exploration of their relationships through the constant comparative method fulfilled the essential characteristic of conceptualisation in the grounded theory method.

Reducing bias

To bring to a close the section on data collection and data analysis, how induction and conceptualisation reduce researcher bias will be briefly explored. Bias is any influence that brings about a distortion in the data collection and analysis^{2,3}. The grounded theory method handles bias by regarding it as just another factor to consider⁴. If not relevant it is revealed as eccentric⁶ and corrected for by theoretical sampling, the constant comparative method, memoing, focusing on the core category and saturation³. In addition, theoretical sensitivity reduces undue influence that would distort data collection and analysis by further assuring induction and conceptualisation.

Theoretical sensitivity, or the ability to think in theoretical terms¹, reduces bias and distortion on the data collection and analysis. Glaser⁶ advised that the researcher should "stay engaged with the data totally and let the abstract patterns emerge through constant comparisons". In order to broaden the researcher's theoretical perspective, Glaser^{6,7} recommended studying many other theoretical codes, or theoretical frameworks, in different grounded theory studies unrelated to the substantive area.

Glaser⁶ was confident that most researchers are able to suspend their knowledge of other models and theories until the completion of the data analysis and to stay open to the patterns identified from their own data⁷. This helps with not falling into any mould of thinking which did not emerge from the analysis⁷ and prevents forcing other models onto the data⁴.

I followed Glaser's recommendations and achieved theoretical sensitivity by applying the principles of data collection and data analysis as described. As well, I looked at the over 50 theoretical codes in Glaser's^{2,4,7} writings and at other theoretical codes in other studies. I also guarded against being unduly influenced by models and theories prevalent in the substantive area, such as the disease model or models on suicidal behaviour. In addition, I decided not to use any medical terminology in the write-up unless used by participants in order to help the reader also avoid any undue association with other models and theories.

Writing up the theory

Glaser⁴ stated that a basic tactic in writing up a grounded theory study is to place theoretical statements and concepts at the beginning of chapters, subsections or paragraphs and then illustrate them with examples that include direct quotations from the interviews. These illustrations are used to persuade readers of the usefulness of the theory and of its correspondence with the data. A second tactic crucial to writing up is to use concepts that carry forward, the "carry-forward notion"². The carry-forward notion highlights the importance of the identified concepts. If a concept does not carry forward it is possibly irrelevant.

In addition, the original wording used by participants in this study was maintained so that the participants' voice could be heard despite the use of some unorthodox language.

Criteria for evaluating a grounded theory study

The grounded theory method uses "fit", "workability", "relevancy" and "modifiability" as a criterion for evaluating a study¹. Fit means that categories are derived from the data, and this criterion is automatically met by adhering to the method¹. Workability refers to the power to explain the pattern of behaviour, or that the "theory should be able to explain what happened, predict what will happen and interpret what is happening"². Both fit and workability combine to produce a theory relevant to affected people in the substantive area³. To test the theory in this study for fit, workability and relevancy the theory was discussed with all participants still contactable and with other people not taking part in the study who had experience with the phenomenon of living with a mental illness. Lastly, a grounded theory should also be modifiable, or able to be easily altered, by being able to integrate new concepts as they come to hand³. Modifiability was achieved in this study during the literature review where further concepts were added.

Glaser and Strauss¹ gave some additional criteria for evaluating a grounded theory, namely logical consistency, clarity, parsimony, density, scope and integration. Participants in particular provided feedback. As part of the process of checking the theory for these criteria, critical reviews from academics and non-academics were sought out.

Ethical considerations

Ethical conduct needs to be part of all research activity and has to be evident in every step of the study from the recruitment of participants to writing up the thesis²⁷. Modern ethical standards came into being after the Second World War in 1947 with the *Nuremberg Code*²⁸. It chiefly dealt with the principles of voluntary consent of participants in research, their legal capacity to give consent and their power to provide free consent without coercion based on sufficient knowledge and comprehension of the research process²⁹. In addition, the World Medical Association adopted the *Helsinki Declaration* in 1964³⁰, updating it in 2008³¹, which covered codes specifically for medical research involving humans.

In addition to these international codes, the *Belmont Report*³² established three fundamental principles, which had to be adhered to when conducting research on humans: respect for autonomy, beneficence and justice. How this study adhered to these three principles in the Australian context, that is, in accordance with the *National Statement on Ethical Conduct in Research Involving Humans*²⁸, will now be explained.

