

Experiences of the Early Implementation of the Mental Health (Care and Treatment) (Scotland) Act 2003:

A Cohort Study



# OF THE MENTAL HEALTH (CARE AND TREATMENT) (SCOTLAND) ACT 2003: A COHORT STUDY

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#### The Research Team

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# LIST OF ABBREVIATIONS AND ACRONYMS

ADSW Association of Directors of Social Work

AMP Approved medical practitioner ASD Autistic spectrum disorder

ASPSA Adult Support and Protection (Scotland) Act, 2007

AWIA Adults with Incapacity (Scotland) Act, 2000

BASW British Association of Social Workers

BMA British Medical Association

BME Black and minority ethnic communities

CMHT Community Mental Health Team

COREC Central Office for Research Ethics Committee

CPA Care Programme Approach
CPN Community Psychiatric Nurse
CTO Compulsory Treatment Order

DoH Department of Health

DWP Department of Works and Pensions

FHEC Faculty of Health Ethics Committee (UClan)
GAMH Glasgow Association for Mental Health

GP General Practitioner

IPCU Intensive Psychiatric Care Unit

IPS Individual place and support (model of supported employment)

LRA Least restrictive alternative

MHCT Act Mental Health (Care and Treatment) (Scotland) Act, 2003

MHO Mental Health Officer

MREC A Multi-Centre Research Ethics Committee A (Research re Incapacity

(Scotland) Act 2000)

MWC Mental Welfare Commission for Scotland NICE National Institute for Clinical Excellence

NHS National Health Service

NSF National Schizophrenia Fellowship

OT Occupational Therapist
RAG Research Advisory Group
RMO Responsible Medical Officer

SAMH Scottish Association for Mental Health

SEU Social Exclusion Unit

SIAA Scottish Independent Advocacy Alliance

SRN Scottish Recovery Network
UCLan University of Central Lancashire

VoX Voices of eXperience (service user organisation in Scotland)

# **EXECUTIVE SUMMARY**

#### Background

This research study, commissioned by the Scottish Government Health Directorate (previously Scottish Executive Health Department), has evaluated the experience and perspectives of those with direct experience of, as well as those working with, the Mental Health (Care and Treatment) (Scotland) Act 2003 (MHCT Act). A team of independent researchers including 8 mental health service users undertook the study, which lasted 2 years from September 2006.

The MHCT Act, which came into force on 5<sup>th</sup> October 2005, brought the most fundamental change to mental health law in Scotland in over 40 years. The Act created a new framework for the use of compulsory measures and it places emphasis on treatment and care in the community, on safeguarding patients' rights and on enabling the participation of patients and carers in treatment and ongoing care.

# **Purpose of the Study**

The broad aim of the study was to evaluate the implementation of the MHCT Act by exploring in-depth the experiences and perceptions of service users, informal carers/relatives, and various health and social care professionals and advocacy workers, and to consider stakeholders' views in light of those expressed prior to implementation of the MHCT Act.

#### **Methods**

The methodological approach was qualitative, using interviews and focus groups as the main tools to articulate different viewpoints and explore individual experiences of compulsion. The study was undertaken in 2 stages: Stage 1 began in February 2007 and ran until November 2007. Stage 2 interviews and focus groups ran approximately 12 months later. In summary, the main methods at each Stage were:

#### At Stage 1:

- Interviews with representatives from national professional or interest groups
- Interviews with practitioners from a range of professions and advocacy services
- Individual interviews with service users at various stages of compulsion
- Focus groups and individual interviews with informal carers/relatives.

# At Stage 2

- Individual interviews with service users from Stage 1
- Focus groups and individual interviews with informal carers/relatives.

The Faculty of Health Ethics Committee at the University of Central Lancashire approved the study in February 2007 following applications to the Central Office for Research Ethics Committees. In January 2007, an NHS Multi-Centre Research Ethics Committee under the Adults with Incapacity (Scotland) Act 2000 (MREC A)

decided that the study comprised evaluative research and did not require ethical approval from NHS Ethics Committees in Scotland. Research Governance committees at each local site including the State Hospital were consulted and approved research access.

Service users were partners in the research from the outset and were involved in the following ways:

- Collaborating with professional researchers to draft the research proposal;
- Advising on the research questions and method through their user organisations;
- Collaborating on the recruitment of service user researchers;
- Joining and participating in the research team as coresearchers/interviewers;
- Collaborating in drafting research measures and agreeing research protocols;
- Contributing to data analysis and identification of key themes in team workshops at both Stages of the research.

The findings should be read within the context of the research study undertaken, and care needs to be taken in generalising from the research to different populations or areas.

# **Research Samples**

In total, the study sampled and explored the views and experiences of 49 service users with experience of compulsion under the MHCT Act; 33 informal carers supporting relatives under compulsion, and 38 health and social care professionals and advocacy workers (i.e. 15 representatives of professional organisations and 23 individual practitioners). Four research sites were chosen purposively to include urban and rural areas and the State Hospital.

#### **Key Findings**

#### Tribunals

- All stakeholders felt that Mental Health Tribunals generally offered an improvement on the previous system of sheriff courts and provided increased opportunities for participation, although they also highlighted variations;
- Service users' and carers' experiences of Tribunals were mixed: while some emphasised improvements, others described them as adversarial settings in which they had little or no control;
- Carers highlighted some problems with the flow of information surrounding Tribunal hearings, and not all felt that Tribunal members had valued their contribution;
- From some professionals' perspectives, Tribunals created high demands on their time; this limited direct contact time with patients and clients, and affected their preventative and community roles and responsibilities.

#### Named Person

- The named person role was found to be complex and not well understood by all professionals;
- Although service users generally understood they could have a named person, they did not always understand the role as being distinct from advocacy;
- Service users were also sensitive to the fact that as named person their relative would have the right to receive information about them that they would rather keep private;
- Some carers felt their role as carer had been legitimised as a result of becoming a named person and found that professionals communicated better with them; however, this could change overnight if the service user chose to revoke this status.

#### Advance Statements

- In principle, Advance Statements were understood to enhance the service user's voice and involvement in their care and treatment. In practice, few people chose to make one:
- While professionals considered low take up to reflect lack of interest, the overwhelming view of service users was that their statements would be overridden;
- The irony was that when service users felt well enough to make a statement they
  often saw no point, in part because they felt they would not become ill again;
- The research detected uncertainties amongst service users and professionals about who should take responsibility for assisting service users in making their Advance Statement.

#### Compulsory Care Generally

- While universally unwelcome at the time, just over half of the service user sample reflected up to one year later that a compulsory order had been right for them. This did not however mean that they were happy with being treated against their will.
- Carers on the other hand, tended to be positive about the need for compulsion as it provided relief and resolution (albeit sometimes short lived) to difficult and painful circumstances;
- Professionals argued that the new Act and its principles had brought about a paradigm shift in the culture of detention, subjecting the decision to greater scrutiny.

#### **Community Orders**

- In theory, most professional groups were in favour of the implementation of community-based Compulsory Treatment Orders (CTOs), although they had reservations on account of what they perceived as gaps in community provision;
- Service users fell into 2 broad camps: some felt that this was a draconian measure, while others that it provided a helpful safety net;

- In practice, community-based CTOs appeared to be limited in use and scope, and often equated to medication orders. Service users had expected that a more holistic approach to meeting needs would be implemented;
- Carers were ambivalent about community-based CTOs, highlighting some positive outcomes and the gaps between theory and practice, fearing that, in reality, care in the community would mean care by the community

#### Hospital Orders

- Even though carers appeared to favour hospital-based over community-based Orders, both carers and service users highlighted problems with compulsory care and treatment when this was delivered within out of date buildings providing poor living and communal facilities, and inadequate daytime occupation;
- Despite negative experiences, some service users felt that hospital had been the right place for them when they were ill;
- Service users and carers were critical of the boredom experienced in some psychiatric hospitals, and resented the restrictions imposed by this setting;
- Carers experienced the discharge of a relative from hospital as sudden and frequently unplanned, rarely involving them in the process. However, there were signs of improvement highlighted by those able to contrast previous experiences.

#### Care and Treatment

- Care and treatment under compulsion appeared dominated by drug therapies and less focused on non-clinical social, psychological and other support;
- Few of those in the research sample had experience of a holistic care plan that they had felt involved in;
- Carers similarly observed that professionals seemed to focus on containing the illness or crisis and on preventing future crises, rather than on longer-term recovery plans.

#### Wellbeing and Social Development Measures

- Some service users had positive experiences of support in the community to enable participation in leisure activities or educational courses, often supported by support workers from the voluntary sector or Community Psychiatric Nurses (CPNs);
- Not all service users were interested in pursuing leisure, education or employment goals, with some preferring to be left alone to decide how to live their lives, although they were socially isolated;
- Carers commented on the lack of meaning, fulfilment and opportunities for achievement for their relatives, which as yet appeared to be little changed by the new mental health law;
- Service users' experiences supported the view of many professionals that there
  had been little improvement in the provision of employment support as a result of
  implementing the MHCT Act;
- Support for volunteering was found easier to access than support for paid employment, and many service users and carers were unaware of specialist employment support services in their area;

 Several individuals highlighted the importance of housing/accommodation and support to their recovery and social inclusion.

# **Key Emergent Themes**

Being subject to compulsory care and treatment, that is, being treated against one's will, is inherently unwelcome. The process is a complex interplay of personal or health crises with the response of carers and various health and social care professionals. It is not something anyone chooses freely, or which is under an individual's control. It thus provides a fraught context for interaction between service users, carers and professionals.

The research findings indicate that there is room for improvement in shifting the balance of control in decision-making about care and treatment towards greater service user and carer involvement. Further, indications were that many people's care and treatment regimes were more often than not based on the medical model, with little regard paid to psychosocial explanations or offering alternative treatment responses. Less attention seemed to be paid to broader issues and strategies that would enable and assist recovery.

Not all the early concerns of professionals were borne out in practice. For instance, the role of GPs appeared to be only marginally changed, whereas that of Mental Health Officers (MHOs) and psychiatrists were radically different. A strong view emerged across stakeholder groups that the impact of the Act would be to create a 2-tier mental health service: one for the few under compulsory measures and the other for everyone else with mental health problems. This was also true for advocacy services, which had had to prioritise meeting the requirements of the MHCT Act over other mental health advocacy work.

Despite appreciating the efforts of the Scottish Government and the MWC to address concerns, there was still uncertainty and confusion among many professionals about overlapping legislation regarding capacity, especially in relation to the Adults with Incapacity (Scotland) Act 2000 (AWIA). This may now have been superseded by the complexities of implementing the Adult Support and Protection (Scotland) Act 2007 (ASPSA) alongside both the AWIA and the MHCT Act.

There are clearly challenges to implementing the principles underpinning the Act in practice, which are often linked to gaps in the range of community resources available. In particular, professionals highlighted the limitations they faced with implementing the 'least restrictive alternative' and 'reciprocity' principles.

While the voice of service users is beginning to be heard through implementation of more deliberately inclusive processes, as a result of implementation of the MHCT Act, service user participation is a complex aspiration in the context of compulsory care and treatment. Key ingredients to success would seem to lie in professionals' willingness to listen actively and to communicate openly; and, essentially, in achieving a balance between professional expertise alongside service users' expertise.

#### Implications for Future Development of Mental Health Law

It is critical that service users, carers and various professionals continue to have opportunities to feedback their opinions and experiences whether it be through research such as this, or one-off and ongoing consultation mechanisms. The challenges to involving the range of service users and carers need to be acknowledged, as do the resource implications of supporting meaningful support mechanisms.

# **Implications for Future Research**

This study has identified a number of issues that would benefit from further research using different research methods and approaches. In addition to urging Scottish Government to develop its future research agenda on the implementation of the MHCT Act with mental health service users and carers, as well as professionals and policy makers, our research indicates that it might be beneficial to investigate the following issues

- In-depth research into the effectiveness and outcomes of community-based orders, exploring regional variations and the scope of community-based orders for promoting social inclusion and recovery;
- An outcomes study of the Tribunals hearing decisions, investigating the extent to which service users' and others' views could be seen to have influenced the panel's decision;
- Detailed investigation of the quality and inclusiveness of care plans of those under compulsory measures, especially focusing on user participation;
- Research into the range of employment support opportunities available across Scotland for people who have experienced compulsory measures, and seeking to identify exemplar practice;
- Mapping the housing needs of those under compulsion, and variations in how these are being met in different parts of Scotland, including looking at the role of accommodation/housing services alongside health and social care services;
- Research into the care and recovery pathways of specific groups e.g. those with complex needs including dual diagnosis of drug/alcohol issues and mental health problems; people with learning disabilities and/or Autistic spectrum disorders (ASD); those from black & minority ethnic (BME)/refugee communities; and those with parental responsibilities;
- Participatory action research into the issues surrounding the implementation of Advance Statements, to promote development of good practice.

#### Conclusion

In conclusion, this research has examined the implementation of the MHCT Act over one year, from 2007-2008, from the different experiences and perspectives of service users, informal carers and professionals. This has been achieved in partnership with service users. The study shows that the new legislation, with its underpinning values, has set a positive framework for improving the care and treatment of those who are compulsorily treated. Moreover, the study found indications of paradigm shifts in process and practice. However, the experience of key stakeholders indicates that improvements in mental health service provision are

urgently needed, as envisaged in Delivering for Mental Health (Scottish Executive, 2006c). Also, the approach of individual professionals needs to change more consistently if the goal is to achieve a more holistic, and recovery orientated approach. Although this research focused only on those with experience of compulsion, the findings have implications for the wider system of mental health services.

# CHAPTER ONE: THE RESEARCH STUDY

#### Introduction

1.1 The research study presented in this report was part of a research programme commissioned by the Scottish Government's Health Directorate (previously Scottish Executive Health Department). The programme of research was established following extensive consultation about the research needed to support the reform of mental health law in Scotland (Rushmer & Hallam, 2004). This study evaluates key stakeholder experiences of implementation of the Mental Health (Care and Treatment) (Scotland) Act, 2003, hereafter referred to as 'the MHCT Act'. A team of independent researchers undertook the study, which ran for 2 years starting in February 2007.

# **Study Aims and Objectives**

- 1.2 The primary aim of the research was to explore key stakeholders' experiences and views, in particular those of service users, carers, and professionals, and to consider these alongside expectations expressed prior to implementation of the MHCT Act. It was expected that the research findings would lead to recommendations for further development of mental health law in Scotland, including how key stakeholders could be involved in ongoing assessment and evaluation of the legislation.
- 1.3 In summary, the 6 key objectives for the research were to:
- 1. Identify and describe the operation and impact of the MHCT Act in practice;
- 2. Provide in-depth case studies of the journeys of a sample of mental health service users over a one year period;
- 3. Examine the ways in which different parts of the legislative system interact;
- 4. Assess the success of measures providing access to leisure and employment services aimed at promoting well-being and social development;
- 5. Assess the extent to which the provisions of the MHCT Act are seen to meet the Millan Review principles;
- 6. Recommend how all stakeholders' experiences can continue to feed into future reforms of mental health law.
- 1.4 In respect of Objective 2 above, it was agreed at the start with the commissioners that the research should focus on individual accounts of the various stages of compulsion rather than aim to provide in-depth case studies. Given the uniqueness as well as sensitivity of the personal accounts, and also that an assurance of anonymity had been given to participants at the outset, it was concluded that presenting individual case studies would mean individuals would be readily identified. Instead, the findings in chapter two explore detailed accounts of aspects of individual journeys through compulsion in a thematic way.

#### Research Design

1.5 In response to the research questions, the methodological approach adopted in this study was qualitative, using mainly in-depth interviews and focus groups to

explore the experience of compulsion from a variety of relevant viewpoints. Adopting a qualitative approach enabled in-depth investigation of the perspectives of those experiencing compulsion as well as of those working to implement the MHCT Act. Qualitative methods offered the flexibility needed to explore individual experience and meaning in all its diversity and complexity (Mason, 1996: Temple, 1998). However, care should be taken in generalising these findings to wider populations and different circumstances.

- 1.6 The sampling frameworks and eventual sample sizes achieved demonstrate the study's engagement with a diversity of viewpoints and contexts. This has enabled exploration of key issues emerging for these samples, and consideration of these in the wider context of compulsion. Further, this methodological approach was chosen because it acknowledges that factors such as researchers' and participants' age, sex, ethnicity etc and, in this particular context, experience as users of mental health services, can have a major impact on both the information gathered as well as the interpretation of findings. The research therefore aimed to be inclusive, involving those with experience of mental health problems and services as an integral part of the research team. How this was achieved is discussed later on in this chapter.
- 1.7 The study design drew upon 'narrative inquiry' (Lawler, 2002, Reissman, 2008) to investigate aspects of compulsion predetermined by the research objectives while also aiming to discover themes and issues emerging from participants' accounts in much in the same way as grounded theory (Strauss & Corbin, 1990, 1994). In common with recent studies of individuals' experience of mental health and recovery (Ridgeway, 2001; Brown & Kandirikiria, 2007; Scottish Recovery Network, 2007), a narrative-based approach sought to place the individual's account at the centre of the research process. Semi-structured interview schedules provided a common framework for analysing consistent themes whilst also engaging with issues raised by participants that had not been anticipated.

#### **Research Methods**

- 1.8 The study was carried out in 2 main stages over a 14-month period, with a planned interval of one year between the 2 stages. While service users and carers were interviewed at both stages, professionals were only interviewed during Stage 1. In practice, the interval achieved between Stage 1 and Stage 2 interviews varied between 6-12 months depending upon when service user and carer participants were recruited into the study. Research samples were drawn from 4 health board areas in Scotland, chosen purposively to reflect rural, urban and mixed geographical areas (Dumfries and Galloway, Fife, and Greater Glasgow & Clyde) and the State Hospital.
- 1.9 In summary, the methods used at each Stage were:

#### At Stage 1:

- Telephone interviews with key contacts from national professional and interest groups;
- Interviews with practitioners from a range of professions and advocacy workers;

- Individual in-depth interviews with service users at different stages of compulsion;
- Focus groups and individual interviews with informal carers/relatives.

#### At Stage 2

- Individual in-depth interviews with service users recruited at Stage 1
- Focus groups and individual interviews with informal carers/relatives.

# Professional organisations and interest groups

- 1.10 During January to early March 2007, telephone interviews were conducted using a semi-structured schedule with key contacts nominated by 15 national organisations and special interest groups identified in collaboration with the Research Advisory Group (see Appendix 3 for details of participating organisations). These interviews lasted an average of 45 minutes and covered 6 main topics in relation to the MHCT Act:
  - Experience and impact of changes to service delivery and practice;
  - Impact of new professional roles and responsibilities;
  - Issues in implementing the Millan principles;
  - Barriers and factors facilitating implementation;
  - Ideas for future improvement and stakeholder consultation;
  - Suggestions for recruiting local practitioners to the research.
- 1.11 The purpose of these interviews was to identify broad general themes and issues around implementation of the MHCT Act as perceived by different professional groups. A practical aim was to assist the research team to identify and recruit relevant practitioners from the 4 research sites.

#### Practitioners and advocacy workers

- 1.12 In-depth semi-structured interviews, ranging from 20 minutes to 2 hours, were conducted over a 4-month period (between May to August 2007) with a total of 23 professionals drawn from across all 4 research sites. Health professionals (General Practitioners (GPs), psychiatrists, Community Psychiatric Nurses (CPNs), nurses, psychologists), Mental Health Officers (MHOs), lawyers, and advocacy workers were interviewed either face-to-face or by telephone according to their stated preference. Professionals were recruited either through their professional organisations, local professional committees (e.g. specialist sub committees), or through direct approaches made to relevant local mental health and advocacy services. Additionally, some professional participants responded to an invitation to participate published in either the Mental Health Nurses Journal or the Scottish Independent Advocacy Alliance (SIAA) newsletter.
- 1.13 Interviews with practitioners and advocacy workers explored 6 main areas:
  - Professionals' roles and responsibilities;
  - Experience of operating new systems and processes e.g. Tribunals, Advance Statements and Named Persons;

- Reflections on implementing the principles of the MHCT Act;
- Interface with other legislation;
- Perceived service gaps;
- Ideas about future improvements.

#### Service users

- 1.14 Semi-structured interviews with services users sought to capture their journeys through compulsion, and to gain an insight into their direct experiences of the new mental health law in practice. Pairs of interviewers (a trained service user interviewer working with a more experienced researcher) conducted face-to-face interviews with 49 service users at Stage 1, and subsequently with 39 of these at Stage 2. Interviews with service users at both Stages 1 and 2 lasted between 30 minutes to 2 hours, and took place in a variety of settings including interviewees' homes, psychiatric hospital wards, resource and health centres, generally wherever individuals preferred to be interviewed, or as advised by the (Responsible Medical Officer (RMO) or other professional consulted prior to the interview.
- 1.15 A purposive sample of those with experience of a range of compulsory measures under the MHCT Act who were resident in the 4 research areas was sought. Service users were drawn from a large sampling frame: all those individuals from these areas who were recorded by the Mental Welfare Commission for Scotland (MWC) as being under compulsory measures as of January 2007 were invited to participate in the study. A letter, along with information about the research, was sent on the researchers' behalf by the MWC. The first mailing in May 2007, posted to around 600 people, achieved a sample of around 38 people. The deadline for recruiting the sample was subsequently extended to achieve as close to 50 individuals as possible. A second mailing in July 2007 to an additional 120 individuals who were either identified through the MWC database, or through Community Mental Health Teams (CMHTs), hospital wards, service user organisations, and other voluntary organisations where the sample numbers were low, increased the final sample to 49 individuals as of November 2007. The latter strategy was particularly successful with recruiting individuals from black and minority ethnic (BME) communities into the study. Service user participants received a small payment for each interview to cover expenses.
- 1.16 The interview schedules for both stages were drafted following consultative processes with service user interviewers, the research commissioners, and the Research Advisory Group. The schedule ensured consistent coverage of key topics and the collection of comparable data across the whole sample, while at the same time remaining flexible to allow service users interviewed to raise issues of relevance to them personally. Service user participants were asked about their experience of and feelings about compulsory care and treatment in hospital or the community, in particular about key aspects of the implementation of the MHCT Act such as their experience of Tribunals, Advance Statements and the Named Person role. They were asked about their individual care plan and the care and treatment they had experienced under compulsion; about leaving hospital and aftercare in the community; what supported improvements in their health and wellbeing; and for their opinion on how compulsory care could be improved.

#### Informal carers

- 1.17 Despite some initial challenges with identifying relevant informal carers, with the help of the local carer coordinators from the National Schizophrenia Fellowship (NSF) and the State Hospital, a sample of 33 individual carers were recruited into the study. They were interviewed either in groups or individually (i.e. 10 carers from 2 of the research sites). The Carers Coordinator at the State Hospital contacted relevant carers across Scotland, and arranged a focus group at both Stage 1 and 2 at this site.
- 1.18 Both group discussions and individual interviews with carers focused on key topics including the impact on their life of supporting a relative subject to compulsory measures, their experience of being a named person, what it had been like attending Tribunals as a carer and/or as a named person, what they thought about implementation of the principles of the MHCT Act, especially Principle 7, respect for carers, and asked for suggestions for improvement. Group discussions lasted up to 2 hours and interviews lasted approximately 1 hour. Carers received a small payment to cover expenses for each interview or focus group. For the majority of carers, participating in the research focus group was the first time that they had shared their experiences of supporting someone under compulsion with other carers and most commented on how supportive and beneficial they had found this opportunity.

#### **Inclusive Research**

- 1.19 The involvement of service users in research has been highlighted as important in research about the MHCT Act (Atkinson et al, 2005), and was further emphasised in the tender. At the consultation event to agree research priorities for the MHCT Act held in 2003 (Rushmer & Hallam, 2004), service users and voluntary organisations identified the need for inclusive research. Further, the Research Governance Framework for Scotland (Scottish Executive, 2006d) requires that service users and carers should be part of the research process.
- 1.20 From the outset, we aimed to make the research participatory. This was based on the belief that people have the right to be involved in research about aspects of their lives and that better quality mental health research is produced when people are involved in the process (Rose, 2004; Turner & Beresford, 2005). We were keen that service user perspectives would inform our approach and its implementation, and particularly that we paid attention to the rights of service users throughout the research process. The research team comprised 8 mental health service users who worked alongside professional researchers with backgrounds mainly in social work, social policy and housing research. Some of the professional researchers also had direct experience of mental health services or as carers.
- 1.21 Professional researchers worked collaboratively with a service user organisation to develop the research proposal (initially *Challenge of Change* then *VoX*) in response to the tender, and our intention was always that the research process itself should be inclusive. As partners in the research team, a *VoX* member led the recruitment and selection of mental health service users, and the organisation was represented on the Research Advisory Group RAG. The Mental

Health Foundation Scotland, who at the time was hosting the embryonic VOX, acted as employer for the service user researchers.

- 1.22 To ensure that the inquiry was rooted in the concerns and issues of service users, 2 user organisations were consulted at Stage 1. During February 2007, 11 service users participated in focus groups organised with the help of *Augment* in Angus, and Glasgow Association for Mental Health (*GAMH*) in Glasgow. Outputs from these discussions informed the early drafting of interview schedules to be used with service users. Importantly, the exercise confirmed that people with experience of compulsion would be willing to speak about their experience and could provide valid insights into this experience.
- 1.23 Service user researchers were recruited in April 2007 and participated in a 3-day training programme. All were subject to an Enhanced Disclosure Scotland check. They were employed specifically to carry out interviews with service users, and were expected to contribute to the research measures, agreeing research protocols and later to the process of data analysis. In addition to training days, the team met regularly throughout the study and ongoing contact was maintained between team members through email and telephone.
- 1.24 The partnership approach adopted between team members was successful in facilitating a good rapport with the service users who were interviewed. The involvement of service users as interviewers conveyed an empathetic approach, which was appreciated by many people and assisted the telling of detailed personal accounts. Interviewing in pairs was both supportive to those being interviewed, who were at different stages of their journey through compulsory care and treatment, and to the interviewers who were meeting service users under compulsion for the first time. Some participants reported they felt the interviewers had really listened to them and that they had understood what it was like to be a mental health service user, as the following selected quotations illustrate:

"To be able to talk about it openly and freely with a receptive ear was for me positive."

"It was nice to talk about it because I'm quite a private person so it was interesting to speak to some other people and also someone that's also been in a similar situation. You get someone that can understand."

1.25 The involvement of service users in the research team directly influenced the approach taken to assessing individuals' capacity to participate in the research interview. Service user researchers contributed to protocols for gaining informed consent from potential participants, commented on the content and format of questions, and made valuable suggestions about how the paired interviews should be conducted. As team members, service users participated in the reflection and discussion of issues and themes emerging from the data transcripts of the service user interviews, and commented on draft reports. Without a doubt their involvement in the analytical process added an important dimension to the interpretation of participants' accounts, complementing the perspectives of professional researchers.

#### **Ethical Issues**

- 1.26 The initial research proposal had been subject to a competitive tendering process, involving peer review. Ethical approval was sought for a National Health Service (NHS) multi-site study through the Central Office for Research Ethics Committees (COREC), as well as through the University of Central Lancashire's (UCLan) Faculty of Health Ethics Committee (FHEC). This process took 6 months, and after consideration by 2 NHS Ethics Committees in Scotland, including the NHS Multi-Centre Research Ethics Committee for the Adults with Incapacity (Scotland), Act 2000 (MREC A), the project was deemed to be evaluation and therefore outside the scope of COREC. Ethical approval was granted by UCLan's FHEC in February 2007. The State Hospital Research Committee later granted approval subject to fulfilling safety practices at the hospital in April 2007.
- 1.27 Ethical guidelines for the conduct of the study were established at an early stage, giving detailed consideration to the welfare of both participants and interviewers. A key concern was ensuring participants would be treated with respect and that they would be provided with sufficient information to enable informed consent to take place. The ethical protocols also served to define the boundaries of confidentiality as well as considering data protection and storage issues. Faulkner's (2004) guidelines for the ethical conduct of research carried out by mental health service users informed the approach taken. Consideration of anonymity and the boundaries of confidentiality and other issues were addressed during training on ethical approaches with service user researchers. In practice, important ethical issues to emerge for interviewers included how to respond faced with information and/or service gaps, and how to do justice to the uniqueness of each account when writing up while at the same time respecting individuals' right to anonymity.
- In the participatory spirit of the MHCT Act, it was assumed that individuals experiencing compulsion have a right to express their views and to be involved in research seeking to understand what it is like to be subject to the MHCT Act. The procedures adopted had to flexible enough to take account of any fluctuations in the mental health status of the sample population. On first volunteering to participate, potential participants were asked to nominate a professional who they agreed could be contacted by the researchers to provide an opinion about their capacity to participate in the research and to ensure that participation would not cause them or anyone else harm. The nominee was to be selected by the participant from the list of persons prescribed by regulations to act as witness to an Advance Statement (Section 275 of the MHCT Act). In this instance, the list was not being used with respect to advance statements, but the types of professionals on this list represented an appropriate set of options for service users to choose who could make an appropriate assessment of their capacity to participate. Each named professional was contacted initially at Stage 1 and again at Stage 2 before any interviews were arranged. Although a vital procedure, this proved somewhat time consuming and complex, partly because the sampling period during 2007 ran over the summer months, and because of the need to authenticate the study with each professional. Interviewers also contacted service users and/or relevant direct care staff just prior to the arranged interview date to confirm they were well, and if necessary re-scheduled the interviews for a later date.

- 1.29 Participants were given several opportunities to consent to or withdraw from the research. First, when responding to the initial invitation to participate and the information sent out about the research, respondents gave consent to be contacted and for their preferred professional to be approached by the researchers. At the time of all group and individual interviews, participants signed a written consent form stating that they understood the research and the implications for themselves, and making it clear that they were free to withdraw at any time without giving a reason. Participants' anonymity and confidentiality were assured throughout the study. However, it was made clear that under certain circumstances these assurances would be limited: that is, if there were any concerns about potential or actual harm to others or themselves. The participant information sheets stated the limits to confidentiality and procedures for dealing with disclosures of a sensitive nature.
- 1.30 We adopted both a preventative strategy and supportive response to the risk that participants might become distressed during an interview. Key to this was sensitive interviewing practice including encouraging participants to take breaks when necessary, encouraging them to involve professionals from their existing care support networks, and providing the contact details of local resources, help lines and advocacy organisations. To ensure participants were comfortable with their participation, they were offered a copy of the typed transcript of the interview at both Stages and invited to comment. This afforded an opportunity for individuals to clarify any points and to remove information they were not now comfortable with sharing in a public document. The second interview was another opportunity for the team to check that individuals did not feel harmed by the research.

#### **Data Analysis**

- 1.31 Interviews and focus groups with both service users and carers were digitally recorded and transcribed in full. Four service user interviews were not recorded, but written notes taken at the time of the interview were typed up. This was either because the individual expressly did not wish the interview to be recorded, or the individual's responses were brief and/or not easily understood whereby it was considered that a written record at the time of interview was more appropriate. Involvement of a third party such as a language interpreter also affected the dynamics and flow of some interviews, making it more efficient to record these in writing at the time of interview. The majority of interviews with professionals were noted in writing at the time of interview, although some were digitally recorded for the purpose of detailed analysis.
- 1.32 Interview and focus group data have been analysed using standard qualitative data analysis methods, beginning with the identification of key themes and patterns (Silverman, 1993; Coffey & Atkinson, 1996). The process of identifying themes was driven partly by the research objectives, the key issues that emerged from the relevant literature, and finally, from our interpretation of participants' individual stories/accounts.
- 1.33 Data was thus coded or labelled, organised and retrieved using NVivo8, a qualitative data analysis software programme. Two members of the research team conducted the coding task. As Miles and Huberman (1994) argued, coding segments of data under themes in this way enables identification of meaningful data

that set the stage for interpretative analysis. Service user researchers were fully involved in the subsequent process of further interpreting the coded data segments, although due to the time available, the project manager was responsible for the main writing task based on the team analysis. All the team examined interview transcripts from service user interviews, to identify themes and secondly, were involved in interpreting the meaning of data segments coded under key themes. Two of the professional researchers coded and analysed data from other interviews (carers and professionals), with the whole team commenting on various drafts of this report.

#### **Report Structure**

1.34 In the next chapter, the background context to the research study is presented with reference to consultation findings from various stakeholder groups and other relevant literature. This is followed by discussion of the research findings from the main stakeholder groups, which are reported in 3 separate chapters: Chapter 3 explores service users' views and their journeys through compulsion using interviews at Stages 1 and 2; Chapter 4 looks in detail at the responses of carers, drawing out key findings from focus groups and interviews during stages 1 and 2; and Chapter 5 presents findings from telephone and face-to-face interviews with a wide range of relevant professionals carried out during Stage 1. In the final chapter of the report, we discuss the findings across the stakeholder groups in the context of the literature review, and identify key themes and issues raised by the research that may have wider import. This final chapter discusses the implications for the future development of mental health law.

# **CHAPTER TWO: RESEARCH CONTEXT**

#### Introduction

- 2.1 The research study reported here was conducted during major reform of mental health legislation in Scotland. The MHCT Act came fully into force on 5<sup>th</sup> October 2005, and deals with the use of compulsory measures in mental health care. This was the most fundamental change to mental health law in over 40 years, and has been described by some as 'visionary and revisionary' (Atkinson et al, 2005). The MHCT Act brings mental health legislation for Scotland into the 21<sup>st</sup> Century, placing the emphasis on treatment and care in the community, on safeguarding patients' rights and on participation of patients and all those supporting them in their treatment and ongoing care.
- 2.2 This chapter briefly sets the background and context for the research, drawing on relevant literature. It discusses (a) the development of the MHCT Act, outlining its key principles and examines compulsory measures under it, including community-based compulsory orders; (b) considers the interface with other legislation; (c) examines stakeholder views and expectations prior to implementation; (d) reflects on the role of the MHCT Act in promoting well-being and social development, especially in relation to leisure and employment; and finally, (e) it identifies key progressive movements and/or strands of policy development that have influenced implementation of the new legislation.

#### **Development of the MHCT Act**

2.3 The new legislation was drafted following a root and branch review of the 1984 mental health legislation conducted by a committee chaired by the Right Honourable Bruce Millan (the 'Millan Review') starting in February 1999. Millan consulted widely with stakeholder groups, including agencies, professionals, service users and carers. The report of the Committee published by the Scottish Executive (Millan, 2001) contained 416 recommendations for future mental health law and practice, which were largely incorporated into subsequent new mental health legislation for Scotland.

# 10 key principles underpinning the MHCT Act

- 2.4 The Millan Review (2001) and its subsequent recommendations formed the core framework for the MHCT Act. While the 'Millan principles' were used to underpin the legislation, Patrick (2006) identifies that, for legal reasons, these were not incorporated into the MHCT Act precisely as recommended by the Millan Committee. The 10 key principles do however, reflect the Millan intentions and apply whenever functions under the MHCT Act are exercised. Importantly, the principles serve to encourage staff to consider service users' views and to promote participation in the decision-making process. The 10 key principles are summarised in Appendix 2.
- 2.5 Overall, the Millan Review represented a positive turning point by articulating recognition of service users' rights as citizens and consumers to equitable, participatory and the least restrictive services. The drafting of new legislation

preceded that in England and Wales and there were some differences in emphasis. For example, while the principle of reciprocity in the Scottish Act obliges service providers to give quality services as a precondition of compulsion, the neglect of this principle at the time in the proposed reforms of mental health legislation in England and Wales influenced concerted opposition from the Mental Health Alliance (Pilgrim, 2007). Additionally, in Scotland the law focuses on mental health as well as control of mental disorder, so offering more balanced messages about patients' rights and needs in terms of health promotion as well as compulsion.

- 2.6 The MHCT Act contained a number of key innovations and new provisions which have been examined in detail in McManus and Thomson (2005), and Patrick (2006). These can be summarised as:
- Compulsory powers enforced in the community in addition to hospital compulsory care and treatment;
- Reciprocity as part of the principled framework of the MHCT Act;
- New rights and safeguards, including a right to access independent advocacy services, and Advance Statements;
- A new Mental Health Tribunal in Scotland which considers the case for proposed compulsory interventions under the Act;
- New powers invested in the Mental Welfare Commission;
- New duties on Health Boards and local authorities in relation to social opportunities and the development of well-being;
- The creation of special professional and supportive roles (i.e. Responsible Medical Officer (RMO), Approved Medical Practitioner (AMP); designated Medical Practitioners and Named Person).
- 2.7 The MHCT Act also covers those who enter into the mental health system through the criminal justice system. From 1st May 2006, an additional right of appeal to the Mental Health Tribunal was introduced for patients who believe that they are being detained through use of 'excessive security' at the State Hospital, and may require their local Health Board to identify alternative accommodation in for example, a medium secure hospital. However, concerns were expressed at the time (see Scottish Association for Mental Health (SAMH) website) that lengthy, inappropriate detention at the State Hospital may occur because of the lack of local secure facilities to which people could be transferred.

#### Compulsory measures under the MHCT Act

- 2.8 The MHCT Act provides for the following range of compulsory measures:
- Short term detention direct from the community for up to 28 days
- Emergency detention, for up to 72 hours
- A nurse may detain someone in hospital for up to two hours to enable a doctor to examine him or her with a view to the use of short term or emergency detention
- The compulsory treatment order lasts for up to 6 months either in hospital or in the community. It can be renewed for a further 6 months and then from year to year;

 An interim compulsory treatment order can be made by a Tribunal lasting up to 28 days, which can be renewed provided the total duration does not exceed 56 days.

(Adapted from Patrick, 2006, p158)

2.9 The process of the 'patient's journey' or 'care pathway' for longer term compulsory care has been conceptualised into a number of stages represented in Table 2.1 below. The process will differ for those treated informally and for those subject to emergency or short-term compulsory orders, as they will not experience the Tribunal Stage.

Table 2.1: Stages in the process of longer-term compulsory care and treatment

Stage	E	Α	В	С	D	E
Part of the	Non-	Episode	Tribunal	Care and	Discharge	Non-
Compulsion	Compulsion	leading to	Process	Treatment	from Care	Compulsion
process	/stability	Compulsion			and	/stability
					Treatment	

(Scottish Executive, 2005, p 18)

- 2.10 Since implementation of the MHCT Act, there had been a reported fall overall of some 8% in episodes of compulsion (Mental Welfare Commission, 2007a). Monitoring information presented by the MWC in 2007 highlighted some important patterns and variations in practice, including that:
- Emergency detentions appeared to have declined in use compared with those under previous legislation;
- Short term detention was the most common pathway into compulsory treatment (as intended by the Code of Practice to the MHCT Act);
- There were significant variations across Health Boards in the proportions of emergency orders compared with short term detentions with Glasgow having the highest rate of emergency orders in Scotland;
- Overall, the number of civil (as opposed to those under criminal proceedings) treatment orders fell between 2003/04 and 2006/07.

2.11 The question of the extent to which risk assessments would play a role in determining pathways to compulsion arose in consultations with professionals and service users prior to the MHCT Act's implementation (Rosengard & Laing, 2001). While risk assessments may have a significant bearing on the decision to impose compulsory treatment, both in hospital and community settings, the MWC's review (MWC 2007a, Table 12) presents an interesting and complex picture of the extent to which those subject to different types of compulsion (community based CTOs; hospital CTOs, emergency and short-term detention) had also been assessed to be 'at risk' (i.e. a risk to others, to themselves or both). An indicative finding was that those on community-based orders were more likely to assessed as risk to others (54%) that those on hospital-based orders (57%) (MWC, 2007a)<sup>1</sup>. Further investigation of patterns over time would help to clarify differences in the extent and role of risk assessments in regard to particular forms of compulsion. Moreover the

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<sup>&</sup>lt;sup>1</sup> During that period the MWC recorded 147 Community-based Compulsory treatment orders and 944 Hospital-based Compulsory Treatment Orders (MWC, 2007a)

significance of risk assessment generally needs to be considered in relation to all mental health service users, regardless of whether or not they are under compulsion.

2.12 Monitoring reports from the MWC also highlight significant regional variations in local decision-making and practice in implementing the legislation, and this may be reflected in varying local pathways in regard to compulsory intervention and routes to recovery (MWC, 2007a). It is important to recognise that such variations potentially reflect the interplay of local patterns in mental health; strategic choices and discretionary decision-making; as well as the range of available local service options.

### Community-based compulsory care and treatment

2.13 Compulsory care in the community is, on the one hand, perceived to be concerned with ensuring compliance with treatment programmes and preventing crises and severe risks, and, on the other, to be concerned with ensuring access to an appropriate full range of community-based services within the framework of an holistic approach of social inclusion and recovery. While many in Scotland regard compulsory care in the community as a positive innovation, it has been argued that such measures serve to limit service users' autonomy, control and self-determination. As Bailey (2000) observed:

"The modernisation agenda that has taken place in mental health policy and practice is accused of replacing the bricks and mortar of the institution with a different yet similarly constraining institution of care".

- 2.14 From various studies (Saks, 2003; Atkinson et al, 2005; Dawson, 2005; Kings Fund, 2006; Churchill 2007) that have researched the use, outcomes and ethical implications of compulsory treatment within the community across different countries, 4 broad pathways emerge: these include conversion of a hospital-based order or 'inpatient commitment order'; community order made at the time of detention or 'outpatient commitment order'; a preventative commitment order; and a 'competence-related order' (Atkinson et al, 2005).
- 2.15 While existing research is inconclusive about the outcomes and benefits compared with other treatment strategies, it does indicate that outcomes of community-based compulsory treatment may improve over time. Use of community-based treatment orders often increases after any initial 'bedding in', particularly if this takes place alongside reductions in hospital beds and a parallel build up of community-based support services (Dawson, 2005). However, increasing the supply of community-based support services also serves to increase, rather than decrease, the overall use of Compulsory Treatment Orders (CTOs). In the early stages of implementation however, there was no evidence of any significant increase in the use of compulsion in Scotland (Lawton-Smith, 2006). Statistics from the MWC (2007a) supported the predicted increase over time: for instance, whereas in January 2006 there were 65 people on community-based orders, by April 2007, this had risen to 280, or approximately 1 in 5 of all those on CTOs.
- 2.16 Consultation prior to implementation predicted that community-based CTOs would be used mainly in cases where people had a history of long term detention,

along with non-engagement and non-compliance with services. In this context, a community-based CTO would provide a less restrictive alternative to hospitalisation. Statistics from the MWC (2007a) support these assertions showing the majority (84% of the 280 people on community-based orders as at April 2007) had had at least one previous experience of detention; and that previous episodes of detention were more likely among people on community-based CTOs compared to those on hospital based CTOs (84% compared with 75%). Further, Lawton Smith's (2006a) research at an early stage of implementation suggested that professionals were identifying those with a history of non-engagement and non-compliance with services, followed by deterioration in health, when authorising community-based CTOs.

#### Interface with Other Legislation

2.17 A recent literature review (Gordon, 2004) highlighted potential for overlap in who was covered by, as well as differences in the purpose of interventions between, the MHCT Act and other legislation, specifically the AWIA. The AWIA provides a general authority for the medical treatment of adults who are deemed to lack the ability to make some or all medical decisions for themselves, due to 'mental incapacity' or severe communication difficulties caused by physical impairment. Both define 'mental disorder' as referring to having a mental illness, personality disorder or learning disability (MHCT Act, s328(1) and AWIA (s87(1)). However interestingly, the AWIA uses the term adult, while the MHCT Act uses the term 'patient'. Gordon (2004) points out that the AWIA applies only to those 16 and over (s1(6) of AWIA), while the MHCT Act applies to adults and children, with adults falling by virtue of s2(1) of MHCT to be patients who have reached the age of 18 years. It is thus imperative that professionals understand the principles and operation of both Acts as decisions may have implications on both fronts.

2.18 Gordon (2004) and the Scottish Executive's consultation prior to the implementation of the MHCT Act (Rushmer & Hallam, 2004) identified potentially problematic areas of overlap between the 2 Acts. In particular this was in relation to:

- An adult who has a Welfare Attorney or Guardian under AWIA and is being assessed possibly for detention under the MHCT Act, and conversely, an adult detained in hospital under the MHCT Act who is being considered under the AWIA:
- Which legislation to apply to support a person with a 'mental disorder' in the community when there are issues of capacity to consider – i.e. whether to use the welfare guardianship route under the AWIA or compulsory treatment in the community route under the MHCT Act;
- An adult with a 'mental disorder' subject to the AWIA who may actually benefit from entitlements under the MHCT Act, such as access to independent advocacy and a wider range of support options, as well as the right to a named person;
- Which legislation to use to enable an adult who lacks capacity to decide on medical treatment, to access such treatment (Section 1.3);
- The roles that may be played by welfare attorneys and guardians in relation to adults under the MHCT Act, including the principle that regard must be paid to their views;

- The Mental Health Tribunal (under the MHCT Act) and the Sheriff Court (under the AWIA) may be making decisions about the same, or similar populations.
- 2.19 The Millan Review recommended that the AWIA and the MHCT Act should be consolidated (Scottish Executive 2001b), and Patrick's review (2007) of the role of the civil justice system in meeting the needs of vulnerable adults supported this option for the future. However, the Government's strategy was to amend the AWIA through the new Adult Support and Protection (Scotland) Act, 2007 (ASPSA). This Act places a duty on local authorities to identify and protect adults at risk from harm by making enquiries to establish whether or not further action is required to stop or prevent harm occurring. As with the MHCT Act, any intervention is required to be the least restrictive and to provide benefit (ASPSA, Part One; Scottish Government Explanatory Notes and Code of Practice).
- 2.20 The ASPSA 2007 amends both the AWIA and the MHCT Act. Regarding the MHCT Act, amendments include:
- A new test added to the criteria for revoking a patient's transfer for treatment direction or hospital direction when it is no longer considered necessary for the patient to receive compulsory treatment in hospital;
- A power to receive into Scotland patients subject to corresponding or similar community-based compulsory treatment orders and compulsion orders;
- Extending the scope of the offence of knowingly inducing or assisting a patient to abscond or harbouring a patient;
- New power to make regulations to keep in charge a person who is subject to escorted leave of absence authorised under other UK legislation;
- Provision to allow patients subject to compulsion orders with restrictions to be absolutely discharged if compulsory treatment is no longer considered necessary.

#### **Consultation with Service Users and Carers**

- 2.21 The former Scottish Executive's wide-ranging consultation with service users and carers in the lead up to the legislation and its implementation, highlighted a broad consensus in regard to the improvements sought by the Millan Review, and views on access to and the quality of services as well as on civil liberties (Rosengard & Laing, 2001; Grant, 2004). These consultations showed that while some service users had at times experienced hospitalisation, with or without compulsion, as being necessary at the time, they frequently referred to negative experiences and lack of control, with power seen to rest with health professionals. Service users reported feeling disempowered by hospital practices, the lack of structured activity, and often by the conditions on wards.
- 2.22 In the community, many service users and carers felt there was poor access to information and advice, while problems of literacy were also highlighted. Often the response at primary care level was not considered to have been understanding or sympathetic, and while some GPs were found to be helpful, many felt they did not have sufficient time to communicate with patients and carers. Examples were given of poor responses to crises, waiting times for hospital services and lack of knowledge or delays in accessing support in the community.

- 2.23 Comment on the State Hospital conveyed a sense of punishment rather than care and treatment, and there was a view that it should be for prisoners and not for those with severe mental health difficulties. Some service users recognised a case for compulsory detention and treatment when individuals were a danger to themselves or others, but that force should not be used as it has been to date, and that human rights should not be forgotten. In similar vein, a service user quoted in Grant (2004) commented, that compulsion should be "done with dignity and respect", which was in marked contrast to some experiences.
- 2.24 Advance Statements were perceived as a positive step towards taking account of users' views, and the right to access advocacy, as a means of protecting rights. Service users welcomed promotion of greater choice and involvement, the emphasis on partnership and service user involvement in the Tribunal process, in care plans and individual care and treatment. Research overall indicates that where service users feel they are consulted and involved, this is valued and improves the service response (Connor & Wilson, 2006).
- 2.25 Informal carers reported feeling isolated and powerless and looked forward to having their role and views considered better under the MHCT Act. There is now widespread recognition that the needs of the many 'informal' and unpaid carers of people with mental health problems have been largely neglected by policy until the Carers (Recognition and Services) Act 1995. Specifically, the Framework for Mental Health Services (1997) emphasised that carers should be involved in planning and service delivery, and the Millan Review (2001), addressed carers rights. However, while the collective voices of carers have increasingly been sought, recent reviews have continued to highlight gaps in the recognition of, and response to, carers' needs (Scottish Executive, 2000; Newbronner & Hare, 2002; Lee, 2007). Carers consulted during the Millan Review commented that consultation with carers was still tokenistic (Rosengard & Laing, 2001). The specific principle in relation to respect for carers in the MHCT Act was therefore a welcome development.

#### **Professionals' Perspectives Prior to Implementation**

- 2.26 The MHCT Act introduced new roles and responsibilities for professionals, service providers and other bodies. These included psychiatrists' role as RMOs; AMPs who can be either psychiatrists or GPs; MHOs, specialist social workers; named persons replacing an assumption that 'next of kin' should be consulted; and independent advocates. Dr Sandra Grant was commissioned to consider the readiness and views of services across Scotland (Grant, 2004), and this next section draws on this and other literature that has considered different professionals' views prior to implementation of the MHCT Act.
- 2.27 Grant (2004) reported widespread concerns about increased workloads, although as Atkinson et al (2007) observe, it was unclear how much was being attributed to the impact of new procedures under the MHCT Act, or related to concerns over gaps in services. There were uncertainties across all stakeholder groups about implementing the role of named person and Advance Statements. Service users, carers and professionals alike, considered these innovations as positive strands of the MHCT Act, with the potential to maximise rights (Rushmer & Hallam, 2004).

#### Health professionals

- 2.28 While psychiatrists, as well as other health professionals, broadly welcomed the framework of the Act, they aired uncertainties in responses to consultation by the Scottish Executive, including concerns about how community-based compulsion might work in practice, how it would differ from previous arrangements (e.g. leave of absence), and whether it would have negative outcomes for civil liberties if used too readily (Rushmer & Hallam, 2004). Particularly amongst GPs and nursing staff, there were strong concerns about workload and administrative implications as well about knowledge and skill requirements. The BMA, alongside other professional bodies, highlighted that there may not be sufficient trained personnel, with resource implications, both in terms of finances and availability of qualified professionals that need to be addressed (Rushmer & Hallam, 2004).
- 2.29 Consultant psychiatrists welcomed the new legislation in Scotland, but raised concerns regarding workload implications and bureaucracy impinging on their direct time with patients as well as on their wider preventative and community-based role (Atkinson et al, 2002; Lawton-Smith, 2006b). Anticipated to be demanding were the likely requirements to complete application forms and to produce reports for Mental Health Tribunals. Psychiatrists as well as other professionals were concerned that care planning requirements might delay Tribunals (Rushmer & Hallam, 2004). In the lead up to the legislation, the Royal College of Psychiatrists conducted a scoping exercise to assess its potential impact on psychiatrists' time, and estimated the need for an additional 18 to 28 consultant psychiatrists (Atkinson et al, 2002). In England, clinicians have been divided over the introduction of supervised community treatment, and a survey of over 1000 psychiatrists in England and Wales found that 46% favoured community compulsory treatment and 34% were opposed (Crawford et al, 2000).
- 2.30 The lack of readiness of front-line services in regard to the implementation of the MHCT Act was of major concern to nurse practitioners, and shortfalls in the staffing complement were again recognised by the profession as well as by the Executive (Grant, 2004). In parallel with the early implementation of the legislation was the Scottish Executive's major review of mental health nursing in Scotland in 2006. This led to recommendations that training and practice should take a more recovery-oriented approach and adopt the spirit of, and values and principles underpinning the MHCT Act (Scottish Executive, 2006a). Radical innovations, proposed as the result of the review, included that a partnership approach should be developed between nurses, service users and carers, as well as increased collaboration with other professionals, services and agencies.
- 2.31 Professions allied to health, including psychologists and occupational therapists (OTs) working in mental health, were concerned about potential shortfalls in staffing levels, which they identified should be prioritised in order to meet increasing requirements of community-based care (Grant, 2004).

#### Social workers and Mental Health Officers

- Prior to implementation of the MHCT Act, social workers questioned how community CTOs would operate and some were concerned that this would do nothing to address underlying social circumstances, and might even predispose some individuals to becoming unwell (Rushmer & Hallam, 2004). In light of the significant role and new responsibilities for Mental Health Officers (MHOs), studies found that issues of staff support, supervision and workload were the main concerns expressed (McCollam et al, 2003). This echoed previous findings from qualitative research by Ulas et al (1995) and Ulas (1999), and the monitoring study collated by Smith (1991). McCollam et al's (2003) survey of local authorities found that 23% of MHOs had not been practising in that capacity in the previous 6 months, representing a decline in practising MHOs since earlier findings. Fourteen local authorities reported plans to increase the number of MHOs, although many referred to recruitment difficulties, including in regard to social workers more generally. MHOs consulted reported high workloads and concerns about the need to access training about the new legislation. Reid (2006) similarly pointed to the risk of there being an insufficient number of MHOs and noted that a proportion of accredited MHOs were not practising regularly.
- 2.33 In short, key issues raised by MHOs related to available resources, capacity and coverage across Scotland. In particular there were doubts that there would be sufficient accredited MHOs with the expertise to meet the requirements across all local authorities and health boards, to implement the legislation appropriately, including by providing timely, quality reports and attending hearings.

#### Advocacy services

2.34 Concerns were expressed in various consultations about potential shortfalls in advocacy services to meet anticipated needs, for example, in providing representation at Tribunals (with around 3000 expected per year) as well as in relation to hospital admittance/care or outpatient services (Grant, 2004). Advocacy services raised concerns about shortfalls in personnel, potential difficulties in recruiting appropriately trained and experienced advocacy workers, and the potential for mental health advocacy needs to dominate the work of advocacy support agencies. Two key issues highlighted in Grant's review were: debating the pros and cons of the 'professionalisation' of advocacy, and the impact of strategic prioritisation of advocacy support in the face of potentially high demand to service the processes of the MHCT Act. Across professional stakeholders consulted by the Executive in the lead up to the Act, consultees, including advocates, raised questions about how far service users would be aware of their entitlement to advocacy, and be able to choose and reach advocacy services at the point of detention when they were most vulnerable (Rushmer & Hallam, 2004).

### Care planning

2.35 While the critical role of social work in care planning was undisputed, some stakeholders were concerned that inter-professional conflicts could arise if care plans were drafted without consultation with relevant professionals who would then be obliged to meet their service provision requirements (Rushmer & Hallam, 2004).

Local authorities questioned the effectiveness of care and treatment planning in regard to complex needs, particularly given the uneven availability of local community services to meet plans. They were also concerned that short-term detention might serve to lengthen the period of compulsion. It was queried whether CTOs would be used as a mechanism to access services that were unavailable otherwise, and the British Medical Association (BMA) queried whether emergency measures might be used as a route to assessment.

- 2.36 Both psychiatrists and social workers raised issues about the availability of suitable and sufficient resources to provide effective community care to meet the Millan Review principles, especially reciprocity (Rushmer & Hallam, 2004). Additionally, consultation pre- and post-implementation of the Act highlighted professionals' concerns that the pressure to respond to the needs of those undergoing compulsion may result in a 'two tier' service, with more restricted access to services for those who have not been detained. (Rushmer & Hallam, 2004; Atkinson et al, 2007).
- 2.37 In regard to those with mental health problems within the criminal justice system, many stressed the need to monitor processes of assessment, use of compulsory orders and care planning and to assess any differences from those detained under civil procedures (Rushmer & Hallam, 2004).

# Housing and housing support

2.38 Although various consultations prior to the MHCT Act (Millan, 2001; Grant, 2004; Rushmer & Hallam, 2004) did not refer specifically to the role of housing/accommodation services in responding to mental health needs, their relevance was implied in consultees' references to the need to focus on social as well as clinical needs and interventions. Previous research and policy has recognised the key role of housing in community care (Petch et al, 2000; Social Exclusion Unit, 2004b; ODPM, 2005). Grant (2004) found that while local authority staff raised concerns about the lack of adequate and affordable housing stock, the voluntary sector were more concerned about their long-term ability to attract and retain experienced and trained personnel (Scottish Social Services Council, 2001).

#### **Promoting Wellbeing and Social Development**

2.39 Significantly, the ethos of the MHCT Act and its underpinning principles emphasise a person-centred, holistic and comprehensive approach to addressing the needs of people with mental health problems. Under Sections 25-31, local authorities have new and extended duties and powers to promote wellbeing and social development, and assistance with travel in relation to provision of these (Scottish Government, 2007). These duties sit within equalities and social inclusion frameworks, and supplement local authorities' powers under Section 20 of the Local Government in Scotland Act, 2003, and duties to ensure equal access to services under the Disability Discrimination Act, 2005. The concept of a 'meaningful day', involving opportunities for meaningful, valued activities, will vary for individuals, but it is increasingly recognised in policy documents as critical both to recovery-based approaches and to inclusion (e.g. DoH, 2005).

- 2.40 Rankin (2005) asserts that while it is important to start from the assumption that everyone can work, some form of meaningful activity is what is important. By 'meaningful activity' is meant education and skills development as well as a broader range of paid, unpaid domestic work and caring duties to voluntary work. In local areas there should be a range of services and support to enable people with mental health problems to access paid employment, mainstream education and training or integrated voluntary work in the local community.
- 2.41 A number of barriers to people with mental health problems moving into work have been identified, including constraints placed by the Welfare Benefit regulations and lack of sufficient appropriate supported opportunities to transfer into work (Robbie and Pressland, 2003). Other barriers include low self-confidence, low expectations among staff, employer attitudes, and a lack of support to access appropriate training and education, as well as to help people retain jobs (Social Exclusion Unit, 2004a).
- 2.42 Research in the US demonstrates success through the supported employment or the Individual Placement and Support (IPS) model. Similarly, recent research commissioned by the then Scottish Executive highlights the barriers and opportunities to employment for people with learning disabilities and/or autistic spectrum disorders, including success stories from supported employment (Ridley et al, 2005). The Scottish Executive's 'Employability Framework' recognised some of these barriers. It currently funds pilot demonstration projects on employability, support and job retention, as well as Pathways to Work initiatives in different parts of Scotland (Workforce Plus, 2006).
- 2.43 Overall, engagement in employment has been shown to have positive benefits for many people with mental health problems (Durie, 2000). The Department of Work and Pensions Labour Force Survey (2000) found that 83% of people with mental health problems severe enough to affect their ability to work were economically inactive, and that 26% wanted to work; a further 5% said they were actively seeking work. Other surveys such as Bates (1996), Rinaldi and Hill (2000) and Secker et al (2001) cited in Secker and Grove (2005), were more positive. They found that as many as 90% of people with enduring mental health problems in some studies aspire to a real job with real wages. Further, Rinaldi et al's (2006) research found that, with the right kind of support, people with mental health problems find and maintain jobs in a wide range of occupations and at various levels.
- 2.44 Researchers conclude that an individual's motivation and the kind of support they receive in finding and keeping a job are critical success factors rather than individual characteristics or situations (Bond, 1998 cited in Secker and Grove, 2005). Further, Secker and Grove's (2005) research shows that the underpinning model of recovery is critical, and argue that a social model of recovery is important in services supporting people with mental health problems into paid work.

# **Planned Improvements in Mental Health Services**

2.45 Alongside changes in the law, Scotland has committed to implementing major change in the development and delivery of mental health services. Planning intentions for comprehensive and integrated mental health services, both in hospital

and the community, were initially stated in the 1990s in the *Framework for Mental Health Services in Scotland* (Scottish Office, 1997). This was further endorsed in the Scottish Executive framework for implementing Health policy, *Delivering for Health*, which called for an updated delivery plan for mental health services (Scottish Executive, 2005). The subsequent policy document *Delivering for Mental Health* (Scottish Executive, 2006c) built on the principles, policy and organisational framework implemented by the MHCT Act. Its vision was comprehensive, addressing both severe and enduring mental illness as well as conditions such as depression and anxiety. Its focus was on treatment, prevention and the promotion of mental health and wellbeing.

2.46 The starting point of the Mental Health Delivery Plan consisted of 3 targets and 14 specific commitments alongside related time-scales. Key targets were: (1) to reduce the annual rate of increase in use of antidepressants to zero by 2010; (2) to reduce suicides by 20% by 2013 and (3) to reduce by 10% readmissions to hospital (within one year) for those who have been admitted for over 7 days by December 2009. The following table presents some of the Scottish Government's 14 stated commitments as relevant to the research focus:

Table 2.2: Summary of Scottish Government commitments relevant to research study

Commitment	Timescales	Related Target
Commitment 1: To establish a tool to assess implementation in	To Pilot in 2007 and	Target 3
regard to equality, social inclusion, recovery and rights	implement by 2010	
Commitment 2: To develop a training programme for peer	To pilot in 2008	Targets 2
support work		& 3
Commitment 3: To work with GPs to ensure formal, standardised	2009	Target 1
assessment of patients with depression; and appropriate treatment models		
Commitment 4: To increase access to evidence-based	2010	Target 1
psychological therapies offered by relevant providers		
Commitment 5: To improve the physical health of those with	2009	Target 2 &
severe and enduring conditions with access to a physical health		3
assessment		
Commitment 6: NHS Quality Improvement Scotland to develop	Standards - 2007	Targets 1,
standards for Integrated Care Pathways for schizophrenia, bi-	ICP-development/	2, & 3
polar disorder, depression, dementia and personality disorder.	accreditation in 2009	
Commitment 7:To train front-line mental health, primary care and	50% target staff by	Targets 2
A&E staff in suicide-assessment tools/prevention	2010	& 3
Commitment 8: To ensure people are managed and cared for	2009	Targets 2
effectively in the community, avoid inappropriate admissions and		& 3
achieve crisis standards		
Commitment 9: Establish acute in-patient forums across Health	2009	Target 3
Board areas, involving providers, users, carers and others		
Commitment 12: Implement Care Programme Approach for	2008	
restricted patients		
Commitment 13: To ensure support for joined up local delivery to	2007	Targets 1,
implement principles of Mind the Gaps and a Fuller Life		2 & 3
Commitment 14: Pilot Programme for improving dementia	2008	Targets 2
services and evaluation with Stirling University		& 3

(Adapted from *Delivering for Mental Health*, Scottish Executive, 2006c, page 20-21)

2.47 Chapter 6 of this report will later consider the findings from this study in relation to some of these commitments.

#### Other Key Influences on Implementation

2.48 Finally, it is important to note that implementation of the MHCT Act has taken place during a period of flux in policy and practice and funding arrangements across all public service sector provision, not just in mental health. While some of these represent key opportunities to strengthen the Act's implementation, others will present dilemmas and challenges. In summary, these include:

- The migration of concepts of 'recovery' from the periphery into the mainstream of services: This approach aims to build on individuals' strengths and aspirations to enable them to exert control over their own recovery, and to guide the care and treatment they achieve (Bradstreet, 2004; Scottish Executive's National Programme for Improving Mental Health and Wellbeing (2004), which launched the Scottish Recovery Network (SRN) initiative in 2004);
- Increased policy emphasis on service user participation and involvement, individually and collectively since the introduction of the National Health Service and Community Care Act, 1990 and related guidance. Although progress has been uneven, the impact is clear, for example, in the extensive consultation undertaken by the Millan Committee (Millan, 2001), and later by the 21<sup>st</sup> Century Social Work Review, with its emphasis on Citizen Leadership (Scottish Executive, 2006b):
- Emergence in policy and practice of personalisation and co-production. Whilst different interpretations of personalisation and co-production co-exist, they share an assumption of change from traditional provision in which decisions are made by experts to one in which service users become 'co-designers' and' co-producers' of welfare. The role of the state is central in creating a positive climate in which such new forms of partnership or 'script' (Leadbetter, 2004) can flourish. Such partnerships between professionals and service users require transformational change in organisational cultures and services: they are not 'bolt-on' extras to traditional provision (Foster et al, 2006; Department of Health, 2008; Hunter & Ritchie 2008);
- Concordance rather than compliance in treatment: Whereas a compliance-based approach refers to the medical professional's role in ensuring that the patient complies with prescribed treatment, a concordance approach stresses that treatment should be developed through a process of dialogue between clinician and patient and "where patients' experiences, values and aspirations about their illness and its treatment are at the centre"<sup>2</sup>. The model essentially is one of partnership and making decisions together. This emphasis falls within the family of ideas related to co-production and the importance of the personalised approach. The pilot project that engaged community pharmacists in an integrated way with community psychiatry is one example (Scottish Executive, 2001a. Managing Medicines, updated 2002). See also recommendations from a

<sup>&</sup>lt;sup>2</sup> Royal Pharmaceutical Society of Great Britain (1997) From Compliance to Concordance: achieving shared goals in medicine taking. London

- SAMH survey on people's experience of psychiatric drugs (Norris, 2004), and UK-wide guidance on concordance (General Medical Council, 2008; NICE, 2008);
- Increased emphasis on support for employment and enabling those 'furthest from
  the labour market' to participate (DWP, 2006, Freud, 2007) This idea of
  'employability' is quite distinct from the model in the States whereby unpaid work
  is exchanged for welfare. Whilst there is concern about changes to incapacity
  benefits, this initiative does recognise the potential 'value-added' spin-offs from
  employment for individuals, associated with improved well-being and social
  inclusion;
- Joint Futures and Partnerships in Care: The policy momentum towards collaboration and partnership working between Health and Social Care has increasingly shaped local joint planning and commissioning systems (Scottish Executive, 2000, 2001b and 2003). This has particular implications for the planning of community-based services;
- Changes in funding and resources: both service funding and individual funding
  have seen some developments to support community-based services and greater
  personalised funding. Allocation levels to mental health, however, remain low
  (Royal College of Psychiatrists, 2008) and participation of mental health service
  users in Direct Payment is very low (Ridley & Jones, 2003) Nonetheless, there is
  recognition of the resource commitment needed and most recently there has
  been additional investment to enable the implementation of the MHCT Act;
- The implementation of Supporting People grant (SP) in 2003 expanded significantly the support to individuals to sustain community living; around 5% of those supported have mental health needs, representing 10% of the budget (Berry K, 2007). The removal of ring-fencing in April 2008 has introduced uncertainty for providers experiencing an increasing gap between the costs and funding of provision. (Supporting People Enabling Unit, 2007).