Respect for autonomy

The first principle, the respect for autonomy, addresses issues of participants' informed consent and follows both the *Nuremberg Code* and the *Declaration of Helsinki*³³. Autonomy means that participants have a right to be informed on the advantages and disadvantage of the research they are consenting to³³. This information will enable them to make up their own mind whether they want to take part²⁷. Issues of informed consent include the freedom from coercion³⁴ and the right to withdraw, whenever the participant decides, without the expectation of negative consequences³⁵.

This study conformed to the principle of respect for autonomy when, with regards to participants with a 'mental impairment', consent was obtained "whenever the person is sufficiently competent and, where the impairment was temporary or recurrent, at a time when the impairment did not prevent the person giving or refusing consent"²⁸. None of the participants in this study were in an acute episode of their mental disorder during the time of the interview as assessed by me, a qualified and experienced mental health nurse. They also had to be over 18 years old to give legal consent without a guardian and be proficient in English so that no interpreters were needed. Participants' competence and willingness to consent was recorded in the field notes.

Participants in this study were informed both verbally and through an information sheet about the study. On initial contact I explained the purpose of the study, and how the interview was to be conducted. On meeting participants for the interview, I again outlined the study. Participants were given an information sheet that explained the type and purpose of the study and the voluntary nature of their participation. They were given time to ask questions before signing the consent form. All participants signed the consent form prior to commencing the interview and were given a copy of it and the information sheet.

Furthermore, as participants might perceive themselves to be in a dependent position or unequal relationship with the researcher, the "researcher [needs to give] an assurance that refusal to participate in or a decision to withdraw from the research would not result in any discrimination, reduction in the level of care or any other penalty"²⁸. I assured participants that I was not employed or otherwise associated with any mental health service to allay any concerns regarding access to and the quality of treatment if they decided against taking part or wanted to withdraw before the completion of the interview. Any possibility of coercion was also avoided by choosing an interview site that was not attached to a health facility and by not offering payment³⁴.

Beneficence

Beneficence deals with the benefits and risks of a study to participants and other stakeholders²⁷. It is concerned with the welfare of all involved parties²⁷. The majority of the participants in this study expressed that their interview had been beneficial in that they were able to air their concerns and get relief by talking about their problems.

Furthermore, no participant in this study was exposed to harm or experienced distress during the interview. Some participants displayed some minor discomfort at times but were able to complete their interviews without distress. During these times of discomfort I offered to cease the interview or change the topic. This offer was always denied. I was also careful in the choice and phrasing of questions so as not to probe for unpleasant experiences the participants did not want to talk about³⁶. The information sheet and the copy of the consent form given to all participants carried my contact details and those of my study supervisors if participants wanted assistance after the completion of the interview²³.

My safety was also an important consideration. As a standard precaution employed when conducting interviews with strangers, some interviews, especially with males, were conducted in a public place. At no time did I feel unsafe in the interview situation, permitting full attention throughout.

Justice

The principle of justice covers fair and equitable treatment of participants²³, particularly regarding privacy and confidentiality³³. Fair and equitable treatment means protecting participants from exploitation and abuse³⁵. This includes the protection of their privacy whereby personal information is not made public in such a way that participants are identified²³. In this study, each participant was allocated a code number, which could only be linked to him or her by me. Only the code number was recorded on the audiotape and transcribed interview. Other identifying features were omitted and replaced by an asterisk. As the theory dealt with abstract concepts and did not describe participants' particular circumstances⁶, their identity was further protected.

Participants in this study were informed on the information sheet that their confidentiality was ensured, and that I was the only person who could link their names with the data. Permission was also sought from the participants to present the findings in publications. The information obtained during the interview was stored in an appropriately referenced form in accordance with the Data Storage and Retention Guidelines outlined in the *National Health and Medical Research Council*²⁸. All transcribed interviews are kept securely for five years after completion of the study and then destroyed. No other person had access to the data. Ethics approval was obtained from the Human Research Ethics Committee of Curtin University of Technology.

Limitations of the study and future research

The objectives of this study were to explore and explain the experience of what it is like to live with a mental illness; to identify conditions, or factors, that influence this experience; and to develop a substantive theory based on these shared experiences. The developed substantive theory of this study was formulated using the grounded theory method based on qualitative data elicited through open-ended interviews with 35 people who identified themselves as having been diagnosed with major depression, bipolar disorder and schizophrenia. Participants were over 18 years old, spoke English as their first language, largely belonged to the Anglo-Saxon culture and lived in the Perth metropolitan area in Western Australia.