#### CHAPTER THREE: SERVICE USERS' PERSPECTIVES

#### Introduction

3.1 This first findings chapter focuses on the direct experiences and perspectives of those who have been subject to compulsory care and treatment. It presents a diverse picture of compulsory psychiatric care under the MHCT Act, both in hospital and community settings. Service users' opinions of the processes of the MHCT Act are discussed: in particular, we explore their experience of Mental Health Tribunals, the named person role and Advance Statements. We reflect on what service users said about the extent of participation and inclusion under the MHCT Act, and their views on care and treatment under compulsion. We discuss their views about the professionals involved in their care plans, and the extent to which these professionals were helpful and/or unhelpful in supporting their recovery. Service users' views on opportunities for leisure, education and employment are discussed. Finally, we assess what 'post-compulsion' meant for the service users interviewed.

### Sample of Service Users

3.2 As described in detail in chapter one, all those living in one of 4 research site areas who had experienced compulsion during 2007 were invited to participate in the study. This resulted in around 770 individuals being approached. Of this total, less than 10% chose to respond, returning the reply slip, telephoning or emailing the researchers. Out of those volunteering to participate (63 respondents), 49 or 78% of those who responded were interviewed for the study at Stage 1. Table 3.1 below summarises, by study area, the number of respondents, number of people interviewed, and the reason for not including some of those who responded in the study.

Table 3.1: Number of responses and interviews carried out with service users in the four research areas

Description	Dumfries & Galloway	Fife	Glasgow	State Hospital	TOTAL NUMBER
All Respondents	12	17	26	8	63
Withdrew	1	-	2	-	3
No consent	-	2	2	3	7
Other	1	1	2	-	4
Interviewed at Stage 1	10	14	20	5	49
Interviewed at Stage 2	7	10	17	5	39

3.3 A professional nominated by the respondent (usually the RMO, CPN or MHO) advised not interviewing 11% of respondents on the grounds that they were too unwell to participate when the research was being conducted, and that participating was potentially harmful to them. Another 4 respondents were not included in the study for other reasons. This included one for whom nursing home staff had completed the form without consulting him/her. A carer who had misunderstood the information, but subsequently participated as a carer. Two forms were received some months after the deadline for arranging Stage 1 interviews (i.e. after November 2007). Finally, 3 individuals who had professional approval to participate decided to withdraw. When approached again at Stage 2, almost 80% (39 out of 49 participants) agreed to be interviewed a second time. A number of interviews were

conducted with a supporter present, for example, a carer such as a spouse, an independent advocate, or language interpreters.

3.4 As a qualitative study, a purposive sample of those with relevant and diverse experience of compulsion rather than a representative sample across the 4 research sites was sought. Nonetheless, as the following table summarising demographic characteristics shows, the sample of service user participants was diverse in many respects.

Table 3.2: Summary characteristics of the group of service users interviewed

Characteristic of the group (=49)	Statistic		
Gender – percent	67% male: 33% female		
Age (mean in years)	40.5 years		
Youngest participant	21 years		
Oldest participant	63 years		
Black or minority ethnic group, including asylum seekers – percent	8%		
Learning disabilities and/or Autistic spectrum disorder (ASD) - percent	8%		
Most recent experience was community CTO – percent	35%		

3.5 Across the sample there was the full range of compulsion experience under the MHCT Act from Emergency, Short Term to Long Term Hospital Orders. Five of the participants were individuals who were detained at the State Hospital, mainly through the criminal justice system route. The table below summarises the most recent experience of compulsory measures as understood by service user participants, although some were unclear about which compulsory treatment order, if any, they were under at the time of first interview. This confusion arose because some people had experienced different types of compulsory measures in succession, or they had recent experience of variance or suspension of a CTO. Being mindful of this, it is therefore possible that the percentage of participants recorded as under community-based CTOs at the time of interview may be slightly inflated.

Table 3.3: Participants' most recent experience of compulsory measures as at Stage 1 interviews by research area

Category of compulsion	Glasgow Fife		Dumfries & Galloway	State Hospital	TOTA	TOTAL	
	No.	No.	No.	No.	No.	%	
Short Term Order	4	3	-	-	7	14	
Interim Order	-	-	2	-	2	4	
CTO in hospital	6	5	1	1	13	27	
CTO in community	8	5	4	-	17	35	
Specialist Orders, CJ Legislation	-	1	-	4	5	10	
Unclear At Stage 1	2	-	3		5	10	
TOTAL	20	14	10	5	49	100*	

#### **Pre-Compulsion Stage**

3.6 Using the model pathway through compulsion proposed by the Scottish Executive (2005) (see chapter two, paragraph 2.9) as our conceptual starting point,

interviews with service users began by asking about the period prior to, and leading The model or ideal type assumes a period of 'nonup to compulsion. compulsion/stability', an 'episode leading to compulsion', Tribunal, care and treatment, discharge and returning to 'non-compulsion/stability'. accounts of moving into compulsory care, the reality was more complex, less linear than this ideal model suggests. In the period of 'non-compulsion', participants told of variable circumstances, many of which were not stable as assumed from the model pathway. For many, this was not the first time they had experienced detention in hospital or even compulsion, and many were at various stages of recovery finding ways to live with the impact of having a severe mental illness. A stressful or traumatic event might act as a catalyst or trigger a period of worsening health. For some, the severity of their mental health problems escalated over time, precipitating with a crisis, followed by compulsory care and treatment. Some described living with serious mental illness for several years without ever coming into contact with mental health services until recently, whereas others had been in and out of hospital (not necessarily under compulsion) for most of their adult lives. Others had been in a period of relative stability, which had changed unexpectedly. Some participants had been voluntary patients and through non-compliance with treatment had been made compulsory patients.

# **Box 3.1: Two Contrasting Routes into Compulsion**

Debbie\* a 30-year-old married woman has a busy life being employed full time and also working as a volunteer in the community. With no history of mental illness at all, she became unwell after experiencing consecutive stressful events in her life. Her concerned family took Debbie to a local psychiatric hospital for help, whereby it was decided to keep her in for 28 days assessment. Although she became well and left hospital, after a short period Debbie became unwell again, which she puts down to sleep deprivation. This resulted in a second hospital detention under compulsory measures. On discharge, Debbie received more community-based support from the psychiatric health services and has gone from strength to strength. She is now off all medication and only sees her Consultant infrequently and has telephone contact with a CPN. Believing her experience of compulsion to be a blip in her history, she does not expect to become mentally unwell in the same way again and feels no need to appoint a named person or draft an Advance Statement.

Jim\* is in his late 40s and identifies himself as having suffered from schizophrenia since his mid teens. He has been in and out of psychiatric hospitals most of his adult life, several times under compulsory treatment and is now on the Care Programme Approach (CPA). The last time he experienced compulsory treatment, Jim had been admitted for assessment and been kept in hospital under a CTO. He was now living back in the community in his own flat with support from various agencies including a CPN who administered an injection, his social worker who he saw regularly to discuss his care plan, a cleaning agency helping with his housework, a befriender helping address his social needs and his psychiatrist. He also relied on regular respite care support at certain times of the year. Jim felt that hospital treatment had changed a lot in the past few years but he strongly disliked being detained in hospital.

\* Real names have been changed to protect individuals' identity.

3.7 Participants gave unique personal accounts about the period prior to compulsion and what led up to their most recent experience. For the following individuals, while there had been a variety of factors leading up to compulsory treatment, a key factor was either the start of, or an escalation of, existing serious mental health issues, which had led to decisions to admit them under emergency, short term, and for some, long term detention in hospital:

"I'd had flu for a long time and I just kept working, I'd had the family staying for a week over Christmas/New Year, which was hectic, I'd had an incident at work. I think my sleep was disturbed for 2 or 3 days so I was getting pretty run down mentally and physically and then my daughter was going through a difficult time and I was worried about that. And then I had the most incredible psychic experience. Later on, because my family were so worried, they got the doctor to come to the house."

"Basically I had like a hyper manic episode. I was first admitted for about 4 weeks and then I was discharged and then I had about 8 weeks of basically just running riot and just kind of anti-social behaviour towards my neighbours, just not really feeding myself properly, not sleeping properly. Just over-activity like spending money on things I didn't need. I was getting delusions and stuff. Shouting in the street and getting assaulted for it. The neighbours were like banging at my door and all that kind of stuff and threatening me, then the police got involved..."

"Sometimes there's a stressful reason why I end up in hospital but no, there was no stressful reason. I was fed up with the situation, with friends and family, and I decided to just take a taxi at 2 am in the middle of the night and go to the airport and get a flight and not come back. What saved me was the flight was that expensive because it was stand-by. I waited all night and the flight was still too expensive in the morning so I took a taxi home...I think it was a graduation of depression and then mania, and I had to go in really."

3.8 Others' could identify and describe in vivid detail, stressful or traumatic events, which might be in the past or more recently, which they felt had been the main reason why they had been subjected to compulsory care and treatment. They had been admitted to psychiatric hospitals usually under Short Term compulsory Orders:

"I would say that the catalyst was the New Year...Christmas time and New Year is always a difficult time for me. The first episode was basically very much stimulated by the news that my mum was terminally ill; it kind of turned the world upside down. The second one was after my mum had a really big operation. I went in again and then the third episode was just before mum died. I totally believe very strongly that the stress was such a huge catalyst in me"

"There were a lot of stresses in my life, a lot of things happening at one point. It was just after I got married and moved here and I had been on anti-depressants for 6 months, and I had levelled out and thought it was time to come off ...So there was a lot of change...There was death and if you go through a check list...I think there was lots of tick boxes, so I think it was a combination of lots of stress that caused me to go into hospital."

3.9 For others, the main emphasis in their accounts was on the impact of social and environmental issues on their mental health. Compulsion had been at the instigation of families, friends, neighbours, police, or housing agencies after they became concerned about the person's behaviour or outward signs of personal neglect. Some had subsequently been detained in hospital and had remained there for several years:

"I wasn't happy in the area that I was living in and I kept saying to my doctors then you know I wanted to move and I feel that every time I go into hospital and come back out I'm going back to the same situation. This wasn't the first time I'd been in hospital under a compulsory order..."

"Well somebody tried to break into my flat and I stayed awake for about a month without any sleep and I didn't eat and I lost a lot of weight and then I started getting delusional and then my brothers took me into X Hospital and had me committed..."

"I was getting bricks fired at the window. I just wanted to get out of the house and sort it. Bags o' flour, bags o' sand, bags o' sewage flying at the windows. Went on for about 2-3 weeks. I went in for help and they kept me in, they put a permanent order on me. The only problem was the little kiddies... I wanted them to sort it out."

3.10 In their accounts, several participants referred to not complying with medication regimes and deterioration in their mental health, at times leading to readmission to hospital compulsory care. In such cases, the pathway typically involved converting from being a voluntary patient to a compulsory order, for example:

"I was feeling quite low and suicidal...I got sent into hospital to get checked over and that's how it started. I stopped taking medication, I thought I was fine and I relapsed and was put back in. At the time I wasn't eating or drinking very well. I was hearing voices that told me not to. They sectioned me because I wasn't looking after myself...When I first went into hospital it wasn't under compulsory. I escaped 3 times so I was put on a short term detention order."

3.11 The pathway into compulsion for some people was through the criminal justice system. Several mentioned how they had been convicted for a 'breach of the peace' just prior to being admitted under hospital compulsory care. Such instances were not always mentioned initially in answer to the question about what led up to

compulsion, but instead they were mentioned in passing. Some had been admitted to the Intensive Psychiatric Care Units (IPCU) following minor incidents or breach of the peace and considered they were there on remand. Although many spent only a short period on the IPCU before they were moved to less secure wards, some had been living on secure locked wards under high security for a number of years. This included individuals with additional and complex needs including learning disabilities or ASD and dual diagnosis. There were also those who during a period of imprisonment had been diagnosed with serious mental illness and subsequently transferred to the State Hospital:

"A psychiatrist came to see me when I was in prison and put me on some medication, I went to court, I got sentenced, I went to prison, then I fell no well again in prison, then I went from one prison to another, fell no well again...I was hearing voices, getting weird smells, then a psychiatrist came out to see me, then they said this will take about 2 weeks for a meeting and that to go ahead whether we know or not if you're coming to the State Hospital."

"I was taken in by the police into detention and the charges weren't pushed against me. I heard the charges when I was in HM Prison for a week and a half. I had to see a doctor up there and then I came through court again then onto this hospital, where I'm on remand."

"My friend took their own life and that's what led me back into hospital. It all ended in me getting done for breach of the peace. Normally you would get a fine at a court and that but they threw me in the hospital and I got four years locked up for it. I've been in a hospital for the last 13 years all because of a breach of the peace."

3.12 It was the understanding of some participants that the decision to detain them under compulsory care was taken because of a perceived risk to themselves or others. These individuals had experienced Short Term orders but also had been subject to hospital and community based CTOs lasting much longer:

"When I wanted to move back to the area, I was asked a series of questions and asked if I'd speak to a psychiatrist because they felt I was potentially unwell. This shocked me but I wasn't surprised because I have a history with the psychiatric services... I was offered accommodation and managed to get on with my life reasonably well until I experienced pains and presented myself at the A&E when staff contacted a psychiatrist...I agreed to see them, somewhat with my arm tied behind my back, to be admitted to the psychiatric hospital, after which I was compulsorily admitted."

"I had a plan to take my child abroad to see my family and I think people were panicking thinking that because I had this label suddenly applied to me that I would do some of the crazy things that people with the label might do but I know I wasn't going to do that, but they didn't ask me. I just feel so offended by it. I'm the one inside here, I know what I will or will not do and just because you've decided to put a label on me it doesn't make me that."

3.13 Descriptions of failed asylum applications and becoming a refugee at an early age, were how some explained why they had been detained in hospital under Short Term and Interim Orders:

"When I was interviewed by the Home Office about my claim for asylum we had an interpreter - but they said what I didn't say and I was refused, turned down. I had felt alright when I came to this country, we had escaped persecutors but after I had been refused [asylum], I fell ill."

"I left my country too young, I was only 18 years old. There was just myself and I have not anybody to support me or family or friends. I had to stay in a hotel room."

3.14 In summary, the non-compulsion and 'episode' leading to compulsion elements of the ideal pathway (Scottish Executive, 2005) based on the research participants' accounts shows that 'stability' was for many a highly fraught and uncertain time, and that the pre-compulsion 'episode' might be better represented in terms of the interplay of personal or health crises with carers' and professionals' responses, rather than as a specific event. The following table summarises key aspects from participants' accounts:

Table 3.4: Participants' accounts of 'non compulsion/stability' and the 'episode' leading to compulsion

Non compulsion/stability	Episode leading to compulsion
From participants' accounts this included:	From participants' accounts this included:
Death and bereavement Abuse – e.g. physical, sexual, emotional Close relationship ended Suicide of relative or someone close Living with long term mental health problems – e.g. hearing voices, severe depression, bi-polar Imprisoned for criminal act Status of refugee / asylum seeker in UK Stability, no diagnosed mental illness Anti-social behaviour or neighbour issues Sleeplessness, stress and anxiety Living with multiple/complex needs Women separated from children	Cumulative issues/ couldn't cope Vulnerability noticed - neglecting self, not eating, drinking, etc Hallucinations Non-compliance with treatment in hospital or community Transferred from prison to the State Hospital following diagnosis of mental illness Other people acting on concerns about strange or odd behaviour Professional assessment Anticipated risk based on past behaviour and history of mental illness

#### **Mental Health Tribunals**

3.15 Understandably, given the range of compulsory orders experienced, not all research participants had experience of attending a Tribunal hearing under the MHCT Act. Some were or had been under, for example, an emergency or a Short Term Order. Others had not attended perhaps because they had been too unwell at the time. Participants' level of knowledge about the Tribunal was therefore variable;

those at the State Hospital being the most knowledgeable as some were pursuing longstanding appeals against being held under excessive security. Understanding of the Tribunal system was variable: some had had no explanation while others had been told about Tribunals and what to expect. Advocates and a range of professionals (lawyers, RMOs, MHOs, ward nurses), as well as other patients, had given them verbal, and sometimes written, information about Tribunals.

- 3.16 The venue where the Tribunal hearing was held had a bearing on how service users felt about them. Venues ranged from some that were held in a hospital café and other rooms in hospital settings, to those held in community-based venues and even in buildings designated for the purpose. For the most part, even when service users were positive about Tribunals, they commented variously that they had felt "embarrassed", "nervous", and that "it was intimidating" to attend them. One commented on how despite its informality, the hearing was still formal and he had felt the need to "watch my p's and q's". One man explained he had taken alcohol beforehand to settle his nerves. The gravity of these meetings was grasped by service users, who clearly understood the importance of the meetings in deciding what happened to them. This will have made them all the more daunting regardless of how expertly or not the hearing was conducted.
- 3.17 Service users' descriptions of Tribunals varied greatly. One perspective held by some participants contrasted them favourably with the old system of Sheriff Courts, describing them as "relaxed", "informal", "fair", and the panel members as "approachable". Some described the experience as simply going into a room with known professionals, supporters (advocate, lawyer), their named person, and the 3 panel members. One participant remarked, "You can have a laugh, not a stony faced judge". A participant from the State Hospital commented:

"They're good in some ways because you can get your point across and they're taking that into consideration...They are better."

- 3.18 At the other end of the spectrum of views was the depiction of Tribunal hearings as adversarial settings. Service users described a sense of hopelessness at presenting their case when it felt as if the decision had already been made. Some did not feel that the Tribunal made an effort to understand their perspective or communication needs, for example, a young man with ASD commented, "They didn't listen to me about Asperger's Syndrome". Another person had a hearing impairment and had not heard, and therefore not understood, everything at the Tribunal hearing. Some participants recognised that they had been unwell when they attended, and that this would have coloured their perception. As one person reflected, "I just didn't have a clue what was going on."
- 3.19 Some service users highlighted difficulties arising from having to attend multiple hearings, which was more common than not for those at the State Hospital, as these hearings were often cancelled at short notice and rescheduled. In some cases, the panel had required more information or assessment, or had asked for a curator to be appointed. For those with learning disabilities and/or ASD interviewed for the study, this was a frustrating experience. A key issue related to attending numerous Tribunals was having different panels considering the case and having to repeat information:

"In my experience of 5 tribunals you don't get the same person, the same team on the tribunal bench 2 times running. And depending on who you get, you could have a totally different attitude."

3.20 The amount of paperwork received, coupled with the level of detail in the reports for hearings, could be overwhelming and upsetting. For example, one participant said that neither she nor her husband were happy with what had been written about her, as it gave an overwhelmingly negative impression. Another was similarly unhappy with the report's emphasis of negative aspects, which had had a detrimental impact on the relationship with his named person, who read about certain events for the first time in the detailed Tribunal report:

"It was really hard because see when you read it in black and white, the way it was put across, terrible man, absolutely terrible you know. It was saying things in the report that were a whole load of crap and it looks as if it's really bad you know when it isn't."

3.21 A burning issue raised by a couple of service users was what they perceived as the inappropriateness of using past information in Tribunal reports, some dredging up information from childhood that had questionable validity in the present circumstances as far as they were concerned:

"There was evidence offered to the tribunal going back to my life as a child, as a toddler, as somebody under the age of 5 and quite personal details about family settings which had not really been introduced in previous interventions and detentions."

"My psychiatrist would pull stuff out of the hat that I'd actually forgotten, and it was actually a false charge...dredging up forensic history going back 20 years or so to my mind is not helpful."

3.22 While the professionals involved clearly considered this relevant contextual information towards the case for compulsion, these service users did not agree and considered it unjust, and argued that including such information put them at an unfair disadvantage. Some considered this an expression of the stigma they regularly experienced of having been diagnosed with a mental health problem.

## Reasons for not attending

3.23 Although some participants had attended Tribunals when they were unwell, others who were unwell had decided not to go because of ill health. Some had only vague memories of Tribunals ever having taken place, and although they felt sure they had been asked to attend, they could not always remember the details. Some typical responses were:

"I didn't feel up to it on the day."

"I'm always too ill to attend a Tribunal, I don't understand the concept of it."

"My mental state wasn't great, I couldn't see the point."

"I couldn't make it because I wasn't well."

3.24 One person had not attended and did not remember being asked to attend a Tribunal, but felt that she would decline anyway because it would be too stressful. A participant with learning disabilities did not attend his second Tribunal because in his words, "it gets boring". Another was cynical about attending because from prior experience, having a Tribunal did not guarantee being discharged from hospital.

## Participation at Tribunals

3.25 The majority of participants who had attended indicated that these hearings provided a better opportunity for participation than the previous system, regardless of whether or not they believed their opinions had significantly influenced the final outcome. Most said that they had been given an opportunity to state their views and ask questions during the hearing. Many referred to the more participatory style of the new panels, which encouraged interaction of all those present, including service users. The following illustrate positive accounts of participation:

"From my point of view, I was in more control of my section order so I was able to take control of my future and have it out with the doctor. Before the doctor was just having the say so and I would have to abide by what was being told. So when the doctor said I needed a longer section I was able to overturn that decision and that felt quite good."

"I felt more involved. They asked me a question. I got a chance to talk you know and to ask questions, they asked how I was and what I thought. Before it was my doctor and the others talking you know, they didn't give me any chance to talk." (State Hospital)

3.26 All the same, this was a formal meeting and although Tribunals afforded service users an opportunity to put their point of view across, many concluded that their views were given less weight than the opinions of professionals, especially those of psychiatrists and MHOs. In a nutshell, what one participant said could sum up the general mood:

"I did get my tuppence worth, but it wasnae really worth anything".

3.27 Nonetheless, despite general agreement that participation by all was better at Tribunal hearings, in some service users' experience, professionals did all the speaking. Others said that they never really got a chance to speak, or at the other extreme, that they were prevented from speaking. One participant for instance, said she had been shocked when at the end of the Tribunal she asked if it was her turn to speak and had been told that she was not being asked for her opinion. Some others had made a judgement that the less they spoke the better, as this would be less incriminating. They had decided to leave their lawyer or advocacy worker to represent their point of view.

#### Tribunal decisions

3.28 Service users' opinions about the decisions made by Tribunal hearings were ambiguous and not easy to summarise. It was for instance possible to agree with the decision but to feel unhappy about it at the same time, for example:

"I wouldn't say I didn't agree, it was a case of I was trying to tell them that I was alright and it was like they weren't listening to me but it wasn't that I didn't agree with the people in it, I was quite happy"

3.29 The decision might be perceived by the service user to be in their best interests, but still remained an unpopular one. There could be aspects of the decision that they agreed with and other aspects they disagreed with: for instance, one participant agreed with a decision to grant a 6-month CTO because he recognised that he had become unwell and needed treatment, but he strongly disagreed with the type of drug treatment decided. Another who was unhappy with the decision at the time, said on reflection that:

"They done the right thing. If they had let me out I'd have been in all sorts of mischief."

3.30 A significant group of participants felt strongly that the decision made by the panel had been a foregone conclusion. They therefore felt that the hearing was a waste of time. The consensus among these participants was that decisions were weighted in favour of psychiatrists' opinions and that it did not matter what they or any of their supporters said. The panel's decision was unpopular if the individual disagreed with his/her assessment and/or the care and treatment plan. Some service users were cynical about seeking independent medical opinions as this rarely, if ever, resulted in a challenge to the initial psychiatric assessment. Rather than seeing this as a measure of practice consistency, service users experienced this as collusive:

"Maybe all psychiatrists are cloned because he just came to exactly the same conclusions as the first one and I thought 'why did we bother?"

3.31 Those appealing against excessive security at the State Hospital were aggrieved at some panel decisions when the decision was to continue to detain them at the State Hospital in spite of a case being made by the clinical team. Decisions taken by Tribunal panels held at the State Hospital were painted as being overly cautious. However, it was unclear to what extent this was driven by resource issues or unwillingness to shoulder the responsibility for transferring patients to less secure settings. Some service users felt there should be closer evaluation of the decisions made by panels, and the extent to which service users' and others' views had influenced this. Regardless of whether or not hearings have been inclusive, some had experienced an overwhelming sense of powerlessness.

#### **Named Person Role**

3.32 Some of the participants knew about, and most did have, a named person, although the research did not seek to establish the extent to which they had appointed their named person as opposed to having a named person by default. Some were uncertain whether or not they had one. Those who did had generally chosen a close relative (e.g. parent, sister, brother, husband, wife, cousin, a grandparent) to be their named person. However some had asked friends because of issues they did not want close relatives to know about, or these friends seemed to them more sympathetic of their point of view. It was also important to service users that the person appointed understood the context of mental ill health:

"I put her as my named person instead of my mum. Her dad was manic-depressive so she can relate to me whereas my mum can't. Plus there are things that I wouldn't want my mum to know. If she'd seen half the things that have happened or I'd done she'd probably have a heart attack."

- 3.33 Many had only heard about it, they knew they could have a named person but did not fully comprehend the role, and often confused it with advocacy: For example, one participant said, "they can fight your corner". When the role was experienced as different from advocacy, it frequently resulted in service users instigating a change of named person.
- 3.34 There were differing viewpoints about the value of the named person role. While some service users were reasonably positive about it, others were undecided or claimed it made no difference to them at all. One participant, who was interviewed in the presence of the relative taking on this role, felt it made little difference because neither she, nor her named person, was ever listened to. Some identified it as either potentially or actually detrimental to the relationship with their relatives. After reading the guidelines and considering who to appoint, one person had opted for her brother as named person rather than a friend because she did not want to take the chance that this might bring her into dispute with her friend. Others referred to feeling "let down" or betrayed by their named person, a viewpoint that at times changed when they became well again. Given the potential for disagreement, one participant had been careful about what he said to his named person, as he was aware that in other contexts (e.g. Tribunal hearings) this could be used against him.
- 3.35 A few had chosen not to appoint a named person, and were unhappy that the next of kin could become named person by default. They could see "no reason" to have a named person. Others had no one to act as named person but could see its' value:

"I've no got anybody, I'm on my tod and they play on that, see if you've got family speaking for you it goes a long way...they don't listen if you're on your own."

3.36 By the time of the second interviews, around a quarter of participants had changed their named person for various reasons. This included situations where the

named person had disagreed with the individual's views about what was needed and had agreed with the consultant and/or MHO:

"I just felt he was not speaking in my interests and perhaps I was mistaken. I think I named a good friend of ours after that."

3.37 It also included situations where the named person themselves had become unwell.

#### **Advance Statements**

3.38 At the first interview, some participants knew nothing about Advance Statements and few had made one, supporting the MWC's assertion that hardly any had been made (MWC, 2007b). Just over half had heard of them, but they had limited knowledge of what they were or whether they were relevant to them. The research team distributed the Scottish Executive purple booklets about Advance Statements to participants, and this was the first time most had seen these. By the time of the second stage interviews, the majority knew what an Advance Statement was, and 7 participants (18% of participants at Stage 2) had made one. Three of these had done so following on from the stage 1 interviews, suggesting that an individualised approach to promoting Advance Statements can be effective. Even at the second interview, some participants did not understand what an Advance Statement was, which underlines the importance of repeat information giving when seeking to promote Advance Statements effectively. This finding was further supported by one participant's observation that at certain stages, people subject to compulsion might very well be interested in making an Advance Statement but be too unwell to absorb the information:

"I had been told about it by my CPN but I was still depressed when you came to see me, so for me to read something would be a challenge. When you're depressed you don't really want to read stuff. If I was given it now, I would be able to work my way through it, it's not a big deal."

- 3.39 Among those who were uninterested in making an Advance Statement were a minority who felt completely satisfied with their treatment, and thus could not envisage any reason to challenge decisions about their treatment. Some believed implicitly in the wisdom of the clinical team. Doubting her own judgement when ill, one participant was happy for doctors to take the decisions, as in the end her health improved and she became well again.
- 3.40 However, tentative interest in Advance Statements was expressed among other service users, even though some were still debating the pros and cons of their particular situation and needed more time to decide. Some of these however had misconceptions or uncertainties about what the Advance Statement should cover, as the following views illustrate:

"I think they're quite good actually. The thing about this is I don't know if you can actually know exactly what to write in it because I mean things happen out of the blue, different things happen just like that." "I don't know what an advance treatment plan should cover. Do you have a say in whether or not you might be sectioned or what kind of restrictions you might be under?

"It only lasts for 6 months anyway so it's like the lottery, the one week you don't do it that's when your numbers are called. Do you want that hassle?"

3.41 Not all of the participants understood that they should make an Advance Statement, and have it signed by a prescribed professional, when they were well. For instance, one said that it was "impossible" to expect to get an Advance Statement to "come out the right way" from a patient in an Intensive Psychiatric Care Unit (IPCU). Advance Statements were felt to be a 'good thing' if they provided an opportunity for service users to state their preference for community-based treatment, or gave them a say in the type of drugs used or the length of drug treatments imposed. For example, although one participant agreed with the decision to use tranquillisers in the short term, she did not want them to be used as a long-term solution/treatment. One who had just made an Advance Statement had this to say:

"What I've said in my Advance Statement now is that every effort should be made that I stay at home before being rushed into the [hospital], and every effort be made by non-drug methods, drugs being a last resort, and that I should have some say in what drugs I'm put on."

- 3.42 A range of professionals including lawyers, advocacy workers, psychiatrists, nurses, and MHOs were reported as having mentioned Advance Statements to service users. A participant at the State Hospital referred to an awareness-raising event about the MHCT Act organised by SAMH, where he had heard about Advance Statements. It was a tiny minority who, at the second interview, did not remember anyone involved in their care mentioning them. Nonetheless, some remained unclear how to go about making one and indicated a lack of support to do so. Following on from the first interview, one participant had approached her RMO and been told to contact the Crisis Assessment Team. Another explained that professionals involved in his community order were too busy to help him do this, as they were short staffed.
- 3.43 There was strong cynicism among those who had not made an Advance Statement, as well as among some of those who had, that there was in fact little point to making one, as they believed that clinicians would most certainly override them. As far as these participants were concerned, Advance Statements did not offer a vehicle for participation in decisions as anticipated (MWC, 2007b). The prevailing belief was that psychiatrists and other health professionals used their power to overrule patients' wishes. One participant, who said he had always been "blocked" by professionals, questioned why Advance Statements would be any different. The following illustrate what many service users felt about Advance Statements:

"I'll write it down and if it doesn't suit them they'll change it or they'll take it out of my hands. They've got the powers to overthrow it so what's the point."

"I kind of feel that once you get into hospital you kind of get blackmailed to take stuff...even like the staff...just their kind of manner with you, I don't mean in an aggressive way but just they can sort of use their charm on you tae kind of make you take stuff..."

"If you get ill they're just going to give you it anyway so it's not worth nothing at the end of the day."

"Mine basically states that I don't want any needles anywhere near me, that's the bottom line. I suspect it won't be worth the paper it's written on."

"Regarding medication, they're going to give you what they want to give you. I mean how much leeway have you got? What is the point, it's wasting everyone's time."

3.44 Some had past experience to confirm these beliefs. Few, if any, service users could think of a situation where they understood an Advance Statement to have positively influenced an individual's care and treatment decision, and so most remained unconvinced of their value. One person, who had made an Advance Statement after being told about it by his social worker, had had his statement "overruled", placing him on a drug that, in his opinion, made his symptoms worse. Further illustrations of individuals' wishes being dismissed as invalid when these had been expressed in advance included:

"They didn't even check my Advance Statement. You can imagine the horror on my face when they're telling me they're putting me back on the same type of medication and I had to go through the whole same torture I did when I was 16 after coming off this high medication that totally completely ruined my life."

"I was in the hospital and one of the doctors was wanting to put me back on the injection medication I had come off and I was in an uproar, and I said, 'I wrote down that I didn't want that again', and I got it anyway. When you're sectioned in a hospital you don't have much of a say what goes on..."

3.45 As has been identified previously by other studies, a barrier to some people making an Advance Statement was that they did not anticipate ever becoming mentally unwell to the extent that this would be necessary again, let alone being so unwell that they required to be detained in hospital against their will. For instance:

"It's just one of those things you push into the background. You think 'I'm not going to be ill'."

3.46 Some simply said they could see "no reason" to make one because they were well now.

# The Experience of Compulsion

- 3.47 Service users used a variety of terms when speaking about compulsion. Some simply stated the legal name of the compulsory order they were or had been under, for example, "I'm on an Interim", "it's a CTO", "I'm on a short term order", or "it's a hospital based order", or "I'm on a restriction order". A general way that many spoke about this experience was that they were or had been "sectioned", or they were "under a compulsory treatment certificate", and some referred to being "on a Section 18" (in reference to powers under the 1984 Mental Health Act). Others described their experience in more emotive and vivid terms such as "it's incarceration", "I'm committed", or "I'm locked up".
- 3.48 Participants had diverse understandings of the compulsory measures they were under. Some said they had been told about their compulsory treatment order and what it meant for them by, for example, their MHO, hospital staff, or CPN in the community. Many reflected that they had not really understood compulsion at the time they were admitted to hospital because they had been too unwell. Even those who understood what compulsory measure they were under and its implications, they might be vague about when the order would end. This could be explained by some having experience of renewals and extensions of past orders, and others of being on orders that had not lasted as long as expected. Such uncertainty is illustrated by the following response at second interview:

"I was appealing the section which to my knowledge I got a letter back to say that it had been rescinded, so I'm not on a section anymore, but I'm not very sure. I couldn't be certain of that. But it makes no difference really, I just keep out of trouble..."

3.49 Often being given little information about compulsion from the professionals involved in their care, some service users were critical that they had had to find out from information leaflets they happened upon or from television or radio programmes. At the other extreme, some felt they had received too much information about new drugs they had to take, some of which described alarming side effects. Others said they only received information when they asked for it, and were of the opinion that professionals should be more forthcoming, both about diagnoses and about the conditions of compulsory care and treatment. Timing was important as some did remember receiving information either verbally or in writing, but being unable to absorb it:

"I'm sure I had enough information but I don't think you take it in. I maybe should have asked but I think you really need somebody to sit down with you and just go through it in basic detail what all this means because they give you all this stuff to read and of course you can't take it in."

### Feelings about compulsion

3.50 Given that compulsory care and treatment by definition is an extreme form of control and constraint, it is perhaps not surprising that those we interviewed did not universally welcome it. While some believed in retrospect that compulsion had been the 'right thing' at the time, others consistently resented the loss of civil liberty, and considered compulsion to be an infringement of their human rights. Some understood it merely in terms of being social control, with no benefits to those subjected to compulsion. This was especially so when they understood the main reason for their order as preventative, that is, based on judgements about anticipated or future risks they posed rather than on events in the present. Unsurprisingly, compulsion was generally accompanied by an overwhelming sense of loss and powerlessness:

"They just basically said that that's what they have the power to do, that they believe that I still need compulsory care treatment and I'm sectioned under such and such and...it's like I've got absolutely no powers whatsoever to change the system, it doesn't matter what I say or do."

- 3.51 By the time of the Stage 2 interviews, some of the 39 participants interviewed at this Stage, who had previously railed against compulsion, had changed their perspective. Although others had not and still considered that it had been unnecessary in their particular case. Over half (52%) felt that on balance, compulsion had been, or was, the right thing for them on account of how unwell they had been and in need of help. In one person's words, compulsion was a "necessary evil". However, even when they did not oppose compulsory measures, not all were convinced that hospital-based compulsion had been the right thing for them. For others, compulsion was accepted as the only way to access treatment when they did not comply as a voluntary patient.
- 3.52 A substantial proportion of those interviewed (42%) considered compulsion had been unnecessary in their case; these participants tended to be especially dissatisfied with experiences of hospital-based compulsion. Some highlighted particularly stressful experiences in psychiatric hospitals, concluding that instead of supporting their recovery, the experience had set them back. For many reasons, which will be explored later, hospital-based compulsion was inappropriate to meet some individuals' needs:

"I think that I maybe needed support and help but I could have had it in my own environment in my own home rather than going into a hospital and being in as I said before it was a strange environment, a different environment, something that's... you know having to live with other people from all walks of life, it can be just a bit strange."

3.53 Some of those interviewed at the State Hospital argued they should not be held under this level of security now, even though they recognised the reasons why they had been admitted there in the past. As might be expected, some of these participants were appealing against excessive security, and during the research, 2 of

the 5 participants moved to either a medium secure ward at another hospital or back into the community.

## Hospital-based compulsory care

- 3.54 There was a spectrum of views about the experience of compulsory detention in hospital. At one end of this spectrum were participants who said that it was "like going to hell", and at the other, were those who emphasised the strong camaraderie that existed among patients and that the staff had been helpful. For one participant under a Short Term Order, it had been "great fun, like being in college". And another said their experience had been like "home from home". Many identified both positive and negative aspects of their hospital stay, although clearly for some people, the experience was negative in every respect.
- 3.55 There was an almost universal dislike of hospital-based compulsory care, although a few participants said that, when they were at their worst, the hospital environment was a "safe environment" and where they needed to be. Others who had been positive said hospital was a distinct improvement on being in prison. Reasons for their discontent included the poor conditions and facilities in some hospitals; being forced to live with other people who were seriously unwell in cramped or mixed wards; enforced treatment especially having to endure Depot injections; having restrictions imposed on them as well as the institutional regimes of hospital environments. From experience, many had not found the experience beneficial in any way to their recovery:

"I wasn't really getting any better in the wards. It wasn't actually, anything to do with the section, it was the ward, I just couldn't get better in there. I was just slowly really going off my head. It was the ward, the environment in there that was making me really, really ill."

#### Hospital conditions and facilities

3.56 Physical conditions and facilities within psychiatric hospitals varied significantly across, as well as within, the 4 different research areas, and sometimes between wards at the same hospital:

"Ward 1 is terrible but Ward 4 is like a holiday camp, you get a real choice about what you do".

3.57 Service users had stayed in single rooms, some with en suite toilets and showers, others had been or were in shared rooms or bays with up to 6 others, and they had experienced larger dormitories. Generally, participants preferred private or smaller rooms:

"I went from a ward which had probably about 50 or 60 people in it to a ward with only 4 people and even though I was delusional and I was hearing voices I was able to cope with it a lot better because I was able to get a room and get space by myself."

3.58 There was experience of staying both on single sex and mixed wards, the effects of which are discussed later. Service users reported that while some wards were clean, others were not. Although the food had been good in some hospitals, in others, relatives had had to step in and cater for their needs. More specialist diets, even vegetarian, were generally not well catered for. Facilities for receiving visitors and maintaining contact with families while in hospital also varied greatly, with some women finding that they could not see their children regularly.

## Regimentation of hospital life

3.59 Having to live under regimes imposed by hospital staff was an aspect of psychiatric hospital life that was universally resented, and for some contributed to the sense of compulsory care in hospital as a "nightmare". But, for the few who went into hospital to have "responsibility taken away from me", having rules and a structure to daily life was a welcome aspect. Regimentation was the most prevalent in secure or locked wards. This restricted time spent in rooms or dormitories during the day, usually dictated waking and bedtime hours, recreation time and restricted other basic freedoms such as when patients could use the bathroom or go outside the ward. Restricted access to hospital grounds was generally an accepted part of life on a secure ward. The following vivid description of daily life in hospital emphasises the sense of waiting as well as of predictability:

"You sit and you wait, and you have your dinner, and you have your breakfast, and you sit and wait on your tea, and then they tell you to take a shower... You have to get up in the morning, take a shower and make your bed and go for your breakfast, and then just sit and relax, and then you get a cup of tea at half past 10, and then you get your dinner at 12, but it's just sitting relaxing between times"

3.60 Strict regimentation, coupled with close observation and the restriction of so-called privileges was 'the norm' for those residing at the State Hospital. Different levels of assessed risk among patients dictated the amount of time patients could spend in their own rooms, when they took time outside the ward, and whether or not they were allowed to attend therapies. Some patients' bedroom doors were locked at night, which meant they had to ring a bell to use the bathroom and be accompanied by a nurse. Others had open doors, which was described as a privilege that had to be earned. However, one participant said he preferred to have a locked door at night, as he felt safer that way - "there's too many lunatics running about". Having access to the hospital grounds was a privilege that could be taken away if, for example, patients tested positive for drugs – "I've had fresh air twice in the past month because I proved positive for drugs". Participants at the State Hospital objected to the close monitoring of all phone calls and letters, claiming this was not necessary and should be used with discretion not applied across all patients.

#### Occupation in hospital

3.61 For the most part, days in psychiatric hospitals were spent watching TV and smoking with long periods in between of doing nothing. Participants repeatedly said there was nothing to do in hospital, or rather that there was plenty of time to do

nothing. One of the younger participants likened life on the IPCU to a "retirement home". Several others said days at the hospital were boring and monotonous:

"I just started to knit and just sat and done my knitting and I taught everybody and before you knew it half the ward was knitting and it kept the ward quiet, so you wasn't getting trouble. There is absolutely nothing, you are put in these hospitals and there is absolutely nothing to amuse you."

3.62 Recreational and leisure activities were generally of a standard variety. Typically this involved watching TV or playing DVDs, using the multi-gym, playing pool or other games in the games room, and playing computer games. Service users said the recreational or leisure facilities in many hospitals were extremely limited. A few people had enjoyed reading and playing music in their bedrooms. There was a distinct lack of personalisation in what was on offer during the day:

"It's also very, very monotonous, there's nothing much to do here and it's nothing that I can really focus on doing. Like I'm an artist and if I had a drawing board or some proper materials to work with, and I could continue doing art and sketch people's portraits but at the moment I'm using printer paper and I only have biro pens to draw with."

- 3.63 Several participants highlighted the impact staffing levels had on the availability and range of leisure activities on offer in hospital, particularly in terms of accessing recreation rooms, and going out of the hospital. Although some IPCUs were said to have well equipped recreation rooms, opening times were typically restricted to 2-3 hours per day, and did not open at all when there were staff shortages. Although some argued they would have benefited from having something structured to do during the day, there was little to do outside of set periods of occupational therapy, which due to resources was not available on all wards. Art sessions provided by OTs were a welcome diversion for some who discovered or refreshed their artistic talent, but did not suit all "not my scene at all". When contrasting the pros and cons of different hospitals, participants spoke positively about having open access to an art room or a quiet room where they could go to read, draw or paint. Some also valued the time they had been able to walk in the hospital grounds.
- 3.64 Participants relied on and appreciated family and friends bringing in books, magazines, jigsaws, crossword puzzles etc, which supplemented the usually limited library and other resources within most hospitals. Although some had found it hard to concentrate or focus on anything, at a certain stage of recovery, some participants said they had found reading and other leisure pursuits to be therapeutic. At the State Hospital, participants ordered books and music from the Internet via the hospital's intranet site.

## Hospital staff

3.65 As conditions and facilities differed, so too did the quality of the staff support, which varied not only between hospitals, but also between shifts and individual staff

members. Participants acknowledged that their perceptions of staff were affected by their mental health at the time, recognising that they and other patients had "not been easy" to interact with. All the same, in most people's experience, there were nurses and doctors who built better relationships with patients than others. As one participant commented:

"I always went to him, he was just helpful and pleasant...his manners were top class, he didn't talk down to you...just a friendly quy."

3.66 One participant at the State Hospital thought it inevitable that not all patients and staff would get on, and that although some staff had an "unhelpful attitude" towards patients that was at times experienced as provocative, others were supportive. Some participants felt that some hospital staff treated patients in a patronising or childish way, often imposing what seemed to them petty restrictions. Rather than being supportive, some service users argued the primary goal of staff was containment:

"My body started going into spasm, my arms and my neck and it was uncontrollable and it was quite scary because it's never happened to me before. A nurse kind of ushered me into my room; shut the door and left me...Nobody came back to say `are you okay?'...Nobody seemed to take note of that or mention it again."

3.67 In contrast, nurses could have a "life changing" impact on patients and their recovery. These nurses were said to have a good understanding of people, were enthusiastic about activities, and responded flexibly to individual circumstances and, as in the example below, seemed to go out of their way to help:

"I wasn't allowed to have razors on my own so one nurse had to come with me and supervise my shaving. He noticed that my shaving technique was wrong and was causing me all sorts of shaving cuts so he actually taught me how to shave. To me that was pretty decent...."

- 3.68 One participant spoke about nurses who were "real people" in the sense that they had the capacity to take the time to listen and to be of benefit to patients. Another epitomised the difference between nursing staff by dividing them into "the A team and the B team". Some argued that younger and more idealistic nurses were more encouraging and interested in responding in a more personalised way to individual need, while more experienced nurses tended to be cynical as they had "seen it all before". The biggest issue highlighted by service users in relation to hospital staff was that they were inconsistent. Even the same individual nurse could suddenly change from being helpful to imposing strict rules. Shift changes could signify a drastic change in patient treatment and could bring about a change in the ambience of the entire ward:
- 3.69 Blame for some of the issues with staff attitudes was laid at the door of inadequate resources. Due to staff shortages, they were often unavailable to spend time on a one-to-one basis with patients. Others commented that nurses were always busy completing paperwork. As one participant testified, "they always tell

you to 'wait a minute we're busy, we're short staffed". Nursing staff were further limited by the system in which they operated according to one service user:

"A lot of the nurses recognise that drug therapy is not the be all and end all, and a lot have studied other therapies but don't get the chance to use them because of this top heavy dogmatic psychiatric approach that seems to be current right across the world really."

3.70 A few participants spoke about their experience of violence and abuse at the hands of nursing staff. This was perceived in relation to unwanted "forceful interventions", for example, being forced to have an injection while being held down. Or actual bodily harm caused by direct violence as one participant said, "getting a beating from staff". This was an issue mentioned in relation to different individual hospitals. Often the person was referring to an historical incident, where the full circumstances were now unclear, but others referred to more recent incidents that had occurred in the past 2-3 years.

### Other patients

"Well one day I'm living by myself and then you're in a ward with 6 people all from different backgrounds and you don't know anybody, and you're sharing a toilet, and it's just that hospitals are horrible no matter where you go."

3.71 The above quotation was typical of what many participants said in relation to their overall feelings about periods of compulsory detention. Some stressed how unsafe these environments can seem, and that other patients could be highly unpredictable or volatile. Their accounts highlight issues of violence, sexual, physical and racial abuse among patients in some hospitals. Several participants commented on what they perceived as an unhealthy mix of patients with serious mental health problems with others who they perceived to be criminals and/or patients with serious drug and alcohol problems. On this theme, one participant commented:

"It was a pure nightmare. You get people with a nervous breakdown but you get real 'crackers' and they're stealing all your stuff and they're throwing chairs at you, it's awful."

3.72 Violent attacks by other patients appeared to be endemic in some hospitals, and upsetting to service users was that these seemed to be regarded by some staff as part of the 'culture of mental health hospitals', meaning they were tolerated and did not appear to be dealt with appropriately. One participant on a locked ward had experienced having chairs thrown at him by another patient for no apparent reason, and staff did nothing to stop it:

"I kept on getting attacked by this person in the locked ward and I hadn't attacked him or said anything bad about him. There was a very small smoking room in the locked ward...so that was probably winding him up more and more and he was already throwing ashtrays at me

and being just basically obnoxious. The nurses just sort of thought `well these things happen in the mental hospital'."

3.73 It was suggested by another participant that nursing staff similarly tolerated racial abuse between patients:

"It was quite evident in Glasgow, such common terms as `black bastard' `nigger' would be common place in daily confrontations as well as physical assault, at times quite violent physical assault. It made me very insecure...A blind eye was taken and in fact on one occasion where there was quite clear racial intimidation present, a nurse said `not in here, take that outside, sort yourselves out outside'."

3.74 Several women spoke of experiences of sexual harassment on mixed wards, but also on wards that had separate men and women's rooms/bays:

"Sometimes you get the males wandering up and just hanging outside your door tapping and knocking on your door and you're trying to relax."

3.75 In contrast, the experience of living with other patients had had positive aspects for a few service users who referred to friendships developed while in hospital, and a growing sense of camaraderie among patients. Others said that that they had gained most insight about their situation and mental health problems from talking to other patients. For one participant, being in hospital was about "building a community", which she still valued. Some friendships formed while in hospital had continued beyond compulsory care, and as the following quotation illustrates, were clearly an important component of people's recovery:

"The good things are meeting people that have got mental health problems. I've made a few friends...and we'll all meet up now and again sometimes here or at P's flat, and it's good because you can relate with each other and you're going through the same experiences."

#### Hospital discharge and aftercare

3.76 On the whole, the picture to emerge from service users' experiences of being discharged from hospital-based compulsory care was one of poor planning and lack of service user and carer involvement, especially for those leaving acute wards. It has to be said however, that this was what a few people wanted, that is, they wanted to leave hospital and to pick up their lives where they had left off with minimal or no interference. For others leaving hospital at the end of compulsory care and treatment was experienced as an abrupt end, with no services put in place to support and maintain their recovery. It was said to be a "daunting experience" to be told, "you're free to go", especially after spending several months in a hospital setting. Some participants felt that assumptions had been made about the capacity of their relatives and other carers to assume or resume care once they left hospital, particularly when the carers had been regular visitors to the hospital. This did not

necessarily ensure that carers received advice or information about how to care for someone after a period of acute illness.

3.77 In contrast, some cited more positive experiences of hospital discharge planning and aftercare services. For instance, one young participant was involved in a phased return to the community, spending a few nights in his new community flat before going out permanently. Others mentioned receiving support from social workers, Community Psychiatric Nurses (CPNs), and their consultant psychiatrist with practical matters such as obtaining appropriate levels of disability benefits, and securing appropriate accommodation in the community – "they didn't discharge me until I got a place to live". Although there had been active discharge planning and it had eventually resulted in a good outcome, another participant felt his return to the community had been rushed, which illustrates the anxiety and uncertainty that can surround returning to the community:

"I wasn't ready for it because they kept putting me off. I was getting told it might be this week and getting my hopes built up...And then I gets the meeting come along, and I had a week to get everything from one area to here and get my stuff out of the hospital. So it cost me a fortune in taxis and buses...It turned out for the best in the end."

3.78 Those whose compulsory order was being transferred to a community-based order often reported involvement in their care planning. They tended to have been introduced to their community support team before leaving hospital, and had visited day hospitals etc if this was to be part of their care plan. Those moving from the State Hospital, were aware of, and actively involved in planning their hospital discharge, usually focused on moving to a medium secure setting rather than to community settings. The main frustration for these participants however was what they described as a rather slow, and overly cautious, process. For some, this had resulted in being held at the State Hospital far beyond the end of their original prison sentence.

#### Community-based compulsory care

- 3.79 The vast majority of those interviewed who were understood to be on community-based CTOs, had experienced conversion of an existing hospital-based CTO rather than being placed directly onto a community-based order. This included some individuals who had been voluntary hospital patients, were then under a hospital CTO, moving to a community-based CTO. Some had been in hospital 6 months prior to the community-based order, while others had only been in hospital a matter of weeks when the order had been varied. Amongst those under community-based orders were some individuals who were required to live in nursing or residential homes or in supported accommodation, as well as some who returned to previous community housing.
- 3.80 Given that those under community-based orders were interviewed during the early stages of implementation of this new provision, it was not surprising that they were somewhat hesitant to offer their opinions. They did fall into two camps however: those who considered community-based compulsion to be a "draconian"

measure" and those for whom it provided a comforting "safety net" as, for example, for one young man:

"I think the psychiatrist would probably think `well he's on a CTO, he's complaining of extreme depression and he can't look after himself currently'. So they're more likely to say, 'well we'll bring him in'...It keeps me within the system and maybe being compelled to stay with it has benefited me because it made me sort of get into a habit of taking my prescription drugs as opposed to being mentally ill. "

- 3.81 In principle, the idea of providing compulsory treatment in the community was welcomed by a few, particularly when their experiences of compulsory care in hospital had been mostly negative. It did not necessarily negate the stigma felt by some of those subject to compulsion. Even those who did not have direct experience of community-based compulsion envisaged that it had the potential to offer more individually tailored care packages than treating people in hospital. It also had potential to be more 'family friendly'. As one person reflected, "It's a huge step forward", adding that it had been "cruel" to be taken away from her 3 year old child. Nevertheless, while community-based CTOs were indeed preferable to being treated in hospital, they were still "not preferable to being allowed to live a normal life".
- 3.82 In practice, indications were that community-based orders were limited in scope, and mainly amounted to medication orders. Service users had been disappointed with this, as they had understood it would mean access to a more comprehensive care package. Often it consisted of no more than a CPN making regular visits to check compliance with medication regimes. One woman was clearly disappointed with the reality: She only received irregular visits from her CPN and the social worker visits had been stopped early on into the community order.
- 3.83 Although most of those interviewed in the community, who were understood to be under community-based CTOs, were complying with their treatment orders, this was still under sufferance, and in disagreement with professionals' assessment of the risks. The intrusion into people's ordinary lives was sometimes deeply resented:

"Just basically restricting because I've got to keep to rules and regulations under it...I normally like to do things at my leisure...I don't like emotional threat of `you'll be re-called into hospital if you don't"

"I want my own private life back, I don't want people coming to my house like a bunch of Mormons and saying `oh you've got to do this today, you've got to do that today'...It's like me and the girlfriend that I've got just now if we have the chance of a child and that, they're going to come in and probably going to take the child off us cause they'll turn around and say `oh by your records you never done this, you never done that'."

3.84 The positive aspect of being under a community-based CTO mentioned earlier, was that it facilitated access to some services, especially admission to hospital when needed. One individual who was under a community-based order

appreciated the ease with which he had been admitted to hospital during a recent crisis after speaking to his CPN. He considered this to be a massive improvement on the previous system. This sentiment was echoed by another participant from a different area who said, "it's been a good safety net if I have to go back into hospital". The only downfall was that the community-based CTO might end after 6 to 12 months, thus ending the safety net for someone who was bi-polar and may experience fluctuations in their health that were outside this timeframe.

### **Box 3.2: Contrasting Views of Community-Based Orders**

Peter is in his late 20s and lives alone in the community with the support of his family. He has had hospital orders renewed several times, and has been in and out of hospital for not complying with his drug treatment. He really didn't consider himself to be ill enough to need treatment. However, he has had a hospital order converted to a community-based order and is now happy to comply with his care and treatment. Peter was also on the CPA, and saw various professionals regularly. He was clear that the purpose of the community CTO was to ensure he took his medication, although he wanted to come off this eventually and get back to work. Eight months after the first research interview, Peter was discharged from compulsory care and had started a college course.

Jim on the other hand is not happy to be under any type of compulsory order, whether or not this is in the community. Jim is in his 40s and has a long history of psychiatric hospital admissions including time spent in an IPCU. At the start of the research, Jim was on a community-based order but this was converted back to a hospital order when things didn't work out. He was unhappy and appealing the decision to keep him under compulsion. Jim wasn't happy with the surveillance in the community imposed by the community-based CTO and wanted his freedom back and to be left alone to live his life on his terms. About 6 months later, Jim was back living in the community under a suspended hospital order and continued to be unhappy with his treatment.

#### **Care and Treatment**

3.85 In most people's experience, care and treatment under compulsion tended to equate with drug therapies, especially in the case of hospital-based compulsory care, and was less focused on non-clinical, social, psychological and other support required for supporting recovery and enabling a good quality of life. Those who were dissatisfied with their care and treatment wanted a more holistic assessment of their needs and the support they needed for recovery. Few had access to psychological therapies or counselling and, as will be discussed later in relation to addressing wellbeing and social agendas, support for employment was rarely, if ever, addressed in individuals' care plans.

3.86 Not only were service users dissatisfied with care and treatment plans because they were limited in many cases to drug therapies, they were also unhappy when psychiatrists applied blanket treatments to certain diagnoses, especially when diagnoses could change in the future:

"I've asked what the side effects are and nobody will tell me...The pills are upsetting the whole system, making you really ill but no, its 'take these pills because you've got this mental illness and everybody who's got this mental illness has to have this pill'."

3.87 Despite recognising some benefits from drug therapies, or at least that the drugs they were taking did them no harm, a common complaint concerned the catalogue of negative side effects often experienced from some of the more commonly used drugs. In many cases, the potential side effects had not been explained to the individual beforehand, and when they did experience them it felt as if no one was listening to their concerns. As one person said, "nothing seems to be getting done" when they complained, even when, as another participant said, such side effects were "horrific". This is a similar finding to that of Rose et al (1998), who found that service users frequently felt they were over-medicated and were distressed by the side effects, despite recognising some benefits. Side effects included being excessively tired and lethargic, which as this account vividly illustrates, can have a major impact on quality of life:

"I'll get up in the morning, have my breakfast, take my pills, go to my bed an hour and a half after taking the pills for a lie down...and I have a doze. Lunchtime, about an hour after lunchtime, have another doze, that takes me through to about 3 or 4 o'clock in the afternoon, go out to the shop, have tea, have another doze then finally go to bed at half past 11 at night...It's no much of a life really."

3.88 Others serious side effects experienced from anti-psychotic and other drugs were serious weight gain, headaches, cramps, shaking, dizzy spells, hallucinations, suicidal thoughts and sexual impotence. One person described himself as "a drooling cabbage", and another related how the Depot injections he was on "tends to cloud my brain up". Another described "a mad rush that goes to my head" after his fortnightly Depot injection, which made him take to his bed for 2-3 days for the full side effects to wear off. Several people referred to unwanted weight gain, which caused depression and affected their ability to participate in leisure pursuits previously enjoyed such as hill walking. The unknown effects of the medication on hormones and the reproductive system were also of concern for young men and women.

3.89 Some had never received a satisfactory diagnosis and were perturbed by the use of powerful drugs to treat something that had not yet been diagnosed. One participant had been prescribed drugs to treat schizophrenia during a short stay in hospital for a condition that had never been explained to her. At the time, the drugs had serious side effects, which had caused her distress. She understood her illness was a one-off episode in her life brought on by stress:

"You kind of think, 'oh I'm taking tablets for schizophrenia' and you know that you're not schizophrenic, your family know that you're not schizophrenic but I know that's just what they call the type of tablet I'm on."

- 3.90 Another levelled a serious accusation at psychiatrists because as she understood (supported by her husband) she had never received a satisfactory diagnosis and had been put on "strange drugs" that made her feel "zombified". In contrast, a participant from the State Hospital who had received a diagnosis while there commented, "at least I know what it is", and that as a result he had been able to extract something positive from support he had received from staff about coping with his mental illness.
- 3.91 Various accounts were given of changes in medication and of finding options that worked better for them as an individual. Participants had mixed experiences of being involved in the decision to stop, to increase/decrease or change their drugs. A change of medication or treatment had been negotiated in partnership with some psychiatrists, reflecting the movement towards there being a dialogue between clinicians and their patients emphasised by the Concordance approach that has been favoured since the mid 1990s. However others' experience indicated that a more traditional or paternalist emphasis on gaining compliance persisted. Many felt powerless to influence their treatment even when they had highlighted detrimental side effects. The following quotations illustrates a positive experience:

"The psychiatrist listened to what I had to say, not straight away but after I complained about it a few times then she decided to change my medication, see if it would make me feel any better and it did. It took a few months to try a few other things and get the right medication."

## Care plans

3.92 The MHCT Act says that the MHO must prepare a care plan to accompany the application for compulsion, which should set out the person's needs for care and how the planned treatment will meet these needs (Patrick, 2006). The Code of Practice indicates that this plan should be drawn up in collaboration not only with other relevant services, but also with services users' and carers' views in mind. Further there is an expectation that the process will be participatory and inclusive. In theory, it is assumed that an individual assessment of needs has been carried out in a holistic way, involving the multi-disciplinary team, whereas in practice, this was rarely the case. The only participants who were affirmative about having a care plan were those who were also under the CPA. Typically, participants said, "I think I've got one but I've never seen it". One said:

"I know I've got a care plan but I don't know what's in it. I see my RMO writing in it all the time but nobody has actually sat down with me like my key worker and told me what's in it."

3.93 Participants did not always know what a care plan was, let alone have a copy, apart that is, from those who were reviewed under the CPA. Care plans were a professionally driven concept and not one that service users related to all that easily. In some participants' experience, they were something that professionals used and owned to record patients'/clients' deficits, issues in their lives that should be addressed such as having problems with budgeting, and where they detailed the services they thought the person should be getting. On a positive note, in some people's experience, they could be used to provide a handy checklist to remember

what should be happening, and could be used in reviews and CPA meetings for this purpose.

3.94 Not everyone was dissatisfied with the services and support they had been offered, and so it follows were not unhappy with their care plan. There did not, however, seem to be much experience of MHOs drafting care plans with service users and other professionals, but rather more mention was made of individual plans referred to as 'care plans' that were drawn up with key nurses whilst in hospital. Their experience suggests little involvement of service users in drawing up care plans, as this response epitomises:

"I had to ask the social worker about the care plan and he said, 'I'm very sorry because I should have given you one a long time ago and haven't', and then he made one up and put it in the post to me. There probably was a care plan in the hospital. I was never asked to contribute to it."

3.95 At case reviews, CPA and other meetings, participants were aware of those involved in their care and treatment discussing broad aspects of their needs, but the basic finding was that in general, service users did not take ownership of, or feel a real sense of involvement in their care plans. However, one service user who had learning difficulties had been closely involved, alongside his advocacy worker, in discussions regarding his essential lifestyle plan and viewed this positively.

### **Users' Views on Professional Help**

3.96 Service users identified a wide range of professionals, including voluntary sector workers such as specialist counsellors (alcohol, bereavement), alongside advocates and befrienders who had been helpful to them and had supported them in their recovery. Overall, professionals were thought to have been helpful to service users when they:

- Were on their side or had at least listened to service users' point of view;
- Were approachable and flexible;
- Took the time to get to know service users properly;
- Gave information about and the potential side effects of drug treatments
- Were prepared to listen to service users' concerns about adverse side effects of drugs;
- Provided practical help for example, with benefits or housing issues;
- Provided emotional and social support and enabled people to have a better quality of life;
- When they advised on coping strategies and focused on recovery.

3.97 On the other hand, service users felt dissatisfied when professionals did not seem to listen to them and/or did not take time to get to know them and their individual needs. They felt let down by professionals who did not follow through with action, or when they were seen as being inconsistent. They felt patronised by professionals who acted as though they knew best with little or no regard for service users' opinions. Participants' perceptions of professionals such as MHOs and RMOs, was adversely affected by their roles in the process of compulsory care and

treatment. Nevertheless, how well they included and how they treated service users during the process played a significant part in service users' perception of them. What follows is a summary of service users' views on specific professional groups, which explores these issues further.

# Community Psychiatric Nurses (CPN)

3.98 While mainly positive, some had had mixed experience of CPNs. Service users spoke highly of CPNs who acted as a kind of "bridge" with the rest of the clinical team. They valued the social and practical support provided by CPNs including helping to complete benefit forms, sort out debts, and to engage in social activities. However, their input was sometimes perceived more negatively as mainly being about control: the CPN was there to check on compliance with medication as part of a community-based CTO. When in this role, CPNs were more likely to be considered as intruding in people's private lives, and not to be assisting their recovery. Some had difficult relationships with their CPN – "I really struggled with her, she felt uncomfy", while another had felt that their CPN was argumentative. One young woman returning to the community had been unable to access CPN services because the local team could not meet her preference for a female CPN.

## Mental Health Officers (MHO)

3.99 MHOs role is essentially dualistic, orientated to control as well as to the coordination of care. That service users expressed ambivalence about their MHOs is therefore not surprising. Participants were largely undecided as to whether the MHO had been particularly helpful to them or not. In their role as the coordinator of doctors' reports and other paperwork to the Tribunal supporting a case for compulsion, MHOs were often perceived as 'the enemy' or at least as being in cahoots with the psychiatrists, especially when the service user disagreed with the psychiatric assessment. The ambivalence felt by many service users in relation to the MHO was expressed as:

"He was my first point of contact but when it came to the Tribunal he was the on the side of the psychiatrist. So he had two hats and you never knew who you were dealing with. Were you dealing with a social worker who was there to help you or were you dealing with the guys who were trying to have you sectioned?"

3.100 Some service users were distrustful of their MHO, perceiving them to be "ineffectual". Others expressed strong negative feelings about the way MHOs operated, and at how little time they spent understanding the situation from the service users' perspective:

"If the psychiatrist wants to section you and he sends for this wee Mental Health Officer and she comes out and says 'sectioned'. She doesn't say 'who are you, where did you come from, what is your problem?' Not a thing, just 'I agree with the doctor'."

3.101 When MHOs were acting in their role as social worker, they were perceived by service users to have been helpful to them, for instance, supporting applications

for disability living allowance, helping find suitable housing, dealing with debt problems etc. In this role, they could be "responsive and really listen". Some expected MHOs to act as advocates, helping service users navigate the process of compulsory care, and ensuring they were aware of their rights, providing advice on such matters as accessing lawyers and/or independent advocacy, appointing a named person, and describing the process of the Tribunal. A few had experience of MHOs visiting them in hospital to ensure they were getting the right treatment. One participant described how his MHO had challenged a psychiatrist's decision to grant or continue a CTO because the MHO believed this was not in the person's best interest, and thus in the service user's eyes had gone from adversary to ally. This particular service user had since developed a strong friendship with his MHO, who he described as very supportive to him.

## Psychiatrists/Responsible Medical Officers (RMO)

3.102 The role of psychiatrists as RMOs in determining whether there is a need for compulsion is clearly critical in the MHCT Act. Not surprisingly therefore, they were perceived to wield most power in the process of compulsion, and by many were seen as adversaries. Some described how they did not "see eye to eye" with their psychiatrist, which was coloured by their opinion about whether or not compulsion had been necessary for them. Many others reported good and supportive relationships with their RMO, which had changed and developed over time, even over the course of the research:

"When you interviewed me last time, I hated her but she's been really good since I've got out of hospital. Dr V is on my side, she thinks I should get a chance. She's put in a lot of time to make sure I get a proper chance."