Several limitations can be noted here. One concerns the selection of participants. A relatively small number of people were selected to be interviewed. However, the grounded theory method uses diverse concepts and their relationships with each other as the building blocks for a substantive theory, and not the number of experiences or the number of people relating an experience. The latter two are unimportant. Data collection is sufficient and interviewing is stopped when no new concepts can be added and the same concepts indicating a recurrent pattern in behaviour are found. This is termed saturation. Saturation was reached at 35 interviews in this study. In the literature review, concepts pertaining to the experience of other people with a mental illness then substantiated the concepts identified in the original 35 interviews. Representativeness is not required for a grounded theory study.

Another limitation of the selection of participants was the restriction of data collection to those people who identified themselves as having been diagnosed with major depression,

bipolar disorder and schizophrenia. These three diagnoses were chosen because they represent the greatest personal and social costs attributed to mental disorders³⁶. Some data from people without a mental disorder were also included in the literature review in order to broaden the scope. Further research is recommended in conjunction with people affected by other mental disorders. However, a note of caution has to be given with regards to including the experiences of the general population and other people, such as health professionals³⁷ and family members³⁸, as their perspectives have been found to be very different to the experiences of participants in this study.

Moreover, the mental health diagnoses were not confirmed by doctor's reports but were based on what participants identified they had been diagnosed with. However, it was evident in the interviews that all participants had experience of the phenomenon under study, namely what it was like to be a person with such a diagnosis living in the Western Australian community. This was the critical criterion for inclusion in the study.

Another limitation concerning selection was that participants were self-selected. All participants, with the exception of two, responded to advertisements placed in community newspapers, through invitations at support groups and a drop in centre as well as through announcements about the study on a community radio station. However, self-selection ensured that the participants who came forward were eager to share their experiences because they saw this study as a way to help other people.

The self-selection of participants also produced a relatively high proportion of those with university degrees and community activists. This may be regarded as a limitation because it may not be seen as typical of the general population of people with a mental illness. However, their comments were in line with those of the other participants. The selected participants were also over 18 years old. This age restriction occurred for consent reasons. Therefore further research is needed to take into account the experience of people under the age of 18.

Another limitation concerning the selection of participants was that participants spoke English as their first language and largely belonged to only one cultural group. The literature review was likewise restricted to English language publications and to the same cultural group. Therefore, the many other people who do not speak English as their first language and/or belong to other cultural groups were excluded. However, it was found that including other cultural groups in this study was beyond its scope. In fact, Read *et al.*³⁹ warn not to export a substantive theory to the experiences of people belonging to other cultures without a great deal of thought. Therefore, substantive theories on the experiences of consumers using other languages and belonging to other cultural groups need to be written.

Another limitation of this study is that participants lived in the Perth metropolitan area, a relatively small geographical region, and interviews were conducted only over a period of three months. However, studies conducted in other parts of Australia and in other countries such as those in North America and Europe ranging over many years were included in the literature review as additional data.

A further limitation concerned using qualitative data as primary data. The reason for this was that qualitative data were deemed most suited to inductively access participants' own accounts and to learning about their experiences. In addition, qualitative data were thought to be the best data to explain the complexity of participants' real life situations and to attain a deeper and more complex understanding of how participants made sense of their experiences. Some quantitative data were then added in the literature review. Further research can be conducted using quantitative data to test the theory of this study.

A limitation pertains to the grounded theory method. It only concentrates on a core category, that is, on how participants resolve their main concern, and conditions influencing it. However, concentrating on this one core category "focuses on the interests of the participants in favour of that of [others]"⁴. It also prevents side-tracking into irrelevant and/or unimportant matters. Reproducibility⁵ and objectivity⁶ are unimportant in a grounded theory study.

In conclusion, despite the limitations listed here the objectives of this study have been achieved. The theory fits, works, is relevant, modifiable and is "applicable in daily life"¹. It has logical consistency, clarity, parsimony, density, scope and integration. However, the limitations indicate that the theory of this study does not speak for all people with a mental illness. It is important that further research expands on the theory so that a sound theoretical base is developed to find a way forward for mental health.

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Chapter 1: Causative factors

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Chapter 5: Why a mental health rights movement is the overarching solution

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Chapter 6: What you can do

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Appendix: The grounded theory method and its application to this study

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