3.103 Several people felt intimidated and over-awed by their RMO. As one said, "I'm afraid of this man", and another that, "He traumatises me". Some said that particular psychiatrists' attitude was "atrocious" or "terrible", that "he acts like he's god". Many reported that psychiatrists spent very little time in determining their mental state and that their decisions sometimes appeared to be based on spurious information and/or extremely brief assessment visits:

"She said, 'we're increasing your compulsory treatment order'. I says 'You're doing what?', and she said 'Yes 7 June' and I said...'I've never even met you and you're telling me I've to get a needle stuck in my backside for another year?' And she said, 'That's the way it is' and went away again..."

3.104 A majority were of the opinion that in their experience, psychiatrists by and large did not listen to their point of view, and service users were often at odds with their psychiatric assessment, sometimes contesting a diagnosis. Some service users criticised the lack of emphasis placed on service users' expertise and understanding:

"It's not easy with the doctor at times because they seem to think they know all the answers and sometimes they don't give you a chance to express yourself."

3.105 The area of greatest contention with psychiatrists was in relation to medication. Protestations about adverse side effects appeared to some service users to be falling on deaf ears. In cases of differences of opinion, psychiatrists had the power to use the prospect of compulsion as a threat. One individual, if given the choice, would rather experience the highs and lows of her manic depression than live the rest of her life "doped" on drugs, but she was afraid to air this opinion with the psychiatrist for fear he would impose a compulsory order for non-compliance. Some said that psychiatrists were not open to looking at alternatives to traditional medicine.

3.106 Despite these views, some had experienced supportive relationships with their psychiatrists, and had been able to talk through their concerns about medication with their RMO, who had been willing to trial different treatment options until one was found that best suited the individual:

"She's a good psychiatrist, she's changed my medication a few times. I've told her that my medication that I was on wasn't working for me and she's changed it about until she got the right combination. Now I'm feeling a lot better than I was."

3.107 It was further suggested that psychiatrists were conservative in their decision making, that they "err on the side of caution". This was argued to be at the core of why there were disagreements between many patients and their psychiatrists. It was however acknowledged that at the root of this were important issues about accountability. Service users also suggested there was collusion between professionals, that sometimes independent psychiatrists felt under pressure to conform:

"He came to do an independent report on us, and he says 'I think your detention is questionable', and that I should be a voluntary patient in a local hospital, that I don't need the security of the State Hospital...He wrote a completely different report saying I should be detained...He says to my lawyer, 'If I back you, the psychiatrists will be wondering what I'm playing at."

## Lawyers/Solicitors

3.108 There was widespread awareness among participants of the right to have a lawyer to represent their interests at a Tribunal. Information about lawyers was passed on by other professionals (MHOs, nurses, advocates etc), and was also to be found on hospital notice boards. Regardless of whether they were aware of this right, some had chosen not to appoint one. Sometimes this was because a compulsory order seemed to them like a foregone conclusion and so there was no point in engaging a lawyer or anyone else for that matter to make their case; or they did not consider they had anything to defend and could not see the need for a lawyer - "I've nothing to hide". The experience of going to a Tribunal hearing without a

lawyer and/or of hearing from other patients about what happens at these hearings, led some people to change their mind and appoint a lawyer. Those who had had a lawyer, were generally satisfied that the lawyer had represented them well and that it had been of benefit to them.

3.109 Some had experienced difficulty in finding a suitably qualified and/or experienced lawyer in their area. This was said to be the case in Dumfries and Galloway for instance. One participant in another area found that not all lawyers had an understanding of mental health needs:

"He didn't think I'm good enough...He thinks I'm a lunatic because I've been in a mental hospital".

3.110 Others suggested some lawyers were only in this area of work for the money and were unscrupulous:

"I changed solicitors because the first one I felt was spinning it out. It was never going up in front of a Tribunal, so I felt he was just after the dosh that he could make from coming here to interview me."

3.111 One problem was that due to the short notice of Tribunals, lawyers did not always turn up to represent their client. Where lawyers were identified as having been helpful, this usually related to successful cases.

## Advocacy workers

- 3.112 Advocacy workers were invariably mentioned alongside lawyers, as having supported service users at Tribunals. They had provided "comfort", helped people relax, had been encouraging to their advocacy partner, and had helped them to participate more fully in the Tribunal process and at other case review meetings. They also were there if necessary to offer explanations and to help people understand what had happened at the Tribunal after the event.
- 3.113 Participants had different opinions about involving professional and volunteer advocates, on the quality of that relationship and the overall effectiveness of advocacy. In situations where advocates were introduced just prior to Tribunals and had not had time to build up a relationship with the individual, there was confusion about who they were and what their role was, as one person's named person comments:

"I thought 'who is the strange man talking to A' and I said 'who are you?' He says 'I'm her Advocate'. We spoke one or two words like and that was the last I ever saw of him. He never turned up at the Tribunal. He was a voluntary chap, you know he wasn't a paid professional like."

3.114 Not all participants had chosen to involve an advocate when offered. Some felt that it was not necessary to have an advocacy worker when they had a lawyer or a named person, even though the named person was there to represent their own perspective on the service user's best interests. Some of those who had had an advocate did not recognise the need for advocacy, whereas others could. It had

been one person's experience that professionals did not value his point of view and "they look right through me". Having an advocate ensured his point of view was put across.

3.115 Those in longer-term advocacy partnerships saw their advocate on a regular basis and found they also helped with practical matters such as helping to find suitable accommodation. One person's advocate visited her regularly at the hospital and "spoke to the doctors about the neglect of my general health". Another was getting help from his advocate to understand the terms of his compulsory order:

"The advocate used to visit about once or twice a week. He'd be in and out helping me and he's researching the paperwork at the moment for this section order...It's pretty good that he's going on a fact finding mission for me."

3.116 A volunteer advocate present at one of the research interviews commented that as such he was there to support and help his advocacy partner to "express what they want". His partner chose not to attend all his review meetings and the advocate attended instead as "a kind of visible conscience". While advocates might be perceived positively, they could also be perceived as not being effective:

"I spoke to somebody from PASS in the past, and I didn't have any result with them. I didn't feel that they were going to make a difference."

## **Wellbeing and Social Development**

3.117 Non-clinical aspects of care and treatment were not receiving as much attention as might be expected given the ethos of the MHCT Act and the thrust of mental health service development towards social inclusion and recovery. In examining the opportunities those subject to compulsion had for leisure, training, education, and employment, we discovered some positive examples but an overall lack of strategic change in addressing these agendas. Also, although the interviews did not specifically focus on people's housing circumstances and views, a number of participants highlighted the significant role of housing in planning for successful discharge and resettlement, and in care in the community. This illustrated that decent standard housing alongside support, or supported accommodation, was a key resource in promoting health and wellbeing, and enabling social inclusion.

# Leisure

3.118 Research participants were involved in varied leisure pursuits and social activities. They were doing this either on their own, or with community or specialist mental health service groups. Some of those living in the community had been encouraged to join but had chosen not to participate in social groups run by voluntary or statutory mental health services, as they valued their independence from organised activities. Others lacked information about what was available in their local community, and remained socially isolated. Significantly, many of the activities the research participants were involved in, were supported by, specialist mental health organisations in the voluntary sector, including mental health

associations, service user groups and clubhouses. These were key sources of social support both in the community and in hospital-based compulsory care. For instance, NSF's *Kaleidoscope* service in Dumfries was frequently cited as an important source of support and offered a range of group leisure activities in the community as well as at the centre itself.

3.119 Particularly motivated individuals pursued their artistic interests independently, or engaged in physical and sports activities such as swimming, cycling and running, while others participated in these activities with support and encouragement from OTs and other paid professionals. Support Workers from voluntary sector organisations and through CMHTs facilitated involvement in some community-based social activities. A support worker from Carr Gomm for instance, had spent time with one person going to the volunteer and community centre to find out what was available locally to suit what they were interested in. In another area, a participant mentioned he had accessed the local community gym on prescription with the support of the mental health services.

3.120 The cost of participating in, and of getting to, leisure pursuits such as horse riding could be prohibitive for some. A contrasting point of view was put by another who had found that with the money he had from disability benefits, he could afford to buy sports equipment and accessed a range of sports facilities, supported by his CPN. Several individuals were motivated to "make my own therapy", and highlighted the importance of integrating physical and other leisure activities in the community into their lives in helping their recovery. For others, getting the motivation to join social activities or even to leave the house could be problematic:

"I used to go to groups but I'm always trying to organise things so that I don't need to go out. It's [social phobia] something I just need to work around as best I can"

3.121 As discussed earlier in regard to hospital compulsion, finding some kind of meaningful occupation while detained in hospital was problematic for many people. At the State Hospital there were many different physical activities including football, badminton, a cycle club and a gym. However, participation in such activities was considered a 'privilege' that had to be earned by, for instance, engaging with group and individual therapies.

#### Training and education

3.122 A variety of computer and other courses had been organised by specialist mental health services, sometimes in conjunction with local mainstream colleges, and some participants had benefited greatly from these. Some had considered them but were anxious about starting courses at mainstream colleges, while they had benefited from courses run through, for example, clubhouses and other mental health voluntary organisations. For some, this had led onto further education at a later stage. Others had experience of joining college courses but had found it difficult to cope and had left. By the time of the second interviews, some were in the process of, or had finished, qualifying courses at local colleges in, for example, welding, education, foreign languages, and social care. Several of the service users were University educated, or had achieved qualifications at Higher level.

## **Employment**

3.123 There was diverse experience of community employment. A number of participants had past experience of employment, and had either lost jobs when they became unwell or were detained in hospital. Some had managed to retain jobs throughout the period of compulsion, and planned to return to work when they were well again. By the time of the second stage interviews, a small number had indeed returned to their jobs. Many had experience of doing voluntary or volunteer work of various kinds, and in general, they were more knowledgeable about voluntary work than paid work opportunities. Professionals involved in their care were more likely to suggest voluntary work opportunities. Although some believed this might lead to paid employment eventually, others were not confident that they would ever be able to return to paid work. Usually this was related to the effects of medication on concentration levels, but there were also self-confidence issues, and the belief that they would be discriminated against by employers. The perceived pressure to enter into employment in light of the recent changes in incapacity benefits nationally was too much for some:

"You get the stigma about it because they're labelling you as mentally ill and a lot of people will not take that responsibility."

"A lot of folk with mental health problems were able to do things but like I say I find right now on my medication I'm stable but I don't think I could handle the added stress of going into full time employment, I'm not fit for that."

"I'm desperate to work. I look at the people every day going to work and think could I do that? And then I think I couldn't do that, I couldn't work at computers because of my eyesight, I couldn't dig ditches like I used to and I'm not good at communicating with people. I just feel in a bit of a rut sometimes."

3.124 Those participants that had expressed an interest in seeking paid employment had rarely received support or encouragement to pursue this from the professionals involved in their care, and they were unaware of what employment support they might access. When support was offered, it often did not meet individual needs or aspirations:

"I need to get work, I need to get proper work and the services I know that are specifically for people with mental health problems tend to put you on placements to ease you back into work and at this point I think, 'oh well I've done enough voluntary work, I just want a job', even though I wonder if I'll manage."

3.125 Participants' knowledge of specialist supported employment services was either low or non-existent. Support for employment was not a feature on most care plans. One young man identified that he needed help with sifting through job vacancies, making applications, and possibly with job interviews. He was not currently receiving any of this type of support, and preferred to continue with a

voluntary position because, although unpaid, it was a challenging position and better than many of the paid positions he could access. Others felt they would benefit from support in and to maintain them in work. One young woman was uncertain whether and how her criminal record would affect her chances of employment and did not know who to turn to about such matters. Others identified difficulties in moving from benefits into work and the need for "some employment guidance". One participant had experienced difficulties with her benefits when she started part-time work, which had not been satisfactorily resolved. This person had been "heartbroken" to give up the job but had been forced to do so because allowances for permitted work had been miscalculated by the Benefits Agency.

3.126 There was little evidence of a strategic approach to supporting employment in most areas, although some mental health teams in Glasgow had begun to work closely with specialist employment services. At the State Hospital, one participant suggested that instead of therapeutic activities, work-based activities would equip people better to enter the world of work once back in the community:

"I think it would be a lot better if it wasn't all going to the gardens or woodwork or craft and design, that you were doing something constructive like learning a trade like brickwork or painting and decorating, mechanic or whatever."

3.127 Those who had successfully entered employment appeared to have done so more or less because they were particularly self-motivated to get a job or they had a good employer, than because they received specific employment support. Some had entered, or intended to enter, positions within family businesses once they left hospital.

# Housing

- 3.128 Some participants at the second interviews spoke about the uncertainties they faced in moving on from hospital and about the impact of delays. A number of participants had positive housing outcomes since the first interview and 2 younger participants had both gained in other aspects of their lives from positive resettlement in the community. Some faced uncertainties in regard to their future accommodation and support arrangements, and they were currently staying in temporary homeless accommodation or supported accommodation. Also, one woman was facing the impact of a divorce on her housing situation, highlighting that people undergoing compulsion may face significant life events that bring additional uncertainties to their living situation.
- 3.129 Others were not happy with their accommodation or related issues for a number of different reasons including that of one person who felt too closely watched and monitored in a supported accommodation service. A refugee who had had mental and physical health problems felt very inappropriately accommodated in high-rise accommodation, which appeared to have exacerbated depression. This household faced uncertainty but were eventually re-housed by a housing association, immediately following the second interview. Security problems related to door entry and to harassment were raised by at least one participant; while others also referred to harassment or the fear of this as being a reason they had wanted a

housing move. Young people described problems with financially managing aspects of their tenancy and in some cases parents or other relatives had assisted.

## **Post-Compulsion Stage**

3.130 Many service users could point to positive steps they had taken towards recovery by the time of the second interview, conducted on average 8 months later, and the interviewers confirmed that there had been observable positive changes in many people. Available information about the type of compulsory order the 39 participants who agreed to be interviewed a second time were under at the time of interview (N=34) found 35% to not be under any compulsory order at Stage 1, which had risen to 58% by the time of the Stage 2 interviews. While another 35% of those interviewed twice were under community-based CTOs at Stage 1, the proportion had decreased slightly to 30% of the sample at Stage 2. Lastly, although 30% had been under hospital-based orders when interviewed at Stage 1, by Stage 2 this proportion had decreased to just 12%. Among those who were under community-based orders at Stage 2 were some who had transferred in the intervening period from hospital-based orders. A number of those who had initially been on community-based CTOs were no longer under any compulsory order, i.e. they were discharged.

3.131 When interviewed a second time, participants spoke clearly about their aspirations for their future. Several looked forward to starting new relationships, or wanted to get married and/or to start families. A few were at a critical point in their relationship, maybe entering divorce or splitting up with their partner, and were anxious how this would turn out as it had implications for where they would live in the future, and for childcare arrangements. Others were looking to take up college places and further their education, take up volunteer opportunities, and some wanted to be in paid employment. Some wanted to go on holiday or to visit friends who were living away, or to go to a football match when they had not been to one for a long time. More than anything many participants just wanted to be well and free of the worst symptoms, to be off powerful medication with its adverse side effects, and to get some sense of normality back into their lives.

# **Summary of Key Points from Service Users' Perspectives**

- Service users perceived Tribunals as an improvement on the old system. For
  most however, they were still perceived as "daunting". Although some described
  hearings as relaxed and inclusive forums, and panel members as approachable
  and fair, others thought of them as adversarial settings, describing their sense of
  hopelessness, and having a fatalistic view of the outcome.
- Many service users had heard about the named person role, they knew they
  could have one but did not fully comprehend what this role entailed, and often
  confused it with advocacy. Service users changed their named person when they
  no longer felt the named person understood their perspective and so was not
  representing service users' interests.
- Advance Statements were something most service users had heard of, but few had made one. By the second interview, the majority understood what they were and 18% had made one; 3 of these after receiving the Scottish Executive information booklet about Advance Statements from the researchers. Individuals

- reflected that they had sometimes been too unwell to absorb such information when it was given.
- Many service users remained unconvinced of the value of Advance Statements, believing there was little point to making one, believing psychiatrists would almost certainly override them. The irony was that when some were well enough to make such a statement, they could not envisage being ill or compulsorily detained again.
- On reflection, over half of the sample of service users (52%) felt that compulsion had been or was the right thing for them at the time. In one person's words, compulsion was a "necessary evil". Not all of these were convinced that hospital detention had been the right thing however, and a substantial proportion of those interviewed (42%), considered compulsion was unnecessary for them.
- Service users were almost universally dissatisfied with hospital-based compulsion. That said, a few said that it was the safest place for them when they were ill. They were dissatisfied with the poor living conditions and facilities in some psychiatric hospitals; being forced to live with others who were seriously unwell and who could be violent; enforced treatment such as having injections while held down; having nothing to do and the boredom of hospital life; and the restrictions of institutional regimes.
- There were those who considered community-based orders to be a "draconian measure", and those for whom it provided a comforting "safety net", ensuring easier access to hospitalisation when required. The general experience indicates that community-based orders were of limited scope, and that they equated mainly with medication orders. There was disappointment that community-based provision had not led to more comprehensive and holistic care packages.
- In most service users' experience, care and treatment under compulsion tended to equate with drug therapies, especially in the case of hospital-based compulsory care, and was less focused on non-clinical, social, psychological and other support required for supporting recovery and enabling a good quality of life. Generally, there was no real sense of service user involvement in care plans.
- Service users were positive about the help they had from professionals when
  they listened to service users; were flexible and responsive to their needs; gave
  information about the potential side effects from drugs and were prepared to
  listen to concerns about adverse side effects; provided practical help with benefits
  and housing; facilitated recovery and worked to improve people's quality of life.
- Service users expressed dissatisfaction with professionals who did not seem to listen to them and/or did not take time to get to know their individual needs. They felt let down by professionals who did not follow through, or when they were inconsistent. They felt patronised by professionals who acted as though they knew best, paying scant regard to service users' viewpoint.
- As with any group, service users had a range of interests and engaged in various leisure pursuits and educational activities, either on their own or with help from community or specialist mental health service groups. Some service users had support workers from voluntary organisations who helped link them into community activities. The cost of leisure activities and/or transport was also prohibitive for some.

 Access to support for voluntary opportunities was more readily available than support for employment. Some people in the sample had been in employment when they came into compulsory care, and had later returned to their jobs. Others were anxious about whether they had the capacity to undertake a full time job, and did not know what options they had. Others expressed a strong desire to find paid work but did not know if specialist support was available to them.

## **CHAPTER FOUR: INFORMAL CARERS' PERSPECTIVES**

#### Introduction

4.1 In this chapter, we use data from both stages of the research to explore findings from the informal carers/relatives (herein referred to as 'carers' or 'carer participants') who participated in the study. First we discuss the research sample, and the range and diversity of caring experiences they represented. We explore carers' experiences of key aspects of the MHCT Act, in particular of the named person role, their experience and views of Mental Health Tribunals and the impact of compulsion on them. We also explore their views about how well their own needs as carers had been assessed, their opinions about how well social and emotional wellbeing was being addressed under the MHCT Act, and their experience of being involved in their relative's care and treatment.

## **Carers Sample**

4.2 At the first stage of the research, 3 focus groups with carer participants were conducted, which also involved paid Carers Coordinators from the NSF and the State Hospital, some of whom were themselves relative carers, and were able to contribute from their wider knowledge of carers/relatives' issues and concerns. In addition, 5 individual carer interviews were conducted (3 face to face and 2 by telephone), mainly in Fife where it proved difficult to coordinate a focus group via carers' organisations. Almost 12 months later at the second stage of the research, carers participated in 4 focus groups, which again involved Carers Coordinators (3). In addition, 5 individual interviews were conducted, (2 face to face and 3 by telephone). Altogether, the research included 33 individual carer participants, 8 participating at both Stage 1 and 2.

Table 4.1: Number and type of carer participant by area

Site/ Area	Stage 1		Stage 2	
	Number	Comment	Number	Comment
Dumfries & Galloway Rural		Focus group - 4 women , 2 men, 1 paid Carer Coordinator (woman)	4	Focus group - 2 women, 1 man, 1 Carer Coordinator (woman)
Fife – Mixed	4	Interviews - 2 men and 2 women	2	Interviews - 1 woman, 1 man
Greater Glasgow – Urban	3	Focus group and interview - all women, 2 were paid Carer Coordinators/ in representative roles	11	Focus group in Glasgow - all women, 1 was also paid Carer Coordinator Focus group North Lanarkshire – 2 women Interviews with 3 individuals – all women
State Hospital	7	Focus group - 4 women and 2 men, 1 Carers Coordinator [woman]	3	Focus group - 1 woman, 1 man, 1 Carer Coordinator (woman)
TOTALS	21	15 women, 6 men	20	17 women, 3 men

## **Experience as Carers**

- Carer participants were all closely involved with relatives with recognised severe and enduring conditions, such as serious depression, manic depression, schizophrenia or dementia, as well as some who had additional and/or complex needs who had experienced compulsion under the MHCT Act. Some also cared for other family members who were seriously ill or disabled. They were carers for a spouse, parent, son, daughter, brother, or sister with severe mental health problems. Among the sample, there were those who were relatively new to this role (a few months), while others described themselves as being carers for 20 years or more. Carers' roles varied in terms of the types of support they provided. experienced significant changes and uncertainties, reflected in periods when their relative was in the community or detained in hospital (including the State Hospital). They often played an active role in monitoring and supporting their relative's wellbeing, at crisis points and in monitoring the impact of interventions and treatment. Across the sample, carers expressed the fears and stress they have faced in coping with emergent episodes and crises in the community, which at times had taken significant toll on their own physical and mental health. Carers mentioned suffering severe depression and being suicidal themselves. Some carers had long standing mental health problems for which they were also receiving variable support.
- 4.4 It is worth highlighting that a carer's experience varies over time and between individuals, and also reflects differences in service approaches and responses. Common scenarios emerged across the first and second rounds of interviews, and we typify these below. The first 3 scenarios were generally the norm for the majority of carers in this study.

## **Box 4.1: Caring Scenarios**

Scenario 1 – Caring in the community - Many carers struggled to sustain their relative in the community and to get help – "it's a struggle to get the help in the community to start with" and "it's a constant struggle trying to care". Often this persisted until a crisis happened and compulsory treatment in hospital was proposed. Professionals involved had not considered a viable or justifiable way forward until then. Carers experienced a sense of relief, that "things will happen now, things will get sorted out" now they're in hospital, despite what were tragic and traumatic contexts. After admission, the initial relief sometimes became an "anticlimax", when support and treatment did not live up to expectations, and their relative became dissatisfied. Hope was eroded and carers/ named persons and the individuals faced huge uncertainty about the future pathway.

**Scenario 2 - Moving on to the community -** When relatives were discharged from hospital, carers experienced relief and hope for the future. Then, they might experience uncertainties surrounding aftercare, particularly where care plans were not clear or clearly communicated. This was often followed by a continuing struggle to obtain access to care in the community. Even where care plans were implemented, the focus may be primarily on maintaining stability through medication and checks on compliance. Carers became frustrated that there was no longer-term vision of recovery and inclusion. Nor did there appear to be the community resources to facilitate this in some areas. Additionally, the care strategy may

variably recognise or address dual or multiple needs, such as addictions. This became especially frustrating for carers of young people, who often became housebound and isolated or socially phobic, and where the future was unclear. Powerlessness and frustration was more intense for carers who felt excluded because they were not the named person. Waiting for a breakthrough appeared to keep carers going, but it many were under significant stress themselves, with serious physical and mental health implications for them.

Scenario 3 - Caring for those in the State Hospital - For those in the State Hospital there was the added dimension that "it's so hard to get out of this place". In this context, the Tribunal system was seen by carers as a force for increasing accountability, initiating reflection on rights, needs, risks, care and levels of compulsion, and opening up individual pathways. Movement towards discharge brought a new dynamic phase and one of intense activity and optimism since the relief of admission and knowledge that the person was now "at least in a safe place". Their experience was typified by a stressful pre-admission stage, an in-between stage of many months or years that was "like fog", and a dynamic discharge stage. These carers were not generally faced with the same ongoing care responsibilities that other carers might face when relatives moved on from hospitals. Usually move on was to a medium secure unit/hospital. Even for the few who were discharged into a community, there was a comprehensive support package put in place that did not expect carers to have direct hands-on involvement. However, many individuals get caught in a cycle of readmission to the State Hospital, and the cycle starts again. For those with additional needs, such as a learning disability, move on might be to specialist establishments, including in England, which had implications for travel costs and time for carers.

**Scenario 4 - Recovery and inclusion -** Positive outcomes were indicated by some carers, and service users, where professionals in hospital or the community, were highly committed to a positive vision that built on a recovery orientation, adopted a personalised, pro-active and holistic approach, and were sensitive and considering of carers views and circumstances. In these cases professionals worked collaboratively with carers and relevant other services sometimes in the voluntary sector to develop creative options for service users. Where this was experienced, carers considered themselves and their relatives as "lucky".

## Named Person Role

4.5 Those treated under the MHCT Act can have a named person to help protect their interests who is entitled to be informed and consulted about aspects of the person's care and to make certain applications. This role has been described as significantly different from that of the 'nearest relative' under the 1984 Act (Patrick, 2006). The majority of carers participating in the research had direct experience in the named person role; only 3 from the State Hospital group did not. Others had experience of having been revoked as named person. Although most had been nominated, some had become the named person by default. Further there were those who had been nominated as named person since initial implementation of the MHCT Act, as well as others who were new to the role.

## Recognition of carers' role

4.6 In some areas, carers felt that as the named person they had better access to information, they were subsequently better informed, and that professionals, including consultant psychiatrists, MHOs and others, listened to them and took their role more seriously. For instance, some carers stated:

"Until we had the compulsory order you really were largely on your own and the information didn't come to you, you had to seek it out and it was hard to come by ... we found that since we had the compulsory order we have found a lot more about what is available, what we're entitled to and had a lot more help"

"At one time when we used to ring up we used to get told 'oh well he's fine, we can't tell you any information', whereas now we do get information relayed back to us so that has been a help."

4.7 Especially in the context of the State Hospital, the introduction of the named person role was perceived as having achieved some positive change for carers, albeit incrementally:

"[The State Hospital] keeps me informed, even if they're raising his medicine or dropping it ... I think we're getting somewhere now, we're starting to get listened to, they're not listening to us all the time but they're starting to listen".

4.8 Being a named person made some carers feel "entitled to challenge the professionals". For some, but not all carers, their experience as a named person was contrasted to that under the previous 1984 Act, when as next of kin they had more limited access to information:

"Before if you were just sort of next of kin then you didn't get as much information, because when my relative is really ill and even when she is really quite well, she doesn't necessarily want stuff discussed with the family, which is fair enough, you've got to respect that. But my argument is...there is certain information you have got to know if you have got to support someone".

4.9 A sense of carers having increased rights in the named person role was however evident beyond Tribunals, for example, carers reported having successfully asserted their right to be present at care programme meetings on the grounds of being the nominated named person under the MHCT Act. A key benefit identified by carers was that the named person role could be reassuring to their relatives and improve communication:

"I think it gives some reassurance to them sometimes...at one point because he was obviously panicking and in quite an anxious state about what was happening and it was a case of you know, 'you're my named person, you go, you tell them"

## Disclosing difficult issues

- 4.10 There is a potential dilemma within the named person role. Although the named person is there to represent the individual's interests, the carer as named person presents their own understanding of events and needs, which is different from advocacy (Patrick, 2006). Some carers however felt that being a named person had increased their confidence to disclose or discuss difficult or uncomfortable issues, for example, in relation to threatened violence/abuse or additional needs, such as alcohol misuse. While previously, even though they recognised that disclosure might be in the best interests of their relative and all concerned, these same carers had been discouraged from doing so. Now as a named person, such action appeared to be legitimised. Carers of those in crisis thus appeared to value the greater certainty about responsibilities, rights and processes associated with compulsory intervention under the MHCT Act, including the rights associated with being a named person.
- 4.11 In other cases however, disclosure was a strategy to prevent or address crisis and did not arise because of the named person role itself. One carer had informed professionals about the extreme damage and physical abuse they had experienced at home at a stage when they could not cope with their relative's behaviour any longer. This preceded the designation of a named person in the family. Acknowledging that there may be a negative reaction, or that it might trigger 'another episode', some named persons still felt they would value an opportunity to meet relevant professionals without their relative present. This indicated that not all carers felt fully empowered in this role.
- 4.12 Carers involved in supporting other carers stressed the need for guidance and even protection for relatives and named persons who have made a disclosure about their relative at Tribunals, particularly as there may be a risk of conflict or indeed of subsequent physical aggression. One Carers Coordinator suggested carers would be better submitting a written report to the Tribunal. However, carers need to be informed about confidentiality rules as they apply to the Tribunal. It is up to the Tribunal (or more accurately the Convenor) whether or not to withhold all or part of a document if it considers that disclosure would cause serious harm to the patient or any other person, and the Convenor must give notice of this intention and an opportunity to make written representations (Patrick, 2006). Comparison was made with children's hearings where not all statements have to be made in the presence of the person.

## Limitations of the role

4.13 From carers' accounts, professionals were inconsistent in the way they informed service users and carers about the role, as well as how they recorded who was the named person, and the extent to which they communicated with named persons. One carer commented that no one had explained the role to her and that her relative just informed her that she had been appointed. Another only learnt about it through a voluntary agency after her son had been detained in hospital and diagnosed with schizophrenia. One carer argued that hospital staff tended to be uncertain about the role and rights of named persons:

"They don't have an understanding. There's a complete lack of education, even though this Act was implemented in 2005...You ask nursing staff who deal with mental health patients what the Mental Health Act says, they will not know, they keep referring to me as 'next of kin' and I'm not next of kin."

4.14 Professionals' uncertainty about the role was identified in situations where carers had become named person by default. It was the perception of one carer that nurses were "intimidated" by the named person role and that getting information about their relative's care in hospital was "like pulling teeth", although this carer expressed general satisfaction with the level of care in the hospital. Two others who were named person by default said that both their status as named person and their entitlement to access information "seemed to be a hazy area", and that staff appeared not to be clear about the role:

"As far as the dispersal of information from the Health Board, they weren't sure what they could tell us and we found ourselves in limbo, when the police were involved we weren't informed ... I think it was because we weren't officially ... a named person at that time because my daughter didn't wish to have a named person."

"I think what happened, some of the nurses didn't know possibly the new regulations. I'm not sure but at one point I phoned back to the Mental Health Officer and I said 'look are we supposed to know this or are we not?' and he said 'you, as an named carer by default, should be able to access that information' - so I was getting crossed lines for a while".

- 4.15 Even as named persons, communication with professionals was not always improved. One carer said that even as the named person, she had learnt from her sister rather than from professionals that her relative was under a compulsory order. This carer was concerned that the hospital claimed they did not know that she was the named person, nor could they access her relative's Advance Statement. Another carer expressed her despair that when she sought information or involvement as the named person, "they kind of look at you as if you're speaking Swahili".
- 4.16 Some carers at the State Hospital indicated that access to information was not standardised, and that this varied from ward to ward, and depended upon staff knowledge and attitude:

"I think, it's made the professionals feel they don't really know what to do with us as named persons ... now they've got to find a place for us, but they're still not sure about what that is".

4.17 Also, although their experience of the named person role varied, there was a feeling amongst carers at the State Hospital that as a carer (not as the named person) there was a sense of being "an outsider". While there were undoubtedly improvements as a result of the named person role, change was a slow and uneven process. Others highlighted how on some wards "it's handed to you on a plate",

while on others "you've got to drag it out of them". In sum, at the State Hospital, carers responded to a question asking whether there are benefits to them from the named persons role, answering – "yes and no".

#### Difference to carers

4.18 Despite many carers feeling positive about being a named person, for others questions remained about the benefits to the broader experience of being a carer. Although some perceived it as affording increased rights to carers, others asserted that current interpretations of the law served to exclude the individual's main day-to-day carer, which was unsupportive to carers. The following examples illustrate this point.

# Box 4.2: Revoking the named person role becomes problematic for carers

A carer whose son had been under compulsion in hospital and then in the community explained that although she had been her son's named person for about 6 months (2 years ago), he had decided he did not want a named person. Previously as a named person she was included in reviews but when this was revoked she was then excluded. She was unhappy with this situation as her son lives with her, and she is the person who is most aware of when he becomes unwell due to not taking medication, which she believes cannot be gauged properly through brief visits from a community psychiatric nurse (CPN).

Another describes herself as the named carer but not the named person. Although her husband is the named person, her son initially nominated his brother, having rejected his parents on account of their instigating the initial Short Term compulsory treatment. This severely limited their knowledge of his care and treatment despite the fact that they were to be the main support for their son when he moves from hospital to the community.

- 4.19 Tension did arise from divergent views held by professionals and carers on the rights to information and representation associated with the authority of the named person role. When one carer wanted to discuss a complaint in regard to their relative, she found that the professionals felt the matter should not be discussed without the permission of the relative. From this carer's perspective, her relative could not "cope with the stress of complaining", and she considered it unfair to subject him to a stressful meeting.
- 4.20 From the perspective of carers, an inherent difficulty in the role was the uncertainty for them arising from the potential that the person could revoke or change their named person, and therefore change their status as a carer overnight. Several carers commented on how easy it was for the named person role to be changed, and usually said that while they recognised the individual's rights, this undermined the role of, and information available to, carers. As one commented:

"It's up to them if they want to change it but you can be totally discarded ... I don't know how that sits because ... you're still the

carer, but you're not going to find anything out unless they tell you themselves. I don't know how you can fix that".

4.21 Although this should not happen under the MHCT Act, one named person recounted how she had not been informed when her relative was released from hospital because he had asked staff not to let her know. The service user had also exercised the right to revoke named person status from one parent to the other without informing either, despite the new named person having limited contact with him. This highlights how potential or actual conflicts of interest between carers and service users could be played out through the named person role. The fact that at any time an individual could change his/her mind about whom they appoint as their named person, was experienced by carers as unsettling as it meant new found rights could be easily eroded.

#### **Mental Health Tribunals**

4.22 Most carers had attended at least one Mental Health Tribunal, and while they generally welcomed the new system, views on its implementation and practice diverged considerably. Views ranged from those who were positive and felt that their views had been listened to and encouraged, to those who felt Tribunals were "an awful waste of time and money". These carers described Tribunals as "horrific", "daunting", un-participative events that served neither service users' nor carers' interests well. Some carers suggested that the Tribunal system was primarily concerned with generating work for lawyers and did not work in the individual's interests. They referred to unscrupulous lawyers actively advertising in some hospitals and encouraging patients to appeal when, in carers' opinion, they were "in no fit state to come out of hospital". Invariably it had been carers' experience that such appeals were turned down.

## Positive experiences

4.23 Some carers thought highly of the Tribunal system, and many saw this new provision as a distinct improvement on the previous Sheriff Court system, although a number of them had not experienced the latter. Comparing their experience with the courts led some carers to emphasise about the old system that:

"It's quite intimidating you know, you feel as if you're actually a criminal, you know, the person's actually done something criminal".

"The court was very much about the legal issues whereas the Tribunal is more about the medical and social. The Tribunal hasn't got the same criminalistic legal stuff around it...It states it's a legal court but its not tarred with the same brush. If you go to the Sheriff Court that's where people go when they commit crimes."

4.24 Negative perceptions of the former sheriff court system were reflected in carers' use of terms such as "archaic" and "frightening" to describe their perceptions of the previous system. One carer said, "I had nightmares about it", and another commented that the difference between the new and the old system was "like day

and night". However, they also objected to language used by some professionals at Tribunals:

"When I did meet with the consultant and I said 'well, you know, my son's complying...I don't like these terms, 'detainment', 'complying'. My son's not a prisoner'. No heart patient, no orthopaedic patient has to comply, or be detained..."

4.25 Many considered the Tribunal process as "fair", and had been "impressed" with panel members' approach. While, by its nature, it was expected to be somewhat intimidating, some carers still felt that both they and their relative had been represented well and that it had been a positive experience overall. It had made all the difference when professionals acted with sensitivity, and with regard to carers' needs as well as those of the individual. Additionally, it had been appreciated when panel members had explained who they were and what would happen at the Tribunal. At some hearings, carers had been encouraged to express their opinions and had felt listened to. Some carers even felt, as one put it, on "an equal footing" with the professionals and panel members, and even in circumstances where not everyone present had grasped the carer's situation, there had been an ally who had understood. For example, one carer told of how the psychiatrist had grasped his parent's situation and recognised that being at home was not viable as it was a strain on his other elderly parent, neither the lawyer nor the advocate understood. Nevertheless, this same carer felt that the hearing had been fair and was in agreement with the panel's decision.

## Communication and information flows

4.26 The quality and amount of information carers received were raised as key issues by carers. Though some were happy with the information they had received and felt involved at every stage, others reported a lack of information prior to Tribunal hearings, and commented that communication with them had been generally been poor. They had experienced problems with the flow of information, such as, when papers for a Tribunal hearing arrived the day before or even on the day of the Tribunal. At the State Hospital, carers experienced Tribunals being arranged and cancelled at short notice on account of "they didn't have enough paperwork." Another State Hospital carer said that on average it took 3 attempts before a hearing was finally held. Commonly, carers at the State Hospital perceived poor communication as "the biggest problem" they faced:

"It's improved slightly under the new Mental Health Act, but it's always been lack of communication. We thought with the new Tribunals that would stop...but it's not working out that way. Sometimes it does, but most times it seems they forget to tell somebody, and quite often it's the named person they forget to tell as well as the lawyers".

4.27 Experiences were variable across the research sample. In one area, several named persons had received good quality information, but one carer had had to fight to be recognised as the named person. When the panel had no record of her as named person, she had shown them a copy of the agreement signed by her relative and by social work. Another, who was a named person for her parent with dementia,

felt she received "too much paperwork" on account of having received both her own and her parent's documents. Even so, she still felt unclear about the reasons why the panel had decided to discontinue the compulsory order and why they had cancelled a second scheduled hearing.

4.28 Some carers felt excluded at times by the dialogue between professionals, including their use of unexplained acronyms and professional jargon. Others complained that information presented in report and discussed at Tribunal could sometimes be incorrect. A State Hospital carer cited an example of a reference that had been made to an historic incident as a clinically significant risk factor, which in their opinion had been unfair to the service user. Carers from other areas reported similar instances, and complained that neither they nor the individual had been able to question it, nor had they been allowed to correct the inaccuracy regarding their relative's past behaviour. They felt it was an important part of their role as named person to ensure that information was accurate and relevant. In contrast, one carer had been invited by the panel to rectify information that was inaccurate:

"(Was requested to) actually submit a report to the Tribunal...That was an opportunity to put right a lot of the things that were factually wrong and that they were basing their assessment on."

4.29 Subsequently, this carer was satisfied that the hearing had been beneficial both for herself as carer and for the person concerned, and that the panel members had clearly listened to their point of view.

## Location, setting and culture

4.30 The physical environment and the location of Tribunal hearings significantly affected how carers felt about them, as well as their potential as forums for effectively engaging carers and service users. Most dissatisfaction was expressed with hearings held on hospital grounds, particularly when the service user no longer resided at the hospital. Two carers described how in one part of their Health Board area, Tribunals were now held in a community centre and both found this to be a good setting, understood to be used because the previous venue in a local hospital had not had sufficient space. However, one point of view was that there should be a choice on offer between hospital and community-based settings. Another carer from this area who had never attended a Tribunal hearing in a hospital setting, reflected on the difference this could make:

"I don't know how happy I would have been if it had been in the hospital, I think you need to get away from that ... I think it would mean, 'it's just the doctors again making a decision', whereas when it's not in the hospital it's something different."

4.31 On the culture of tribunals, although some described them as pleasant, well run forums, with understanding and empowering panels, others said quite the opposite. A carer at the State Hospital for example, commented very positively that there had been "3 wise people" on the Tribunal panel they had attended, whereas another said that on both occasions he had attended hearings at the State Hospital

there were too many security staff, which made for a tense atmosphere. Another carer highlighted that a gender imbalance on the panel could prove inhibiting:

"The last one I went to there was 6 or 7 men all sitting round the table, sort of judges corner you know, and if I hadn't gone with my daughter that day she would have been the only woman there...It was difficult enough for her."

- 4.32 In terms of inclusion, there was a consensus of opinion that carers were encouraged to speak out at Tribunal hearings, that they felt able to do so when they disagreed and that their views were generally considered and/or taken into account. One State Hospital carer commented that the panel members had gone out of their way to make the hearing informal and they had been approachable and easy to talk to. However, it did not seem to be common knowledge that carers and/or named persons could access advocacy. A fundamental issue raised by carers as affecting their participation at Tribunal hearings was the inflexibility of scheduling, as this sometimes had excluded working carers from even being present let alone from participating. As one carer said, "It'll go ahead regardless of whether me as named person can go."
- 4.33 One carer reflected that the experience had been empowering up to the point of the panel decision, which he/she did not agree with. It was seen by carers to make a difference when professionals recognised that the experience was stressful for the service user. One carer related a time when 2 nurses brought her relative, who was a patient at the hospital, to the hearing and made time to speak to and reassure him/her afterwards. Another had this to say about the approach of an independent psychiatrist who had been present at the hearing:

"He was very quiet and nice and trying to be sure X understood and knew what was going on, rather than just this great bit of paperwork".

4.34 It was noted though that it could take time at the Tribunal for the carer/named person to be consulted, largely because "a hierarchy of power and authority" operated, as one carer explained:

"It's the lawyer, psychiatrist, then the lay member who in turn will address the psychiatrist, MHO, the support workers, anybody else who happens to be there, and then they might get to the named person".

#### Tribunal decisions and outcome

4.35 There was mixed opinion about the decisions and outcomes arrived at by Tribunal hearings. While some carers agreed with the decision and supported compulsory care and treatment as the right course of action, others were less convinced that their's or their relative's opinion had been taken into account in arriving at the decision. A particular view expressed was that although as named persons they have more opportunity to express their views under the new system, this did not mean that these views would be acted upon. As one commented, "to be honest, I knew the outcome before even contesting it". Another carer was critical of

hospital-based detention generally and did not believe that individuals should be robbed of their human rights through incarceration in psychiatric hospital.

4.36 One perspective to emerge from carers' experience is that while Tribunal hearings may on the whole be more humanised and participatory, and mostly take place in more normalised settings, just like the previous system under the old Act, they can be associated with structural power imbalance. Further, even when carers felt freer to express their opinions under the MHCT Act, and especially at the Tribunal hearings, they were wary of speaking out, or of "rocking the boat", in case it "comes back" on their relative when that relative was in hospital.

## **Compulsory Care and Treatment**

4.37 The parameters of and what compulsory care and treatment entailed, especially when this was in relation to a community-based CTO, were not always clear to carers. Being detained in hospital under compulsory care was a far clearer concept, although carers did not necessarily understand what their relatives' rights and options were in hospital. Their experience suggests variable access to information and that support, care and treatment under compulsion has varied in sufficiency, quality and appropriateness. Sometimes it felt like the onus was on carers to find out more. Some were critical of the inaccessibility of written communications, which raises issues in relation to those with reading or language difficulties:

"The format of the forms that you get through, the CTO things, the wording is awful, I mean it's just like Chinese really, you've got to sit down and try and work out what it means. I find it's really confusing"

4.38 Some said they had little or no information about the provisions under the MHCT Act, and were sometimes uncertain as to when a period of compulsion had ended, for example, one carer supporting his spouse in the community commented:

"I'm not quite sure whether she's already been taken off it. My understanding is that that is still ongoing."

4.39 In several carers' view, the MHCT Act had brought about greater recognition of carers' rights, and carers of those under compulsion felt an appreciable difference in how well they were listened to. Detention and compulsion under the MHCT Act had increased both carers' and service users' rights and in some cases, their access to services, as the following quotations illustrate:

"There's so many more things kick into place. Your son's/daughter's got more rights, you've got more rights, you've got a right to this and a right to the next thing..."

"I think we've got more help surprisingly because of a compulsory treatment order than whatever we got when it was just the other ordinary way of going into hospital. I think people take the seriousness on-board...I can't complain about the two doctors that I see, they couldn't be doing more to involve me or to keep me up to date."

4.40 However, difficulties were experienced with variance in compulsory orders. When one carer's relative had a hospital CTO varied to a community-based CTO, both she and her relative were unclear about the specific conditions this imposed, and this was not helped by the documentation they received after the Tribunal hearing:

"I personally left that Tribunal sort of thinking, I must get back to the office and look at these wee books to find out now exactly what does that mean that she's now under a CTO in the Community. Does that mean that if she doesn't take her medication, misses her appointments or whatever she can be whipped back into the hospital? That wasn't made clear to me."

4.41 Similarly, carers at the State Hospital highlighted that when professionals referred to numbers to denote the compulsory order (i.e. referring to Sections of the MHCT Act) without elaborating further, this caused confusion for the service user and/or carer, who were uncertain about what this would mean in reality. Some carers also highlighted gaps in information about mental illness and their need for explanation and education (see Box 4.2).

# Box 4.3: Lack of information for carers about what compulsory treatment means

One carer for his partner commented that, "no-one has, if you like, sat down with me and gone over what I should do" as a preventative measure. The best education this carer had had was from a mental health programme on a BBC site and a chance listening to a Radio 4 documentary in which 2 women were interviewed who had had paranoid schizophrenia. A BBC 'help-line' had put him in touch with a national voluntary agency, which had led to contact with the local NSF carers support group. No information was forthcoming from any of the mental health services or professionals involved with the couple.

## Impact of compulsion on carers

- 4.42 Across research areas, there was a broad consensus that even when carers had been wary about compulsory intervention, it was overwhelmingly experienced as "a relief": that is, as a welcome short-term resolution of difficult and painful circumstances. Typically, they stated that, "you know something is going to get sorted out hopefully", and that, "now at least, something might be done". A carer whose parent had been diagnosed with dementia felt relieved when her parent was admitted to hospital under compulsion, because this meant she could now focus on her caring responsibilities towards her other elderly relative.
- 4.43 Compulsion meant that treatment regimes were enforced and closely monitored by services, that someone else other than the carer was "keeping an eye on them". As one carer said:

"She's getting an injection now, which is a huge relief to know that she is at least getting, whether she likes it or not, a level of medication which is keeping her reasonably stable...she wouldn't have got that without the compulsory order."

- 4.44 Nonetheless, despite an apparent sense of relief, carers were understandably concerned when they heard reports of unsatisfactory or poor care and/or physical standards in hospitals from their relatives. In other words, such relief and resolution could be short lived. For example, some carers whose relatives resided at the State Hospital said they were sometimes scared by their relatives' comments, including one whose relative had said to them, "wait till they shut the door".
- 4.45 Another indirect impact of compulsion commented upon by carers was the role reversal that went on within traditional relationships or families when coping or adjusting to caring for someone under compulsion. For instance, a male carer had adjusted to his spouse's condition by learning to cook and undertook more of the household domestic chores than previously.

## Hospital-based compulsion

- 4.46 Hospitals as built environments vary considerably, which was reflected in carers' comments about hospital-based compulsion. Although some were more than satisfied with the hospital care their relative had or was receiving, others highlighted major problems with out-of-date buildings ("like the 19<sup>th</sup> century"), poor communal facilities, shared rooms and mixed sex wards lacking privacy, dirty conditions ("rotted carpets"), concerns over safety and security, and a general lack of activity within hospital settings. In Dumfries and Galloway, despite knowing that a hospital modernisation programme was planned, carers complained about "sheer negligence", concluding that hospital care in this area was generally poor. Additionally, the location of the State Hospital was problematic for carers living in other parts of Scotland. Several described how travelling to and from this hospital took them all day, and that it was also costly. The accommodation and grounds at the State Hospital were in need of modernisation according to some carers and there was known to be a replacement programme in place at the time of the research.
- 4.47 One carer contrasted their female relative's stay in a hospital in England, where she could lock her bedroom door, with the open ward setting at the hospital in Dumfries and Galloway, where she had felt "absolutely terrified" in a ward with men next door and only 2 staff on duty. When the carer complained and asked for a lock to be put on her relative's door, she was refused because "it's not policy". Those whose relatives were in the State Hospital contrasted this with the lack of security they had experienced in previous hospitals, and not having their needs properly assessed and treated. They considered the State Hospital an improvement in this respect.
- 4.48 Carers in Dumfries and Galloway were particularly concerned about the lack of organised activities in the hospital. Access to physical activities and leisure facilities tended to be infrequent. The hospital activity room was said to be inadequate and the computer did not work, although some people accessed books and magazines, listened to music in the conservatory and were able to smoke.

There was limited availability of occupational therapy. Overall, the carer participants consulted did not think patients' needs and preferences were generally considered within needs assessment or care planning processes. Rarely had they, as carers, been consulted when planning care. However, on some wards patients had been helped to engage in activities such as swimming, cycling and art; and in the evening bowling and games were organised. Carers understood that staff appeared to organise these events in their own time. Some of these activities were co-ordinated between the NSF and the ward staff.

## Leaving hospital and aftercare

4.49 Several of the carers had a poor experience of hospital discharge and aftercare planning for their relative, although there were some positive experiences. They had experienced hospital discharge as sudden and frequently unplanned. The process did not routinely involve them as carers or as named person, despite expressing a desire for carers to be more involved. When some had asked to be involved, they were "made to feel that there is something weird about you". The anxiety caused by the experience of poor planning with carers was evident:

"X was very suicidal when he came out. There was no care plan whatever, nobody in place, no crisis number, nobody to phone..."

4.50 In one scenario, the service user simply arrived home with no advance notice, in another, the carer could be informed on the day of discharge that his/her relative would be returning home. One carer was consulted about whether she could care for her relative at home only after it had been decided to discharge them. Her personal circumstances and past relationship with the individual was not taken into account at all. In other circumstances, the responsibility for aftercare arrangements was sometimes left largely to families themselves as the following case examples show (see box 4.3):

## Box 4.4: Responsibility for arranging aftercare left to carers

A carer of an elderly parent with dementia said that they had not seen the care package and were aware that the social worker classed his parent as 'bed blocking', even though the doctor acknowledged that patients did not leave this particular ward "in a hurry". As far as the carer was concerned discharge planning was being left to the family, with the route out being that they would locate a suitable nursing home themselves, following which the social worker would decide because there were few options in the area.

Another family had resolved not to have their relative return home from hospital because from past experience, it soon became unsustainable. However, they were also aware of the lack of suitable accommodation for him to move to, and the lack of any appropriate options being offered by the services. The family therefore, found temporary accommodation "because they've got nowhere to put him within the town - they're talking about places 10-12 miles outside the town where he'd be totally isolated". The carer also commented, "I know they feel he's bed blocking...but it needs to be thought about before they discharge people from hospital to places that are totally unsuitable".

- 4.51 Carers identified important differences in planning for discharge and the involvement and preparation of carers in the context of longer-term hospital stays/discharge, compared with from acute wards. Essentially, in their experience, those leaving acute wards left with little planning or support "you just pack your bags, go home and eventually you go to your GP". In contrast those leaving long-stay wards, experienced better planning and aftercare arrangements.
- 4.52 Those carers who could compare hospital discharge arrangements under the old with that under the MHCT Act, broadly identified signs of improvement, particularly in regard to planning suitable accommodation and support and in terms of involving and informing carers:

"The other times I wasn't really all that much involved when he was in hospital. [This time] I've actually been allowed to speak and say how I feel."

4.53 One carer had been closely involved in planning her relative's rehabilitation, accommodation and support. Initially staff had arranged overnight stays at the new accommodation of increasing duration, and once discharged, the aftercare support package would be reviewed to ensure that it remained appropriate. This approach had reassured her relative, and been beneficial to the carer:

"They seem to have got that into a fine art. They don't seem to rush him into things either. They sit and reassure X before anything happens, as well as [explain] who is going to be involved and how it's going to work out".

4.54 State Hospital carers who had experienced, or were currently involved with, hospital discharge planning process at this hospital tended to describe it in positive terms as a dynamic phase, as "light at the end of the tunnel". The key advocacy role played by MHOs in this process working alongside carers and other professionals was highlighted:

"I have great respect for her [MHO] because she's not taking sides, but she is there for X, and so she's doing the best and listening to the professional people, but also she has listened to my side as well...I actually trust her".

4.55 For service users with more complex needs, options for moving out of the State Hospital were more restrictive given the severe shortage of quality specialist resources in Scotland. Carers highlighted the case of 2 individuals who had eventually moved from the State Hospital to specialist units in England, which had proved challenging for the carers.

#### Community-based compulsion

4.56 Carers were ambivalent about community compulsory care and highlighted differences between the theory and reality. From experience, care *in* the community amounted to care *by* the community, with the main responsibility for care resting with

informal carers. Most agreed that compulsion may be needed in both hospital and community settings, but felt that compulsion in hospital was essential at the crisis stage, because as one carer summed up:

"You don't get anybody looking after you in the community 24/7 so [they] really had to be sectioned [in hospital]".

4.57 From a positive perspective, those who had experience of community-based compulsory care highlighted how their relative had subsequently enjoyed some freedom to choose what they wanted to do, and make their own decisions about daily regimes. Regardless of setting however, compliance with treatment regimes and motivation remained problematic issues. Some service users resented being required to let professionals into their home, and community-based compulsory care did nothing to relieve isolation and boredom. Comparing community- and hospital-based compulsion, the discussion centred on the view that there were less differences than had been expected between these. The following comment was typical:

"To be honest I don't think there's a lot of difference. They still have the same, as I call it, 'hold' over you...to take you back into hospital at any time that they feel is necessary".

- 4.58 Community compulsory care acted as a 'safety net' for carers, who saw some benefit in having professionals, rather than they themselves initiating a return to hospital should there be a crisis. But for the service user, it meant some felt professionals had too much power over them and they resented this. As one carer commented, his/her relative experienced community-based compulsion as "blackmail". The threat of hospitalisation was an undercurrent in the service user's relationship with the CPN and their psychiatrist.
- 4.59 In their experience, support in the community could be variable. Additional or complex needs were often not addressed, although some carers had experience of good community-based day hospitals and support services being available to support their relative. One carer commented:
  - "I just feel it's not care in the community. They're dumped into the community and it's left 'get on with it' and that's it, and then as I said, we've to wait until something (a crisis) happens".
- 4.60 Many carers felt that community-based compulsion did not in fact offer more rights to service users. Although compulsory medication may be essential, carers highlighted the detrimental side effects from some drugs, which impacted negatively on people's quality of life, a factor that did not appear to them to be considered. Additionally, many carers felt that the care provided was not sufficient to meet their relative's needs and some found that care could be lessened without a reassessment of needs.

## **Wellbeing and Social Development**

4.61 In the main, carers suspected that quality of life, recovery and inclusion issues tended to be neglected in respect of compulsory care and treatment. Commonly, they said that their relatives' lives often lacked meaning, fulfilment and opportunities for achievement. Carers expressed a general sense of despair, a feeling that "there's nothing", a sense of hopelessness, that appeared little changed by services:

"There's an acceptance that that's X's life, and they don't realise there can be a future."

4.62 However, it was recognised that in some parts of Scotland there were now local resources dedicated to promoting leisure and volunteering opportunities. One carer whose relative had had opportunities for hill walking, cycling and other outdoor activities whilst in a hospital rehabilitation unit, demonstrates that there is positive practice emphasising inclusion and recovery. She contrasted this with other families' experience:

"I feel as if now I'm off the wheel and I'm getting somewhere and so is he and it's just made such a difference to everybody, it's just great."

- 4.63 Opportunities for employment were understood by carers to be severely limited by the benefits trap, regardless of individuals' qualifications or motivation to work. Some had relatives who had been advised by professionals that they would be unable to work, on account that it would affect their benefits. Employment did not seem to be a realistic option. Few were aware of supported employment services, although a few had relatives receiving such support.
- 4.64 Overall, carers considered that professionals' focus was mainly on containing the illness or crisis, or was on preventing future crises. However, one carer who had relatively low expectations said that the psychiatrist had felt that planning for discharge would consider the individual's housing, work and social situation. The family was pleased that discharge planning would address their relative's wider needs, although they were not too hopeful about this given past experience.

## **Needs Assessment and Support for Carers**

4.65 There was a degree of bemusement among carers when we asked about assessment of their own needs as carers and how these had been addressed. A typical response was:

"Nobody ever approached me for 10-12 years as a parent of somebody with mental illness to give me any advice, or about any help, or who I could see, who I could talk to."

4.66 Most carers had not had their needs assessed in the past, and although this was seen to be changing under the MHCT Act and community care legislation, some remained sceptical that their needs would be addressed, especially if their relative was living in the same household. Carers accounts of their own experience distinguished between types of caring roles, reflecting differences in intensity of

required support. They differentiated between providing care and providing support, affecting whether or not they considered themselves even entitled to an assessment of needs. That some carers may also have, or have had, mental health problems themselves underlined the importance of assessing carers support needs.

4.67 Some carer participants had never heard of carers' right to a needs assessment under community care legislation. Others felt that there was little point in having an assessment anyway as it had little or no influence over obtaining support and therefore they said it was "not worth the paper they're written on". There was a harmony amongst carers that trying to get help and advice for themselves was "an absolute nightmare", or at the least, was an uphill struggle. One carer referred to the futility of getting a carer's needs assessment, arguing:

"Carer's assessments are important but if people know that nothing's going to happen with them why waste 50% of [your resources] having people running about getting forms that aren't going to go anywhere, and then employ another 50 people to count the forms?"

4.68 A common theme was that carers were not well advised or supported at stages when their relative was currently, or was becoming seriously ill, and in some cases, heading towards a crisis/high risk point. Support for carers was usually not forthcoming from professionals except in some cases at hospital discharge and rehabilitation stages. Often it was the voluntary sector and carers support groups in particular who were able to provide the information or advice they needed. Unfortunately these were not available in all areas, and they varied in quality. Carers suggested that voluntary groups often "pick up the pieces". One described a meeting that involved presentations by people who had been diagnosed with schizophrenia. She felt that this was the first time she had gained some appreciation of her relative's condition – "what they are describing as the illness they've encountered, is what I've seen". Such groups also importantly provided mutual support from other carers:

"It's great to talk to people in the same circumstances as yourself because we're the only ones who fully realise what it's like you know."

4.69 Knowing what the options are and about rights was only part of the story. It was turning these into reality and principles into practice that was a huge struggle in their experience. It seemed that carers were "left a lot of the time to get on with it, to bear the brunt of it all", and they had to be "carer, nurse and whatever else". In spite of this, some carers identified supportive relationships they had with individual professionals, in particular with CPNs and MHOs.

## **Carers' Involvement**

4.70 In respect of implementing Principle 7 underpinning the MHCT Act, that 'informal carers should receive the advice and support they need and have their views heard', carers broadly agreed that their needs and entitlement to be consulted and informed were now better considered under the MHCT Act. However, there was also scope for much improvement on this agenda. Across the board, carers agreed in general terms that they were being considered more since the MHCT Act, and

especially as a result of compulsory measures being imposed. As discussed earlier, carers who were named persons felt they were more involved than other carers:

"I think if a carer is just a carer and not the named person, you know what I mean, I think folk are still struggling."

- 4.71 Even so, many remained isolated, struggling with their responsibilities and dissatisfied with their level of involvement on both an individual and collective level. Some did not think their views were considered at all by clinical teams: one carer rated their involvement as "4 out of 10". Carers were not routinely consulted on care plans for those being discharged from hospital. Illustrating the isolation carers often experienced, 2 carers said they had gone "8 years with no help at all thinking we were the only people". Another had been involved with mental health services for 22 years and had had to learn from experience "as you go along".
- 4.72 State Hospital carers were somewhat ambivalent about whether or not there had been any progress. On the one hand, they could identify goodwill on the part of the State Hospital and a desire to listen to carers and their views, the positive appointment of a Carers' Co-ordinator and the establishment of a Carers Centre, increased involvement of carers at case review meetings, and increased representation on individual cases. On the other hand, consultation with carers appeared piecemeal and was at times tokenistic e.g. "picking their token rep as part of a multi-disciplinary group". While a Carers' Reference Group had been established, it was said to be "the few and the brave" who were willing to join. In sum, while carers' involvement at the individual level had increased perceptibly over the years, the collective voice of carers at the State Hospital remained restricted.
- 4.73 Carers identified the constraints on their full participation at the State Hospital. One was the location of the facility and the burden of travel for carers who visit patients and whose priority is to be with their relative or friend. As a result, it tended to be a small pool of committed 'usual suspects' who were involved in consultation. A second constraint on openness with carers was confidentiality. Examples were quoted of situations where there could be a high risk of danger, or other harmful consequences to some individuals, because of the impact of past crimes on particular family members, if such information was shared with carers. Additionally, it was suggested that the reason some people do not want a named person in the family is because they might then learn about all aspects of their personal and formerly private history. It was further suggested that involving carers was felt by staff to somehow betray the patient.
- 4.74 Some carers saw service user involvement to an extent as competing with carer involvement. This emerged in situations where carers felt excluded because their relative opted for confidentiality. Here the carer's perception was that the extent to which their relative was listened to and involved in their care was to the detriment of themselves as carer being informed about what was happening, for example, with treatment, hospital discharge and temporary release and so on.

## Carers' groups

4.75 Beyond the issue of involvement of individual carers through support and care planning, carers also discussed their experience of collective involvement. Broadly, although a range of systems had been established in some areas, in others such mechanisms were not yet in place. In discussing the value of carers' groups, a number of reasons for and benefits for carers were identified, including that they provided the opportunity to discuss and share experiences, although there was some ambivalence expressed. One carer said "it helps to see how others are coping", while another who valued this also said sometimes you "come out feeling worse", and sometimes that "you don't have the energy" to participate in groups. Other benefits included that support groups reduced social isolation, helped people gain access to information, and in fact carers groups were sometimes "the only place you got information". Finally, they helped people seek assistance and gain access to counselling.

4.76 One problem highlighted was the insufficient time and resources available to fund staff to support carers, co-ordinate the input of carers' responses to Scottish Government policy, feed carers views into generic local partnerships and cover the costs of travel to meetings. Most appeared to be funded in part-time posts, and one Coordinator commented that, "I end up picking up the tab myself just so as my one or two carers can get their voices heard...it's basically falling onto the goodwill of the workers themselves."

# **Summary of Key Points from Carers' Perspectives**

- Nearly 30 informal carers of individuals who had experienced compulsory care from the 4 research sites participated in the research, either in focus groups or individual interview. The majority were women ranging in age from 20 to over 60 years. Eight of these carers were involved at both stages of the research.
- Some carers felt that as a named person their role was legitimised and that professionals took them more seriously. Some, but by no means all, also felt that it empowered them when disclosing uncomfortable issues about their relative. However, questions remained about whether this had improved carers experience more broadly, with some claiming it made no difference. Furthermore, because the named person could be changed, increased rights and status could be lost overnight.
- Overall, Tribunals were seen by carers as an improvement, offering greater opportunity for participation and inclusion. However, carers experience had been mixed they either "went very well" or they were "an awful waste of time and money". Problems were highlighted with the flow of information, for instance, not receiving paperwork until the day before or on the day. Professionals were sometimes poor at communicating with carers as well as with service users, using jargon and acronyms, which they didn't always explain.
- There was broad consensus that even when carers had been wary about compulsory intervention, they overwhelmingly experienced it as "a relief", as a

welcome short-term resolution of difficult and painful circumstances. Typically, carers felt that it meant something would now happen and that their relative would receive the care and treatment they needed.

- Although some carers were more than satisfied with the hospital care their relatives had or were receiving, others highlighted problems with out-of-date buildings, poor communal facilities, shared rooms and mixed sex wards lacking privacy, dirty conditions, concerns over safety and security, and a general lack of activity within many hospitals.
- Carers often experienced hospital discharge as sudden and frequently unplanned. The process did not routinely involve them even when they were the named person, despite expressing a desire for more involvement. Those who could compare hospital discharge arrangements with the old Act, broadly identified signs of improvement in both planning and in the inclusion of carers under the MHCT Act.
- Carers were frequently ambivalent about community-based compulsory care, highlighting differences between theory and reality. In their view, care in the community often amounted to care by the community, with the main responsibility for care resting with informal carers. Most carers agreed that compulsion might be needed in both hospital and a community setting, but that in many cases compulsion in hospital was essential at the crisis stage.
- Carers suspected that quality of life, recovery and inclusion issues were neglected in care plans under compulsion. Instead professionals seemed to focus on containing the illness or crisis, and on preventing future crises. Commonly, they said that their relatives' lives lacked meaning, fulfilment and opportunities for achievement. Carers expressed a general sense of despair, a feeling that "there's nothing", a sense of hopelessness, that appeared little changed by services, despite a handful of positive experiences.
- Most carers had not had their needs assessed. Some had never heard of their right to an assessment of needs under community care legislation. Other carers could not see the point, as they did not believe it would not result in getting support. Most carers had turned to the voluntary sector (e.g. NSF) and other carers for the information, advice and support they needed.
- Although there had been improvement in involving carers since the MHCT Act, many carers remained isolated and unsupported, were struggling to cope, and felt dissatisfied with their level of involvement on both an individual and collective level. The collective voice of the carers of those subject to compulsion, especially those from the State Hospital, was still lacking.

# **CHAPTER FIVE: PROFESSIONALS' PERSPECTIVES**

#### Introduction

5.1 Chapter Five now considers the perspectives of a wide range of health, social care, legal, and advocacy professionals working with the MHCT Act. Professionals at national organisational level and at individual practitioner level were interviewed for the study. Their opinions of the implementation and impact of the new legislation on wider mental health service delivery; the difference new systems and ways of working had made to their own role and responsibilities; and the experience of translating the principles of the Act into practice are discussed. Contrasting views on the barriers to implementing new practices and processes, as well as identifying the factors professionals felt supported implementation are examined. Also, professionals' opinions on the interface with other legislation, and how well implementation of the MHCT Act addresses the social and emotional wellbeing agenda are explored. General themes will be drawn out across the whole sample of professionals, distinguishing between opinions of different groups where these were notable.

## Sample of Professionals

5.2 A mix of relevant mental health, legal and advocacy professionals was interviewed for the study. In consultation with the commissioners and the Research Advisory Group, the main professional groups approached included advocacy workers, GPs, lawyers, consultant psychiatrists, psychologists, MHOs and nurses. While a comprehensive range of professional organisations and interest groups was included in the telephone survey (15 interviews), a different mix of professionals was achieved at each of the 4 local research sites. In total, 23 individual practitioners and advocacy workers were interviewed. The mix varied according to availability and willingness of local professionals, as well as whether these interviews could be achieved within the timescale for completing this aspect of the research. Although there was representation from all relevant professional groups, slightly more advocacy workers, MHOs and psychiatrists participated than other professionals. In Dumfries and Galloway, 2 advocacy workers from the same organisation were interviewed jointly; and, in addition, one of these submitted a written statement.

## **An Overview of Impact**

- 5.3 Broadly speaking, the MHCT Act had impacted on all professional groups to some extent, but had impacted most on the role and responsibilities of consultant psychiatrists and MHOs, the nature of which is discussed later on in the chapter. In summary, the main impact for these professionals was around applications for CTOs, Interim Orders, the new appeals process, and servicing and attending Mental Health Tribunals.
- 5.4 As Atkinson et al (2007) recently found, professionals' experience was that the MHCT Act had impacted both on those subject to compulsory measures and, indirectly, on those who were voluntary or informal clients/patients. They expressed concern that other services were being compromised as a result, and that there was a danger of a 2-tier system developing. The general perception however, was that

the MHCT Act had brought about positive developments that had introduced greater accountability to practice, especially around decision-making about hospital detention. As one local psychiatrist stated:

"The criteria that must be met for detention are more detailed. For example the 5 tests in Section 64. This supports your practice and makes reasons for detention more transparent." (Psychiatrist)

5.5 Administrative procedures were perceived as being "more rigorous" and recording requirement as "more stringent". The following quotation from the MWC was typical of other commentators:

"It was too easy to put someone under an emergency order under the old Act without justifying why on paper. The MHCT Act has appropriately made it necessary for medical practitioners to justify and document systematically why someone needs to be deprived of his or her liberty." (MWC)

5.6 An enthusiastic legal exponent of the MHCT Act commented further that:

"The Act has brought in a level of accountability that didn't exist before in the old system... It's a whole different ball game when the Responsible Medical Officer has to sit in front of a tribunal and be exposed to questioning about their diagnosis and care plans..." (The Law Society)

- 5.7 Although generally the Mental Health Tribunal (Tribunal) was a welcome development that many claimed was more inclusive than the old system, it was also widely perceived as making the greatest demands and impacting the most, on professional practice and service delivery. On the downside, new administrative processes associated with the Tribunal system were argued to be resulting in duplication and time consuming demands for several professionals. The Royal College of Psychiatrists identified issues with managing priorities, resources and time, and were of the opinion that Tribunals did not yet have sufficient understanding of community psychiatry. Although the MHCT Act was generally thought of as "a good piece of legislation", it was not uncommon for criticisms to be aired in relation to what professionals perceived as overly bureaucratic systems. The recent study of the early impact of the administration of new compulsory powers under the MHCT Act should be referred to for detailed consideration of this issue (Atkinson et al, 2007).
- 5.8 The impact on service user outcomes, insofar as professionals felt they could comment on this, were perceived in 2 key areas: as increased opportunities for participation and involvement and an emphasis on more person-centred processes; and secondly, success for those appealing against excessive security at the State Hospital. Most professionals were agreed that new systems including the Tribunal, Advance Statements and the named person role, had improved service users' rights and encouraged their input. Some voluntary organisations and advocacy workers were more cautious, perceiving limited gains at this juncture. Although the MHCT Act undoubtedly meant that service users and carers now had more opportunity to

have their say and had greater protection under the new legislation, this did not necessarily translate into greater user control and/or self determination:

"There's a big difference between control and participation. The Act has made it more difficult for professionals in that they have to justify actions more but it doesn't necessarily mean that if comparing desired outcomes for professionals or service users that has changed any. Some experience under the new act have been frustrating and they say 'its not made much difference to me' or 'they might have listened to me more but they don't have to hear me!" (Advocacy Worker)

- 5.9 One voluntary organisation (mental health) commented that had it not been for the MHCT Act, people would still be "trapped" in the State Hospital. MHOs also highlighted the changes achieved for those who had applied against excessive security. According to one participant from the State Hospital, there had been over 25 successful applications for transfer from this hospital since implementation in 2005.
- 5.10 Where outcomes seemed less optimistic was in relation to treatment options and availability of services. For example, availability of psychological therapies was thought to have remained unchanged as a result of the MHCT Act. Community services and resources remained patchy across Scotland. The only enhancement of community options directly related to the MHCT was the provision of community CTOs. Changing the law was recognised by professionals as only one part of a long-term process of changing attitudes and cultures. A programme of service development was needed alongside legislative change. Professionals therefore welcomed the Mental Health Delivery Plan for Scotland and its focus on outcomes including user-led outcomes, alongside a number of performance indicators and crisis standards.

## **Changes in Roles and Responsibilities**

## **Psychiatrists**

- 5.11 As had been anticipated prior to implementation (Atkinson et al, 2002; McCollam et al, 2003; Grant, 2004), the MHCT Act had impacted significantly on MHOs and consultant psychiatrists, although the extent of this depended on their specialism: For instance, the MHCT Act was perceived as having the greatest impact on those in General and General Old Age psychiatry. The workload of psychiatrists had increased overall but, as one psychiatrist highlighted, this had not been entirely unexpected, and there had been a pay award to account for it. Nonetheless, the level of workload increase arising from the Tribunal system had not been entirely anticipated, nor that related to Interim Orders. As the Royal College of Psychiatrists' nominee commented, "we did not see that coming". The impact had been felt in other areas of work for psychiatrists, such as clinics, reviews and other work with the wider mental health population.
- 5.12 There were both positive and negative aspects to changes in the roles and responsibilities of psychiatrists. As the Royal College of Psychiatrists' nominee observed, some aspects of implementation had been better than expected, for

instance, the anticipated increase in appeals against short-term detentions, and concerns about possible increased out of hours work, had not materialised. On the other hand, implementation of the new Interim Orders had reportedly created a far heavier workload than predicted, as had Tribunals.

5.13 Although processes were undoubtedly taking longer than had been expected, the increased joint working and time spent discussing cases with multi-disciplinary colleagues was a positive spin-off:

"In the past, when considering a Section 26, you didn't always arrange to interview the patient with the MHO, whereas now I haven't done a short term detention where the MHO hasn't been with me. Sometimes it's so obviously that someone has to be detained, but where it's not, it's quite useful to have a second and different opinion. It's a different way of working." (Psychiatrist)

5.14 Other professionals, including MHOs, had also positively highlighted this aspect of new working arrangements.

#### Mental Health Officers

5.15 On the one hand, it was perceived that the MHO role had been enhanced under the MHCT Act, and MHOs interviewed reported increased job satisfaction. On the other, MHOs felt frustrated and under pressure mainly from administrative responsibilities associated with applying for a CTO and Tribunals. Despite recognising its value, the legislation in some respects was described as a "nightmare" for MHOs. Practically speaking, applications for CTOs were said to take about 3 times as long to complete and MHOs were responsible for completing three quarters of an online 26-page form:

"There has been a dramatic increase in preparing paperwork, both in terms of the application and the amount of liaison needed, which was done more informally before. The actual physical completion of the form has been quite an issue. It relies on having Adobe 7.0 as some MHOs type straight into the form." (MHO)

5.16 When psychiatrists made late decisions about applying for a CTO, often for good reasons, this created major logistical challenges for MHOs. Although this had been an issue under the old system, it was the extra paperwork now required and the tight timescale for submitting this to Tribunals that was an issue. As McCollam et al (2003) highlighted prior to implementation, the MHCT had workforce implications that needed to be addressed: some MHO teams were thought to be well resourced, but this was not so in all parts of Scotland, and it was further suggested there are fewer MHOs to work with older people and learning disability services. Consequently, some teams felt "swamped" by new demands, and even in well-resourced areas such as Glasgow, MHOs reported feeling under pressure and rushed by new demands. The expectation that MHOs will attend Tribunals to 'defend' their report and deal with questions from legal representatives, proved an added pressure. Linked to this were new responsibilities arising from the process of

appeals against excessive security at the State Hospital (TSH), as one participant explained:

"The increase in forensic work in Glasgow has been dramatic. In this area, between 30-40 patients in TSH who didn't have contact with MHOs before now have to have a designated MHO liaising with them and family, attending reviews and are involved with the transport of that patient" (MHO)

5.17 The introduction of a requirement within the MHCT Act that an MHO from the individual's local area should undertake the assessment and be fully involved in the care and treatment of individuals detained at the State Hospital, was perceived as a welcome element. The MWC argued that continuity of MHO generally, not only at the State Hospital, would lead to better individual outcomes, greater chances of receiving services, and potentially shorter periods of detention and compulsion. MHOs now had to be consulted whenever a compulsory order was extended. However, one MHO reflected, the downside was that their work is now concentrated far more on statutory responsibilities rather than "on doing social work".

# Other professionals

5.18 Those perceived as least affected by the MHCT Act were GPs: their roles and responsibilities remained largely unchanged or as one GP suggested, the impact on them had been "neutral". Thus far, GPs had infrequently been involved in emergency detentions, or acted as an AMP, providing a second medical opinion about the need for a compulsory order. One participant suggested this happened about once a year at most. Although GPs could in theory be asked to attend Tribunals, in practice this was not happening on any scale. The main challenge for them was the need to consult with MHOs when considering emergency detention, particularly when this occurred out of hours. On the whole though, GPs fears about increased workload had not materialised as the BMA nominee commented:

"There was concern that there would be an increase in CTOs and that hasn't happened. Thought there would be more advocates coming in demanding, but this hasn't happened either...I expected patients might be coming in about the Advance Statement prescribed persons list, but that hasn't happened." (BMA)

5.19 The Tribunal introduced new procedures for lawyers who had had to adapt, but, as the Law Society nominee asserted, this had created a "more fulfilling role" for them. Although lawyers' workloads had reportedly increased with Tribunals, so too had their job satisfaction. Lawyers reported being frustrated with the short notice given for many Tribunal hearings, and the challenges for prioritising work and liaising with other professionals that this presented. There was both the suggestion that fewer lawyers were specialising in mental health work under the MHCT Act, and conversely, that it might be attracting the "wrong kind" of lawyer into mental health work given that patients could draw upon legal aid. Indeed, a hospital nurse gave an example of a lawyer "constantly pestering a client" once in the community. One lawyer, who also served as Tribunal convenor said the MHCT Act had transformed

his experience. Lawyers were engaged more with advocacy workers, with whom there was now a much better working relationship.

5.20 Although the role and responsibilities of hospital nurses were supposedly largely unchanged by the MHCT Act, other than increased paperwork and monitoring patients out on pass, CPNs on the other hand felt better supported by new provisions regarding community-based CTOs. Some nurses felt their contribution was now more valued under the MHCT Act, and that Tribunals were keen to hear what they had to say.

## Advocacy services

5.21 The consensus of opinion among professionals was that the MHCT Act had enhanced the role of advocacy support, establishing the right to access advocacy in law. As one advocacy worker asserted, advocacy was now a recognised part of the support structure. Advocacy workers were reportedly more common on hospital wards and supporting patients at Tribunals according to healthcare staff, lawyers and MHOs, and the relationship between advocates and professionals was felt to be changing for the better. Although their involvement did not necessarily change the outcome of a Tribunal, their involvement in the process positively influenced inclusion and participation. SIAA argued the legislation meant that professionals who were not willing to acknowledge the role of independent advocates had less ground for doing so, and were in the minority. The Royal College of Psychiatrists commented:

"Overall advocacy input is productive and in my experience it aids communication and improves the therapeutic relationship....There is generally a better quality of interaction and more can be achieved." (Royal College of Psychiatrists)

5.22 The MHCT Act had raised the profile of advocacy and many professionals commented that the quality of advocates had also improved: For instance, the Law Society asserted:

"Advocates seem to be of a much higher standard and motivation than before - possibly because the role is now recognised in law. They are great as supporters and friend...Very useful role." (Law Society)

- 5.23 The consensus across professional groups was that the intention to ensure advocacy was available to people under the MHCT Act was being implemented. The MWC confirmed there was "good evidence" to show those subject to the Act were getting good access to independent advocacy. Moreover, although in recent years the profile of advocacy and investment in independent advocacy support has received growing policy attention, the MHCT Act itself was perceived to have specifically moved this agenda forward.
- 5.24 Professionals also identified some gaps in accessing advocacy. The practice of prioritising compulsory intervention and supporting people through Tribunals meant those not subject to compulsion faced major barriers to accessing advocacy. As anticipated in consultations prior to implementation (Grant, 2004), and noted

above in respect of the impact on psychiatrists' priorities, this was argued to be detrimental to other demands for advocacy support. Additionally, they identified gaps in services for those with learning disabilities and mental health problems:

"Sometimes we get referrals from professionals who really would like a learning disability advocacy service but because there isn't one they'll come to us and they'll say `well the person has got depression as well' but the real issue is their learning disability...." (Advocacy Worker)

5.25 Overall there was felt to be a better understanding of the role of advocacy. However, some professionals remained confused: for example, a psychiatrist commented on his confusion around whose role it was to speak on behalf of the patient at Tribunal hearings, and a psychologist reportedly finding it hard to separate out the role of advocates from that of lawyers. In contrast, lawyers were strongly in favour of independent advocacy, perceiving advocates as complementary to their own role, and as clearly distinct from the role played by lawyers.

# **Training and Support on MHCT Act**

5.26 Training in the philosophy, principles and details of the MHCT Act prior to implementation had been intensive for key groups such as for psychiatrists and MHOs, whereas for others, it was described as more hit and miss. professional participants spoke highly of Scottish Executive-organised transitional training programmes of 2-5 days prior to implementation: MHOs and psychiatrists in particular had benefited from mandatory training. Others, such as advocacy workers, had had to opt into official training events and/or organise their own group's training. The SIAA had, for example, organised events for advocacy workers across Scotland. Lawyers, who have to work closely with MHCT Act,, remarked that as far as training went, there had been "next to nothing in real terms". There had been role-play, papers in advance and a copy of the Act given to one lawyer. Another said their training on the MHCT Act had been "grossly inadequate", amounting to an hour on the Act organised by the local authority's legal team. Yet another was aware of seminars about the philosophy and basics of the Act about a year before implementation, but that he had been expected to learn through experience. For advocacy workers too there had been a strong self-taught element and an expectation of experiential learning. Those in allied health professions, including psychologists, had had fewer training opportunities than most, although there they had opted into local health board and nationally run events. Though initial training events appeared to focus on specific professional groups, participants were most complimentary about multi-disciplinary events, which provided opportunities to learn about other professionals' roles and to discuss issues from different perspectives.

5.27 Since implementation, there had been a number of conferences organised at both local and national levels. For example, British Association of Social Workers (BASW) MHO Forum organised study days for MHOs, and a Glasgow-based MHO Forum had organised a training day on Tribunals, which had been well received:

# **Box 5.1: Local training for MHOs in Glasgow**

"There were 2 elements - the whole morning was put over to a mock Tribunal involving real Tribunal members and Convenor and had an experienced lawyer who acted as commentator to the process, and would stop it at various points to engage in discussion or comment. This was a really good process. In the afternoon, there was training with the Council's legal section about rules of evidence procedure and working together with the legal section. Subsequently the Council's legal section has been approached by MHOs to discuss issues and they are more likely to appear at the Tribunals on our behalf now."

5.28 Professionals had relied upon a number of learning strategies from attending mandatory training days, specialist conferences and seminars, web based learning, and cascading information to new workers (a strategy used particularly in advocacy organisations). Scottish Executive codes of practice, guidelines, training manuals, annotated versions of the Act, introductory booklets on the MHCT Act, and the Act itself were regularly referred to, as was Hilary Patrick's (2006) book about mental health, incapacity and the law in Scotland. Other resources consulted were professional journals, newsletters and web sites, such as the MWC *Principles into Practice Network* pages. The MWC was used for reference and discussion particularly when there were problematic cases or issues. Professional forums were an important source of support for many, as was informal discussions with colleagues in the multi-disciplinary team, and peers in professional groups:

"I got a call from a more junior psychologist who was going to a tribunal and she didn't know how to prepare for it so she phoned me because we're quite a small profession, word of mouth you find out who to phone about what ..." (Psychologist)

5.29 The need for ongoing and continuous professional development in relation to the MHCT Act was raised, as was the need for regular dialogue around dilemmas with implementing the principles in practice. It was suggested that conferences and other events organised by the MWC's *Principles into Practice Network* would continue to have a key role to play in this.

## Implementing the Principles

- 5.30 The principles of the MHCT Act derived from the work of the Millan Review (2001) formed the strong ethical basis of this legislation. As such, there was tacit agreement among all professional groups that these principles provide a useful framework for good practice. The principles provided the foundation for upholding individuals' rights, and helped clarify statutory responsibilities. The principles were described as embodying or making good practice explicit, although some were felt to be more aspirational.
- 5.31 On one hand, one sceptic suggested that the principles were used during the development of the Act but had less import post-implementation. Contrary to this, there was widespread support among many other professionals for active continuous dialogue about the dilemmas and issues surrounding implementing the principles

into practice. In short professionals expressed their desire to keep the principles alive and to the forefront of practice and service development. The principles informed discussion, were a driver for change, and, it was optimistically suggested, would filter down over the years to the way services are resourced and organised. Many professionals highlighted the MWC's *Principles into Practice Network* as an important forum for all to debate and share ideas about best practice.

### Experience of Implementing the Principles

5.32 It was claimed that implementation of the principles had brought about a positive culture change in terms of detention, despite this happening slowly. There was some optimism that service user participation had improved under the MHCT Act but there were experience and knowledge gaps limiting its further development. Practice in implementing the principle of participation was perceived as highly variable:

"There is some very good principled-based practice, where people have been given choice, very good involvement of individuals, keeping person informed...Seen areas where they have involved people in designing own care plans and also seen areas where when you ask someone about their care plan they say 'my what?' They don't even know that a care plan exists." (MWC)

- 5.33 Professionals thought the quality of information given to service users had improved but that it could be improved further. A particular issue was raised in relation to people with learning disabilities and the accessibility of information: People First was critical of its involvement over 2 years in contributing to easy read, accessible information about the MHCT Act for people with learning disabilities when the Scottish Executive had not published this in 2007. One leaflet had been produced in small print and in A5 format. There were no known plans to produce this information in alternative format such as DVD.
- 5.34 Although the existence of the 'least restrictive alternative' (LRA) principle had forced discussion and prompted systematic questioning at Tribunals for instance, it remained a challenge when local resources were limited:

"It still seems that referral to emergency is to hospital as this is the only alternative in a crisis situation." (GP)

- 5.35 The Royal College of Psychiatrists claimed that LRA underpinned psychiatrists' practice, and the MWC nominee said the statistics showed this principle was being met. The variability of IPCUs across the country was however a cause for concern. Others raised issues about the lack of specialist resources, for example, for those with alcohol related dementia.
- 5.36 In relation to carers and Principle 7 or 'respect for carers', it was argued by one voluntary organisation (mental health) that the needs of carers and families were still poorly understood, and that their needs should be better recognised.

5.37 There were mixed views about the principle of 'reciprocity'. While some felt that this principle was definitely being implemented, many others commented that this was simply not so or that it had to remain "an aspirational principle". Constant reference was made to the resource issues at the heart of implementing this principle and how much easier it was to implement in areas with well-resourced services. At the very least, the principle "plants an idea that takes time to grow", does at least raise questions about the suitability of current care and treatment options.

#### **Mental Health Tribunals**

5.38 Professionals resented the amount of time spent leading up to, and at, Tribunals despite welcoming this as an improvement on the Sheriff Court system. The issues raised about Tribunals closely mirrored those found by Atkinson et al's (2007) study of early impact of administration under the MHCT Act. Professionals reported variability in the way different Hearings operated: some were said to run like "flexible case conferences", whereas the style of others was "legalistic and bureaucratic." In one psychologist's opinion it took time for those involved to appreciate the need for informality while at the same time conducting a legal process. In some areas of the country, the majority still took place in hospitals, although the intention had been that there should be a range of venues. The extent of participation by service users and carers also varied but for the most part, Tribunals appeared to professionals to be more person centred and inclusive.

5.39 Key problematic areas for professionals were the short notice given for Tribunals and the length of Hearings. They acknowledged that the short notice was not always down to the Tribunal system but could result from hesitation on the part of psychiatrists and MHOs about whether or not a CTO was needed. Ensuring that everyone who should be there could attend was an organisational challenge that, from experience, was not always met. One MHO commented that they had to leave their diary blank when a Tribunal was expected as it could last a few hours or a whole day. The Royal College of Psychiatrists were of the opinion that the conduct of Tribunals was not always efficient:

"Sometimes there is a need for an authoritative intervention but it does not always happen. As a result, in a few cases a Tribunal hearing may last for up to 7 hours, when 1-2 hours should have been long enough to find out what is necessary and to progress from one hearing to the next." (Royal College of Psychiatrists)

5.40 From another perspective, it was suggested that the Tribunals required new skills and approach, and demanded a different, more collaborative style of communication. One participant identified the need for psychiatrists to learn how to take part in the more participative forum of the Tribunal. Another had been appalled by a legal argument that had arisen between the Convenor and person's lawyer, which had resulted in the patient becoming distressed. It was argued that the process of Tribunals could be "disturbing and repetitive" for individuals as it was rare for CTOs to be granted at first sitting, and more the norm to have to attend 2 or 3, or even 4 Tribunals.

- 5.41 Psychiatrists highlighted further that the volume of Interim CTOs experienced had not been anticipated. MHOs claimed that the process of repeat hearings could be "traumatic" for some patients. The Royal College of Psychiatrists' nominee argued that new procedures had the potential to encourage more CTOs, whether or not this was the right option in every case, as applications had to be made in the early stages of a short term order. He argued that with more time to review an individual's situation and progress, psychiatrists might decide that a CTO is not the best way forward.
- 5.42 Servicing the Tribunal system was argued to be creating logjams in the wider system of mental health services, caused by prioritising crisis management above early intervention and preventive support. Psychiatrists confirmed that they had had to cancel clinics to attend Tribunals at short notice or had cancelled other meetings. They identified a risk of ending up with 2-tier services one for the relatively small number of people subject to compulsory measures and one for everyone else. As one voluntary organisation had observed:

"There's growing unease around just what impact the pressures on professionals' time is having on those receiving services on a voluntary basis. We have heard from a number of people who have had appointments cancelled at short notice when psychiatrists have been called to Tribunals. (Voluntary Sector, Mental Health)

- 5.43 Similarly, advocacy organisations were being forced to prioritise support for those facing compulsory measures which, it was suggested, was having a detrimental impact on the availability of advocacy for people with mental health problems who were not subject to compulsion. The result was waiting lists and growing unmet needs for advocacy support. Service level agreements with independent advocacy organisations served to reinforce this imbalance in provision. Further, additional monies for the development of advocacy support had to be earmarked to fund advocacy worker posts that would meet the needs of Tribunals.
- 5.44 From experience, repeated hearings were problematic for everyone as one psychologist observed:

"It's very difficult when you have a whole different panel and it's a complicated story or saga, it's not particularly easy for anybody, either the patient, their carers or the professionals have to start all over again to explain the situation especially if there's disagreements between say the carer and the professionals, and you've been through it once for hours" (Psychologist)

#### **Advance Statements**

5.45 Advance Statements were understood to be one provision under the MHCT Act, along with Tribunals and the named person role, which had brought about an appreciable increase in participation. Yet, most professionals claimed low uptake and little demand from service users for Advance Statements. This reluctance was explained in several ways: one explanation was that it was related to individuals' perception of their illness. In particular, when individuals believed they would not

become ill again, they did not comprehend the need for an Advance Statements. It was recognised that such statements could be overridden, which resulted in many service users concluding that there was little point in making one:

"There's a cynicism on behalf of clients – 'they'll (psychiatrists) do it anyway'." (Voluntary organisation, mental health)

5.46 There had been attempts to promote Advance Statements by MHOs, nurses, psychiatrists, and advocacy workers, but it was claimed that interest among service users remained low, for reasons stated above. There was however hesitancy among some staff from the prescribed professionals list to sign a statement. For example, nursing staff were said to be wary in case they "got into trouble" with the consultant who may disagree with what the service user had proposed. It was also suggested that Advance Statements made while someone was detained, regardless of whether the prescribed professional had signed to certify him or her as well when drafted, had a higher chance of being overridden or ignored. One lawyer made an observation about psychiatrists' attitudes to capacity and the impact on how predisposed they were towards Advance Statements:

"I've come across psychiatrists who say, `but he can't have a Lawyer because by definition he's here and so he can't make any decisions'. But many psychiatrists take a completely different view, which is that as long as they're able to express a view and discuss it and think about it, even if they're deluded or whatever, then they're entitled to legal representation." (Lawyer)

5.47 A key point raised by several professionals was that as the law stands there is no clarity about who was responsible for supporting service users to make Advance Statements. This had the potential to affect efforts to promote Advance Statements. It was suggested that professionals did not always inform service users of their right to make an Advance Statement because there was no one identified to support them to make one: different professionals had reasons as to why it was not their individual responsibility, claimed one MHO. Advocacy workers were acutely aware that there was an implicit expectation, which unfortunately had not been backed up with extra resources, that advocacy organisations would offer this support.

#### **Named Person Role**

5.48 Generally, the named person role was considered to be an advance on the old Act and the assumption of 'next of kin'. However, professionals felt that in practice it appeared problematic. Many individuals had not appointed a named person and the role was passing by default to their next of kin. It was suggested by advocates that health professionals often reverted to contacting the next of kin and ascribing them the rights of named person, whether or not the client agreed. An initial assumption that there would always be a named person had proved spurious said one psychiatrist. In his experience some patients did not want a named person, and this wish should also be respected. There was currently no provision within the law for individuals opting out of having a named person altogether. A Glasgow advocacy organisation had recently devised a system to avoid next of kin being appointed by default when this was against an individual's wish. The local Tribunals

had subsequently accepted this. MHOs and advocacy workers identified that many of those who could benefit from having a named person had no one they could appoint, other than paid supporters who, by definition, could not become named persons.

5.49 Professionals recognised that conflict could arise between the individual and their named person. Attention was drawn to difficulties and tensions for carers and the relationship with their relative, which sometimes resulted:

"There are unforeseen circumstances. This is a very tough role. One example was a manic patient who didn't want detention. His named person (relative) saw the need for detention but was keen to be as supportive as possible. They were forced to testify against their relative and this undermined the relationship." (Royal College of Psychiatrists)

5.50 A fundamental problem with the named person role was that clients/patients did not always understand the role and its limitations. They often perceived the named person to be an advocate. This had led to misunderstandings and tension between individuals and their carers/relatives, often leading to multiple changes of named person. This was particularly so for those who resided at the State Hospital:

"The named person means full participant and they are exposed to a lot of information about the patient. In the case of restricted patients who have committed serious offences, the descriptions can be vivid and have caused distress, and meant they didn't want to be the named person, and had fears for their safety and community safety. We need as professionals to prepare patient and named person more about what they are entering into." (MHO)

### **Community-Based Orders**

- 5.51 By and large, community-based compulsion was considered to be a better option by a range of professionals, offering a less restrictive option to being detained in hospital, and offering more flexible, person centred care packages. Experience so far however, had led professionals to conclude that there was no perceptible shift towards more community-based CTOs. This may have changed since the research was conducted. Essentially, consultant psychiatrists were understood to be erring on the side of caution in recommending community orders, at least during early implementation and the majority were individuals who had transferred from hospital orders.
- 5.52 Professionals expressed concern that in practice community based CTOs equated to so called 'medication orders' and did not address needs holistically. The context to this was inadequate infrastructure of community mental health services. The lack of psychology services in the community for instance, was arguably why some remained as hospital patients. While MWC statistics (2007a) showed an increase in the pattern of applying community-based compulsory powers across Scotland since implementation, the overall perception was that poor community infrastructure was hampering progress. One lawyer highlighted a case of an

individual who could not be granted a community-based order because it was concluded that the community resources needed to support her in the community were not available. This subsequently provided a basis for appealing a hospital-based order.

5.53 Of concern to some professionals was that subjecting people to community-based compulsory orders could potentially result in compulsion of longer periods if not monitored closely:

"How do you ever show that you're able to come off that? Has to be regular reviews and that there's responsible risk taking otherwise you're subjecting people to a lifetime of never coming off medication, never making choices of their own volition ever again." (Association of Directors of Social Work (ADSW))

5.54 Community-based CTOs were said to have been useful in being able to recall people to hospital when necessary, but there was less certainty about their overall effectiveness.

### **Interface with Other Legislation**

5.55 Professionals generally were most exercised about the interface with the AWIA. There had been less experience of the interface with criminal justice legislation, forcing professionals to seek advice on individual cases. Understandably given that the research interviews were conducted during early part of 2007, there was little comment on the interface with the ASPSA. It was however expected that this would have similar overlap to the AWIA. In relation to the AWIA, professionals experience could be summarised as:

- If there is a choice between AWIA and the MHCT Act, recourse is to the AWIA
- If the person is resisting treatment and is detained in hospital, the MHCT Act is used, whereas when they are residing in the community, the AWIA is used
- The AWIA is often used in cases concerning an older person with dementia
- The AWIA can sometimes be seen as the 'easier option'.

5.56 One viewpoint expressed was that different overlapping legislation dealing with incapacity and the need for compulsion was frustrating and confusing. Current guidance was described as "a bit vague". It was argued that there was no consistency in which Act was used, and confusion when working with people with learning disabilities about which was more appropriate. As one voluntary organisation (learning disabilities) commented — "We now have three sets of compulsory powers legislation — take your pick!" The tendency was to resort to the AWIA because it was more familiar. The need for more guidance was highlighted by the SIAA as well as others:

"Advocates can tell stories about how the different Acts have been used. When choice is there, recourse is to the AWIA. Maybe they need some kind of framework, a sort of flowchart to add transparency to the decision making and to be clear about why they use the Mental Health Act or the AWIA." (SIAA)

5.57 Some practitioners argued that the AWIA and MHCT Act went hand in hand; practice had to be adjusted according to needs and circumstances. A member of the BASW MHO Forum commented on a 'one door approach', where professionals had had to become experts on both pieces of legislation and remain flexible about which to use in any given situation. Experience had taught that it was not always an either or, but both were sometimes needed. Both nursing and social work participants indicated they regularly engaged in discussions about this interface and were becoming increasingly skilled at making fine tuned judgements:

"You have to look at what's happening for the person, what are family members saying, what are other professionals saying, and take a judgement about the application of any form of legislation. There are occasions when people have to be subject to both Acts. You need to know about not just those Acts but the Disability Discrimination Acts, Children's Act etc to make good decisions." (ADSW)

- 5.58 A key challenge was thought to lie in "the interpretation of clinical decision" and whether the individual was opposing or resisting, as force could not be used under the AWIA unless 'absolutely necessary'. These are clearly complex decisions, requiring detailed knowledge of several pieces of legislation. It was the view of the MWC that as the AWIA is in many ways a less restrictive piece of legislation, it should be considered as a first choice for people in certain care groups, for example, people with learning disabilities.
- 5.59 Some issues were highlighted around the Guardianship role under the AWIA and how this interacts when an individual becomes subject to both Acts. One concerned the respective roles of Welfare Guardian and the named person, and whether the person under Guardianship had the capacity to nominate a named person and/or make an Advance Statement. There was felt to be a lack of clarity between where the AWIA stops and the MHCT Act starts. An example from experience was the following:

"We had a difficult case recently where the daughter was the Guardian [under AWIA]. The patient had to be detained, which the daughter was very happy with. When we went for the community treatment order the Mental Health Tribunal insisted on appointing a curator when the daughter was saying, 'I'm here to make the choices because I'm the guardian, why do you need a curator?' Then the curator ad litem was appointed, but not the legal firm that the family wanted, and it just raised a lot of issues about what was the role of the Guardian and if there's a Guardian why would they not be given special status at the Tribunal?" (Psychiatrist)

5.60 In such cases, unless there were concerns about the Guardian (appointed under the AWIA) not acting in the patient's best interest, it was suggested there was no need for a curator to be appointed. ADSW highlighted another issue in respect of people with learning disabilities and older people with dementia. This concerned the practice of holding multiple Tribunal hearings when a curator ad litem became involved, as it became confusing and sometimes distressing for the individual

concerned. It was also identified by professionals that access to advocacy was unequal under the 2 Acts. An individual's needs might dictate that they are entitled to advocacy under the MHCT Act but not under the AWIA, except as a matter of good practice. Another challenge was in cases involving individuals with both physical and mental health problems, for example, when treating a patient with diabetes who has schizophrenia. The Royal College of Psychiatrists' nominee commenting on such a case argued that confusion about the boundaries between these Acts was detrimental to patients and their treatment. A GP from the BMA added:

"The Mental Health Act would give certain powers to treat the mental health problems but not the diabetes. Would need to possibly be detained under the MHCT Act and use AWIA certificate to be completed to allow treatment of the diabetes." (BMA)

- 5.61 A professional at the State Hospital highlighted problems with leaving in an amendment, S200 of the Criminal Justice Act, 1995, regarding notification to MHOs by the courts. As expressed during the Millan consultations, professionals in this research suggested these should be integrated under one piece of legislation.
- 5.62 Generally, it was felt that more could be done to look at how different legislation interacts and that there should be further training focusing on legislative interfaces. This was an issue the MWC with the Scottish Government were addressing at the time of the research and would be addressed in new Codes of Practice. The MWC provided advice and guidance to professionals especially in relation to complex cases where there were doubts about which legislation to use. It was suggested by one participant that a bank of case studies dealing with interface issues, possibly held by the *Principles into Practice Network*, would be a helpful reference point for practitioners.

# **Promoting Wellbeing and Social Development**

- 5.63 A common viewpoint among professionals was that the MHCT Act had limitations in its scope for directly progressing social inclusion and employment agendas. There was little direct comment on these issues except to say that it is a good thing that the social inclusion agenda was linked into statutory frameworks. Research participants commonly expressed bewilderment when asked about the impact of the MHCT Act on leisure, education and employment. Many stressed that the Act should support, not drive such developments. Although the legislation was presumed to have increased the rights of those it covered to access such opportunities, it had done nothing to increase their availability. Nor was this felt to be the role of legislation.
- 5.64 Many professionals argued that employment support for people with mental health problems was underdeveloped in most parts of Scotland. The *Pathways to Work* programme was the mainstay even in Glasgow where participants were generally more optimistic about developments. Furthermore, promoting social and emotional wellbeing was considered by many to be "low down the priority list", being subject to constant budgetary constraints. In some of the research areas, both Dumfries and Galloway and Glasgow for instance, the NSF and other voluntary

organisations were pioneering employment training and support, whereas some services faced closure or cut backs. The Mental Health Nursing Association nominee asserted that there was more talk than action about supporting people's social needs. And, according to the Royal College of Psychiatrists' nominee, employment was "on the radar but not central", adding "this may be an area where we need a kick up the backside." Moreover, there were also gaps in providing leisure and other activities for those detained in hospital under compulsory measures.

5.65 A sense of disappointment with the slow development of the social inclusion agenda pervaded participants' responses:

"With implementation of the MHCT Act, ideally people's lives would change quite drastically not just about care and treatment, more holistically. But I'm not sure this has happened. Services are not looking at quality of life issues particularly." (SIAA)

5.66 Nonetheless, at the least the MHCT Act with its underpinning principles and values of social inclusion and recovery, was forcing questions to be asked about the content of care and treatment plans, which was considered a 'good thing' in itself:

"The questions are being asked whereas before with the old Act it was about detaining people in for treatment. With the principle of 'reciprocity' these questions can be asked by the Tribunal and should be in the care plan." (Mental Health Nursing Association)

5.67 Although major refocusing of services as a result of the requirement on local authorities to implement Section 25-31 (Scottish Government, 2007) was asserted by ADSW, others were not nearly so optimistic. One voluntary sector participant reflected on the contradictions in the funding system for training and employment programmes, many of which were run by fragile voluntary sector organisations:

"There are things happening in relation to funding that seem to be at odds with the Act. We are facing possibly having to close some of our training programmes because of how the European programme is working and other funding requirements. The duty to provide those services was welcomed but rather than services being increased or strengthened we're facing the situation of closing services." (Voluntary Sector, Mental Health)

5.68 The separation of Community Mental Health Services and support services enabling wider access to employment and leisure opportunities was perceived as hindering progress. One voluntary organisation (mental health) identified a need to consider how CMHTs links with, and enable clients to use, mainstream education, training and employment services. Another indicated that some areas at least (e.g. East End of Glasgow) had begun to forge closer links between formal service teams and the voluntary sector.

### **Barriers & Factors Supporting Implementation**

#### **Barriers**

- 5.69 The main barrier to implementation was perceived to be a lack of resources and investment in new service developments in line with the policy direction: commonly highlighted by professionals as the reason for not fully implementing the principles of 'reciprocity' or the 'least restrictive alternative'. As well as identifying a need for further investment in the infrastructure of community mental health services, some professionals' highlighted poor standards on acute wards, which some said was "shocking".
- 5.70 Professionals emphasised the complexity of the MHCT Act. Training and the development of skills to implement the new law therefore should not, in many professionals' opinion, be under-estimated. While not a barrier as such, the implication was that full implementation needed time and would improve with experience. And, even though the Act had brought professionals in closer working relationships with each other, ongoing issues between health and social care professionals was highlighted as a problem "when these two organisations try to work together as in care planning, they seem so different" (BMA)
- 5.71 Resistance to cultural change, and issues of power and control were major barriers to achieving full implementation according to several participants. Some said that attitudes among some professionals had not changed from the days of large asylums, even though they had no place in the new vision for mental health services. The MHCT Act as "a modern Act" addressed such issues by shifting power and control as far as possible to the service user. The history of psychiatry however, was argued to be counterintuitive to inclusion and power sharing:

"There's one rule for one group of professionals and another for advocates. We always have to battle against this notion that people don't have the capacity in all aspects of their lives. It's said to us that this person's psychotic and keeps changing his mind so why don't you go and work with someone who needs an advocate. I'm not being anti-psychiatry but there is a big element of control and other people knowing best." (SIAA)

- 5.72 In defence of psychiatry, one participant argued that the key tension was not necessarily that between doctors and patients but between service user and carer, with the latter desiring greater restrictions to be imposed than professional opinion sometimes advised. Also it was not necessarily professionals' but society's attitudes that were the barrier. Until respect for diversity, non-discrimination and equality filtered through society's attitudes, there would be barriers to people with mental health problems.
- 5.73 So-called rigidity and unevenness in the conduct of Tribunals were identified as barriers. As one participant claimed, professionals often felt a "sense of frustration" with Tribunals and the bureaucratic and time-consuming processes they imposed. The Mental Health Tribunal for Scotland as a corporate body was accused of being blind to some of the problems already identified by professionals.

5.74 As discussed earlier, one of the biggest barriers to successful implementation of the MHCT Act was perceived to be the way the law works in relation to incapacity and mental health problems, that is, the complex interface between the MHCT Act and the AWIA, particularly in cases involving learning disability or older people with dementia.

#### Success factors

5.75 Despite all of the above, all professional groups expressed genuine enthusiasm for the MHCT Act and a high commitment to change, which they commonly cited as a key factor in successful implementation. That many of those involved were able, skilled professionals was identified as another key success factor. Extra resources into advocacy had also been helpful as had raising the profile of the importance of advocacy.

5.76 The Scottish Executive's programme of research to monitor implementation of the Act (Scottish Executive Social Research, 2005), which had given rise to this study, was identified as a success factor. The level of information and guidance on the Act produced by the Scottish Executive had also been appreciated:

"The Scottish Executive did make huge efforts to get a range of information out there to people when you contrast that with the 1984 Act. There has been a lot of good information and efforts to disseminate that." (ADSW)

### **Summary of Key Points on Professionals' Perspectives**

- While the MHCT Act had impacted on aspects of many professionals' roles and responsibilities, MHOs and psychiatrists had experienced the greatest change, and GPs the least impact. Increased demands were associated with the Tribunal process, the level of Interim Orders, and, positively, the impact had come from the increased emphasis on joint decision-making.
- Advocacy workers' role had been enhanced under the MHCT Act and, despite some professionals still expressing confusion about the role of advocates, many others said how much they valued their role more than before. The drawback from advocacy services prioritising support to people with mental health problems under compulsion was that others who were not subject to compulsion now faced barriers in accessing advocacy.
- All professional groups had received some form of training prior to implementation of the MHCT Act, but some groups such as lawyers, considered this had been insufficient. Joint training opportunities were generally felt to be the most effective. Additionally, good local support mechanisms now existed both for individual professionals (e.g. MHO Forums), and jointly across professions. The Mental Welfare Commission for Scotland (MWC) and its Principles into Practice Network were identified as key sources of advice and information regularly accessed by a range of practitioners.

- Professionals argued that the principles had brought about an important shift in the culture of detention, although some principles appeared more aspirational than others. There were difficulties in measuring implementation of, for example, 'reciprocity' and 'least restrictive alternative'. At the least, having such principles raised questions about the suitability of current care and treatment options.
- According to several professionals, Tribunals were a major improvement on the
  old system of Sheriff Courts. They were aware however, of inconsistencies in the
  conduct of hearings and that some were more inclusive than others.
  Professionals tended to stress the time consuming aspect for them, both prior (for
  some professionals), and at the hearings. As a result, professionals were
  neglecting other duties, which they argued was leading to 2-tier mental health
  services, one for the few under compulsion and the other for the rest.
- Some psychiatrists argued there was a bias inherent in the Tribunal system towards CTOs as they were expected to make their recommendation at too early a stage into a short-term order to meet the timescales of the Tribunal.
- It was suggested by health and social work professionals that the low uptake of Advance Statements was largely due to lack of interest. That said, it was pointed out that many professionals were hesitant to promote them when it was far from clear who should support service users to make one. Some professionals argued that variations in psychiatrists' attitudes towards deciding capacity were having an impact on uptake.
- Professionals perceived the named person role as complex and easily confused with advocacy, which had caused service users to instigate a change of named person. Some health professionals were said to resort to next of kin and did not understand the named person role. There was no system to record when a service user expressly did not want next of kin to be appointed by default.
- Most professionals thought of community-based compulsion as a 'good thing', but predicted that inadequate community services infrastructure would impact negatively on the level of community-based orders granted.
- Overlapping legislation dealing with capacity was felt by some professionals to be confusing and frustrating, and they did not take comfort from the official guidance available. Others stressed the need for flexibility and for professionals to develop their knowledge of a range of legislation. From experience there had been clashes where a welfare guardian appointed under the AWIA had not been given proper regard under the MHCT Act.
- Most professionals had not witnessed much improvement in the provision of social, leisure and employment support since implementation of the MHCT Act. Furthermore, they did not perceive it as within the ambit of legislation to achieve the necessary change. Perversely, some voluntary organizations providing such support had experienced funding cuts and some had closed specialist training or employment projects.

- Professionals identified a number of barriers to implementing the MHCT Act including attitudinal issues, resistance to change among some staff, conflict between the needs of service users and carers, levels of bureaucracy created by new systems, the confusing interface between legislation in relation to capacity, and, especially, under-resourced community services.
- Factors for successful implementation identified by professionals included the
  underlying enthusiasm and commitment to change that was evident, the skilled
  and able staff resource, the injection of extra resources, e.g. for advocacy, the
  systematic programme of research, and the level of information from the Scottish
  Executive about new systems and processes aimed at different groups.

# **CHAPTER SIX: EMERGING ISSUES AND CONCLUSION**

#### Introduction

This research has evaluated the operation of the Mental Health (Care and Treatment) (Scotland) Act 2003 (MHCT Act) using qualitative and participatory methods to explore in-depth the various stakeholders' experiences and perspectives. The Act was implemented in October 2005, and the study began just over a year later. Invariably, new systems and processes need time to bed down, and some viewpoints were more speculative and tentative than they might have been had such research been conducted say 5 years into implementation. That said, the qualitative nature of this study permits a window on a range of experiences and perspectives indepth over time, drawing together responses from the key stakeholders sampled from 4 research sites: 49 individual service users; 33 individual carers/relatives; and 38 professionals. This final chapter discusses the emergent issues and key findings against the study's objectives. The findings should be read within the context of the research study undertaken, and care needs to be taken in generalising from the research to different populations or areas.

# **Journeys Through Compulsion**

6.2 Service users' accounts of their experience of compulsion highlight the complexity and individuality of their journeys through compulsion. Moreover people's pathways into compulsion are exceedingly varied, although there are some common themes. Frequently, the lead up to compulsion includes self-neglect, strange or odd behaviour, non-compliance with treatment, transferring from prison to psychiatric care, and anticipated risk based on previous events (see Table 3.4). Many were at various stages of recovery having become ill after stressful events such as bereavement, which then caused carers and/or professionals to act to detain them. For some, the experience of compulsion was an isolated event made worse by having to deal with an alien system. Being placed under compulsory care is thus a complex interplay of personal or health crises with the responses of carers and various health and social care professionals. For most of those in our sample, this had been a traumatic and sometimes confusing experience, which some still did not understand nor accept at a later date. Not surprisingly, involuntarily hospitalisation or being treated against one's will is inherently unwelcome. It is not something anyone chooses freely or which is perceived to be under individuals' control. It therefore provides a fraught context for interaction between service users and professionals.

# Critique of hospital based compulsion

6.3 Being detained in hospital under compulsion was a common experience shared by all the service users in the study, whether or not their most common experience was of community-based compulsory measures. Some service users were commenting on recent experience while others had been in hospital some years ago. Consultations prior to implementation of the Act (e.g. Rosengard & Laing, 2001) indicated that many service users feel disempowered by hospital practices and were critical of the lack of structured activity, as well as of the poor conditions on some psychiatric hospital wards. This research indicated that while

this situation is clearly changing, some of the same issues remain in some hospital settings. The range of care and treatment available in psychiatric hospitals in different parts of Scotland is a matter of concern. In addition to the physical conditions and activities in hospital, the research found that staff attitudes, ward cultures and the behaviours of other patients have a significant bearing on people's perception of compulsory care and treatment. Some people's accounts referred to instances of violence, physical and sexual abuse, and racial discrimination between patients and from staff. It should not be forgotten however, that several service users were also positive about the help they had received from hospital staff, highlighting how this had contributed to their recovery. While some people felt on reflection that hospitalisation had been needed at the time, the research findings indicate there is no room for complacency, and that there is room for improvement in psychiatric hospitals in the new millennium.

### Reflections on community-based orders

- The picture of community-based compulsion is complex and deserves 6.4 detailed discussion. Despite expressed concern about how community-based compulsion would operate in practice and a slow start to implementation, this research was able to explore some experiences of compulsory measures in the community. Approximately one third of the study sample referred to their recent experience of compulsion as being community-based compulsion; however at the second interview stage it emerged that some were in fact under a hospital-based order that was suspended, and they had been living in the community for some months. Many service users were unclear about the detail of the powers conferred by particular orders, especially between suspended hospital and community orders. In practice, a suspended hospital order could appear to be exactly the same as a community-based order, even though they grant different powers for the Responsible Medical Officer (RMO). There is therefore much room for confusion not only among service users, but also carers and professionals, about which compulsory orders apply.
- 6.5 The operation of a broad definition of 'community' was also evident in the finding that several who were placed under community-based orders were residing in units in hospital grounds or in residential and nursing care homes. It emerged that it is not always possible to predict people's living situation from the definition of their compulsory order. Among the sample of clients interviewed, some were living in hospital under community orders; others were in the community under hospital orders, and those living in sheltered accommodation or nursing homes could be under either type of Order. Thus people's living conditions are more varied than the categories of compulsion might suggest. Given this complexity it is clearly not straightforward to assess the effectiveness of community-based Compulsory Treatment Orders (CTOs).
- 6.6 The assumption within the legislation that being treated in the community is preferable was not entirely supported by the opinions of service users in this study, who reported discontent and feeling stigmatised by compulsory treatment, even if it was based in the community. Leading up to implementation of the MHCT Act, some professionals had voiced concerns about possible negative outcomes, for example, for civil liberties (Rushmer & Hallam, 2004). While some service users did regard

community-based CTOs as a positive innovation, the limits on autonomy, choice and control of any form of compulsory care were universally resented. Although for some it was preferable to hospital, it was not preferable to "being allowed to live a normal life". The findings also indicate that for some people community based treatment orders may be an opportunity lost if used solely as a means to monitor medication compliance.

#### Balance of control in care and treatment

- 6.7 The research findings indicate there is room for improvement in shifting the balance of control in decision-making about care and support towards greater involvement of service users and carers. While some service users were happy with their care and treatment and saw no reason to change anything, many perceived care plans as something that professionals were in charge of and kept as a record of deficits, assessed needs and allocated services. This would indicate that there is some way to go before service users perceive their care plans as being personcentred plans in which they are fully involved and engaged. Although concordance and partnership between professionals, service users and carers was in evidence, for many, feeling over-medicated and having their experiences of adverse sideeffects to powerful drugs discounted, was not uncommon. From service users' experience some consultants, for whatever reasons, were more prepared to be open and engaged in a dialogue about medication/drug regimes. More generally, if concordance is perceived as the way forward, the research findings suggest that the conditions that support a concordance-based approach are worthy of wider investigation.
- The conceptual framework on which treatment under compulsory care is 6.8 based emerged from the study findings as an issue deserving of further investigation. Indications were of care and treatment regimes based on the medical model, and which paid less attention to psychosocial explanations and alternative responses to drug treatments. This is an area of major contention and one where service users feel the balance of power to be firmly in the hands of psychiatrists. Although the research did not specifically investigate individual care plans, it did consider these from service users' and carers' perspectives. In their experience, less attention appeared to be paid to broader issues that would assist recovery. Additionally, professionals highlighted shortfalls in psychology services and gaps in other community services such as leisure and employment support services. The availability of a more comprehensive range of alternative treatments has been recognised by Scottish Government who is currently addressing this agenda through service developments, as identified in the Delivering for Mental Health commitments (see Table 2.2, chapter two). This includes, amongst other things, commitments to increase access to psychological therapies (Commitment 4), and a commitment to ensure that people are managed and cared for effectively in the community (Commitment 8).

# Impact of New Roles and Responsibilities

6.9 Prior to the implementation of the MHCT Act, various professionals were concerned about the workload and administrative implications as well as about how the knowledge and skill requirements of the Act would be met (Rushmer & Hallam,

- 2004), and a recent study (Atkinson et al, 2007) examined the early impact of administration of the Act on professionals' workloads, and impact of new bureaucratic procedures. Here we discuss health and social care professionals' perceptions as they emerged in this research (as reported in chapter five).
- 6.10 The research findings suggest that not all the early concerns of professionals were borne out in practice. For instance, GPs in our study appeared to be only marginally affected, whereas the role and responsibilities of psychiatrists and Mental Health Officers (MHOs) were significantly changed by the Act. Their experience did however appear to vindicate some earlier concerns about potential shortfalls in personnel resources, such as psychologists in community-based mental health teams. In terms of meeting the knowledge and skill base required to implement the Act effectively, indications were that training and support had been available and at an appropriate level for key staff groups such as psychiatrists and MHOs. However, some lawyers reported they had had surprisingly little specialist training, and advocacy services had had to opt into official training events or arrange training sessions for their advocacy workers and volunteers themselves. Professional networks, informal inter-disciplinary support networks set up in local areas, as well as advice and guidance provided by the MWC, were considered to be effective by a range of professionals.
- 6.11 A key area of concern identified by this study, as well as by the consultation conducted prior to the Act's implementation (Atkinson et al, 2002; Rushmer & Hallam, 2004), was the impact of new professional roles and responsibilities under the Act on the wider system of mental health services. Concerns that workload implications and bureaucracy, especially those arising from the Mental Health Tribunals, would impinge on psychiatrists' direct time with patients as well as on their wider preventative and community-based role, were borne out by the experience of many of the professionals in this research. A strong view emerged across stakeholder groups that the impact of the Act would be to create a 2-tier mental health service, one for the few people under compulsion and the other for everyone else with mental health problems. This is an important issue and one that would merit further investigation.
- 6.12 Predicted shortfalls in independent advocacy to meet anticipated need did not appear to be realised in practice from the experience of participating service users and professionals. Service users had been able to access independent advocacy support when they wanted to, and it was the perception of various professional groups that there was access to advocacy support when needed. An issue highlighted by professionals and advocacy services was around the perceived danger that independent advocates' role would become professionalised. This arises at least in part because of the short notice given of the need for an advocate when this is just prior to a Tribunal hearing. In order to meet demand many services deployed paid professional advocates for mental health work, and such advocacy services had to respond speedily. In terms of access to advocacy for people with mental health problems more generally, our participants' experience pointed to the development of a 2-tier advocacy service emerging as a consequence of the strategic prioritisation of advocacy services by commissioners to meet the requirements of the MHCT Act.

### **Interaction with Other Legislation**

- 6.13 The research was tasked with examining how different parts of the legislative system interact. The experience of all 3 groups of stakeholders identifies issues in relation to the Adults with Incapacity Act (Scotland) 2000 (AWIA). Due to timing, the research could not explore perceptions of the more recent Adult Support and Protection (Scotland) Act 2007 (ASPSA). As previously identified by Gordon (2004), problematic issues had indeed arisen when an adult with an appointed Welfare attorney or Guardian under the AWIA was assessed for detention under the MHCT Act. The principle that regard must be paid to their views was not always heeded in practice, and had, for example, resulted in curators being appointed with no recourse to existing Guardians.
- 6.14 The research findings point towards a degree of uncertainty among some Tribunal members and professionals in applying overlapping legislation. Despite being an area that the Scottish Government and the MWC were actively addressing at the time of the research, professionals identified the interaction between the MHCT Act and AWIA as frustrating and confusing, and as requiring further specialist training input. As professionals' experience grows however, issues around deciding which legislation to apply to support a person with 'mental disorder' in the community when there are issues of capacity should lessen.

# **Wellbeing and Social Development Measures**

- 6.15 It was notable that many of the service users and carers in the research samples were unaware of what services were available to them in their communities, including support for leisure and employment. They gained access to information mainly from other service users and the voluntary sector, and often it appeared through informal contacts. This has been found in the past to be an issue of import to other people with mental health problems. Furthermore, the range of experiences found in our study indicates that opportunities to access information as well as specialist employment support are not equally accessible in all parts of Scotland. Previous research regarding support to access employment, training and education has found a lack of support to people with mental health problems generally (SEU, 2004). Recent work by the Scottish Development Centre for Mental Health would confirm this applies equally to the situation in Scotland, and proposes future developments (Durie, 2000; 2005). The findings from our research point to a need to investigate patterns of employment support services locally, especially those in more rural and isolated communities.
- 6.16 There were indications that a wide range of services has a role to play in promoting inclusion and recovery, including housing, employment and education services. Research increasingly reports that the most significant factor in people's recovery journey is a return to work or gaining employment. This message does not appear to be filtering through to the benefit of those under compulsion. On the whole, specialist employment support services were poorly promoted to people with experience of compulsion, and there were strong indications that employment generally is not systematically considered as part of care planning. Collaboration and links between Community Mental Health Teams (CMHTs) and employment

support services in some areas may need to be strengthened to ensure employment moves up the agenda.

- 6.17 Elsewhere, an integrated approach has been found by researchers to be the model preferred by service users (South Essex Service User Research Group et al, 2006). The experience of South West London and St George's Mental Health NHS Trust Employability Team further shows that having employment specialists embedded in CMHTs contributes to success (Rinaldi et al, 2004). Their experience has also shown that sustained efforts and support at both senior management and clinician level, in particular through frontline managers and clinicians who deliver the change, is critical.
- 6.18 Other conditions for recovery include access to and sustainability of decent accommodation (Edgar et al, 2000). This assertion was borne out by the experiences of several service users in our sample even though the research did not specifically focus on housing circumstances and views. Housing emerged naturally from some people's accounts as a significant element of their care in the community. Service users spoke about the importance of feeling safe and settled, of having a sense of pride in their home, and of the independence that having one's own home can bring.
- 6.19 Several people's accounts highlighted the difference that decent housing and support can make, not only to the individual but also to the carers or family who are supporting them. Additionally, there was evidence that mental health professionals have a key role to play in liaising with housing providers. This emphasises how important it is for housing needs to be considered routinely in hospital discharge planning as an integral part of integrated care pathways. Additionally, there were indications that access to advocacy, whether provided by professional advocacy workers or by social care or mental health professionals, was key to gaining positive housing outcomes for some. The research also highlighted that a range of housing options may be appropriate, ranging across independent housing with visiting support (the most common for our interviewees), to supported accommodation with 24-hour staff presence.

### **Implementing the Millan Review Principles**

6.20 There was evidence from all key stakeholders of a number of challenges to implementing the principles underpinning the MHCT Act in practice, especially with implementing the 'least restrictive alternative' and 'reciprocity' principles when community resources were scarce or under-developed. There were indications that in the ordinary lives of many people with mental health problems support provided in the community is often limited, and many carers continue to be concerned about how their relatives' needs will be met in the longer-term. Shortfalls in community services were also perceived as impacting on the decision about whether hospital or community-based compulsory care was appropriate in individual cases. Improving the scope of mental health services and how service users are supported and managed in the community are at the centre of the Scottish Government strategy Delivering for Mental Health (Scottish Executive, 2006c). Overall this suggests that this situation should change for the better, provided that there are sufficient

resources to implement the Government's commitments and to support the joint working at ground level that will be required to realise the targets.

- 6.21 Prior to implementation, carers emphasised the need for partnership approaches. Although Principle 7 of the MHCT Act states that 'informal carers should receive the advice and support they need and have their views heard', there was a prevailing sense of exclusion, rather than of positive inclusion, from some carers. Overall, carers' experiences of being included whilst supporting their relative under compulsory care were inconclusive: while some did feel compulsion under the MHCT Act gave them new rights, these could easily be denied, or lost overnight if they were no longer the named person for instance. Despite some improvements in communication with professionals, especially when carers were named persons, they were often alone struggling with difficult issues, and some carers felt they were forgotten when planning for future aftercare from hospital was being undertaken. This study, alongside specific reviews such as Newbronner & Hare (2002), and Lee (2007), highlights that gaps in the full recognition of carers remain. Only those carers who were named persons, and not all carers agreed with this point, were satisfied that the MHCT Act had implemented positive change for them.
- 6.22 Principle 6 of the MHCT Act states that people should be involved, as far as they are able to be, in all aspects of their care, treatment and support; that their past and present wishes should be taken into account; and they should be provided with information and support to enable them to participate fully. The research findings confirm that the voice of service users is beginning to be heard through implementation of more deliberately inclusive processes such as the new Mental Health Tribunals. They were consistently identified as less formal, less intimidating, and were generally perceived as a more accessible forum than the previous system of Sheriff Courts. Also, to some extent, service users' voice is promoted through Advance Statements and the right of access to independent advocacy under the law.
- 6.23 Across the range of positive and negative experiences of participation of the service users in this study, a key issue to emerge was the extent to which service users believed their views and opinions had tangibly influenced decision-making about their care and treatment. In other words, while they understood they had opportunities to voice their opinions and used them, they did not believe they were being heard. This was particularly evident in the expression of reservations about making Advance Statements. Service users' perceptions and the continued low uptake demonstrate an underlying belief about a power imbalance in the clinical relationship in favour of consultants. That said some were completely satisfied and trusted the professional judgement of those involved in their care, seeing no need for an Advance Statement. There were indications however that Advance Statements are not promoted well enough, and that the support to make one is not always forthcoming.
- 6.24 Theoretical discussions of participation attest to this being a complex notion with levels of participation ranging from tokenistic information giving to passive consultation through to user-control (Turner & Beresford, 2005; Humphries, 2008). In respect of compulsory care and treatment, participation is even more complex as, by definition, a person is being treated against their will. The research shows that aspiring to participation in a general sense is far easier than achieving it in this

context. The key ingredients for positive participation indicated by this study are professionals' willingness to listen actively; to communicate openly; and essentially, to achieve a balance between professional expertise alongside service users' expertise.

6.25 It would be helpful for those involved (service users, carers, and professionals) to debate in more detail what levels of participation are desirable for people at different stages of compulsion, and for managers and practitioners to have clearer guidance about what is realistic. That is to say, at points of crisis, very low levels of participation might be possible, whereas, much higher levels of participation should be sought at various stages of care planning. The research findings do nevertheless indicate that professionals are aware of the principles and actively attempt to engage with them despite the difficulties.

# Implications for Future Development of Mental Health Law

6.26 Many of the research participants including professionals, considered research such as this study to be the most effective mechanism for ensuring their opinions were taken into account in future developments. Several service users explained they had been motivated to participate because they believed that those who can influence change would hear their voices through this research. This underlines the importance of using more individual and personalised approaches. Previous research has shown that if information is not fed back about what decisions have been taken and whether or how the views of service users or the public have influenced these, then the effort to formulate and give opinions may be wasted, and reduce the motivation to engage in the future (Scottish Health Feedback, 2001 cited in Ridley & Jones, 2002).

6.27 Conducting this research with carers has highlighted that there are practical challenges to engaging with the informal carers of those under compulsion. This relates both to the situation many carers or relatives find themselves in, which limits the time and energy they have to get involved in consultation or research, and to the lack of resources to fund staff to support carers and cover the cost of travel to meetings. We also found that the collective voice of this group of carers was somewhat lacking, with particular difficulties experienced by those supporting someone at the State Hospital. Ensuring the collective involvement of carers in the future would mean proper consideration of the resources needed to support this meaningfully. Finally, professionals proposed a programme of continuous consultation and involvement of all key stakeholders, engaging hard-to-reach groups, and deploying a range of techniques including focus groups and ongoing consultation with existing forums/interest groups.

### Implications for Future Research

6.28 This study has identified a number of issues that would benefit from further research using different research methods and approaches. In addition to urging Scottish Government to develop its future research agenda on the implementation of the MHCT Act with mental health service users and carers, as well as professionals and policy makers, our research indicates that it might be beneficial to investigate the following aspects:

- In-depth research into the effectiveness and outcomes of communitybased orders, exploring regional variations and the scope of communitybased orders for promoting social inclusion and recovery;
- An outcomes study of the Tribunals hearing decisions, investigating the
  extent to which service users' and others' views could be seen to have
  influenced the panel's decision;
- Detailed investigation of the quality and inclusiveness of care plans of those under compulsory measures, especially focusing on user participation;
- Research into the range of employment support opportunities available across Scotland for people who have experienced compulsory measures, and seeking to identify exemplar practice;
- Mapping the housing needs of those under compulsion, and variations in how these are being met in different parts of Scotland, including looking at the role of accommodation/housing services alongside health and social care services:
- Research into the care and recovery pathways of specific groups e.g.
  those with complex needs including dual diagnosis of drug/alcohol issues
  and mental health problems; people with learning disabilities and/or ASD;
  those from black and minority ethnic (BME)/refugee communities; and
  those with parental responsibilities;
- Participatory action research into the issues surrounding the implementation of Advance Statements, to promote development of good practice.

#### Conclusion

6.29 In conclusion, this research has examined implementation of the MHCT over one year, from 2007-2008, from the different experiences and perspectives of service users, informal carers and professionals. This has been achieved in partnership with service users. The study shows that the new legislation, with its underpinning values, has set a positive framework for improving the care and treatment of those who are compulsorily treated. Moreover, the study found indications of paradigm shifts in process and practice. However, the experience of key stakeholders indicates that improvements in mental health service provision are urgently needed, as envisaged in *Delivering for Mental Health* (Scottish Executive, 2006c). Also, the approach of individual professionals needs to change more consistently if the goal is to achieve a more holistic, and recovery orientated approach. Although this research focused only on those with experience of compulsion, the findings have implications for the wider system of mental health services.

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# **APPENDICES**

# **Appendix 1: Members of the Scottish Government Research Advisory Group**

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The views expressed in the research are not necessarily those of the Research Advisory Group

Appendix 2: Principles of the Mental Health (Care and Treatment) Scotland Act

Principle	Description
Non- discrimination	People with mental health problems should, wherever possible, have the same rights and entitlements as those with other health needs.
Equality	There should be no direct or indirect discrimination on grounds of physical disability, age, gender, sexual orientation, language, religion or national or ethnic or social origin.
Respect for diversity	Service users should receive care, treatment and support in a manner that accords respect for their individual qualities, abilities and diverse backgrounds, and properly takes into account their age, sexual orientation, ethnic group, and social, cultural and religious background.
Reciprocity	Where society imposes an obligation on an individual to comply with a programme of treatment or care, a parallel obligation is imposed on health and social care services to provide safe and appropriate services and ongoing care.
Informal care	Wherever possible, care treatment and support should be provided without the use of compulsory powers.
Participation	People should be involved as far as they are able to be, in all aspects of their care, treatment and support. Their past and present wishes should be taken into account. They should be provided with information and support to enable them to participate fully.
Respect for carers	Those who provide care to service users on an informal basis should be afforded respect for their role and experience, should receive appropriate information and advice, and should have their views and needs taken into account.
Least restrictive alternative	Any necessary care, treatment and support should be provided, both in the least restrictive and the least invasive manner, and in an environment which is compatible with the delivery of safe and effective care.
Benefit	Any intervention under the Act should be likely to produce for the service user a benefit that cannot reasonably be achieved other than by intervention.
Child welfare	The welfare of a child with mental health problems should be paramount in any intervention imposed on a child under the Act.

(Adapted from SAMH Guide to Mental Health Act; Scottish Executive 2006a)

# Appendix 3: List of Organisations Consulted at Stage 1

Association of Directors of Social Work

British Association of Social Workers Mental Health Officer Forum

**British Medical Association** 

British Psychological Society

**ENABLE** 

Law Society

Mental Health Foundation for Scotland

Mental Health Nursing Association

Mental Welfare Commission for Scotland

National Schizophrenia Fellowship

People First Scotland

Royal College of Psychiatrists

Scottish Association for Mental Health

Scottish Independent Advocacy Alliance

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