

**Transition from institutional care to community care for  
residents of community care units in Greece:  
Construction of the notion of “asylum” in  
community care units**

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A thesis submitted in partial fulfillment of the  
requirements of the University of Greenwich  
for the Degree of Doctor of Philosophy.

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## **DECLARATION**

I certify that this work has not been accepted in substance for any degree, and is not concurrently being submitted for any degree other than that of Doctor of Philosophy being studied at the University of Greenwich. I also declare that this work is the result of my own investigations except where otherwise identified by references and that the contents are not the outcome of any form of research misconduct.

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## ABSTRACT

This study aimed to explore the shifting meaning of “asylum” for people with severe mental illness (SMI), who are residents of community care units (CCUs), by comparing and contrasting participants’ experiences of CCUs with their previous lives in institutions. Currently, there is a gap in the Greek context in the field of qualitative studies exploring the issues of deinstitutionalisation and community care based on residents’ and staff members’ experiences.

Semi-structured interviews were conducted with residents (N=35) and staff members (N=20) of four CCUs run by Klimaka (a non-governmental organisation) in Attica, the legal advisor of Klimaka, two mental health officers, a psychologist and a psychiatrist from Dromokaition Mental Health Hospital. Data were analysed thematically.

Most residents felt that institutions provided a “temporary asylum” based on: 1) financial security; 2) stress-free daily routine; 3) segregation from the pressures of the outside world; 4) good or neutral relationships with staff; and 5) trust in their treatment. But most felt that the hospital had never become their actual home. All residents felt that CCUs offered them a temporary or permanent asylum, based on: 1) financial security; 2) enriched daily routine; 3) wider social networks; 4) an increased degree of freedom; 5) good relationships with staff; 6) trust in treatment, with increased awareness; and 7) absence of abuse. Twelve residents felt that the CCU was their permanent residence, while for seven of them it was a temporary one, before moving to more autonomous living conditions.

The study concludes that “Asylum” does not represent a physical entity, but a set of interrelated criteria which, if met by services, can be achieved for people with SMI anywhere.

# CONTENTS

<b>DECLARATION</b> .....	pg. ii
<b>ACKNOWLEDGEMENTS</b> .....	pg. iii
<b>ABSTRACT</b> .....	pg. iv
<b>CONTENTS</b> .....	pg. v
<b>TABLES, DIAGRAMS AND FIGURES</b> .....	pg. xiii
<b>INTRODUCTION</b> .....	pg. 1
<b>LITERATURE REVIEW &amp; IMPLICATIONS FOR RESEARCH</b> .....	pg. 7
Introduction .....	pg. 7
<b>Chapter 1: Shifting notions of “asylum” and two different models of mental health policy and deinstitutionalisation</b> .....	pg. 13
<b>1.1.</b> The concept of asylum .....	pg. 13
<b>1.2.</b> The deinstitutionalisation movement: Community care units offering “asylum”.....	pg. 16
<b>1.2.1.</b> Driving forces behind the deinstitutionalisation movement .....	pg. 17
(a) <i>The perception of deinstitutionalisation as a “cost-saving” policy by policy-makers</i> .....	pg. 17
(b) <i>The discovery of anti-psychotic drugs</i> .....	pg. 18
(c) <i>The “anti-psychiatry” movement</i> .....	pg. 19
(d) <i>The community care movement and the ex-patient movement</i> .....	pg. 22

<b>1.3.</b>	Different models of mental health policy and deinstitutionalisation .....	pg. 24
<b>1.3.1.</b>	The Deinstitutionalisation Movement and Mental Health Policy in the United States .....	pg. 24
<b>1.3.2.</b>	The Deinstitutionalisation Movement and Mental Health Policy in the United Kingdom .....	pg. 31

## **Chapter 2: Mental Health Policy and Deinstitutionalisation**

<b>Movement in Greece</b> .....	pg. 42	
<b>2.1.</b>	The era of institutional care in Greece .....	pg. 42
<b>2.2.</b>	The transition to community care .....	pg. 45
<b>2.3.</b>	Housing units and occupational therapy workshops .....	pg. 47
<b>2.4.</b>	The «Psychargos» Program for the return of patients with SMI to community .....	pg. 48
<b>2.5.</b>	Stigma and Severe Mental Illness in the Greek context .....	pg. 50
<b>2.6.</b>	Negative attitudes to residents of CCUs as neighbours: NIMBYism in the Greek context .....	pg. 53
<b>2.7.</b>	The impact of the financial crisis on community care units in Greece .....	pg.57
<b>2.8.</b>	The impact of the financial crisis on state psychiatric hospitals.....	pg.62
<b>2.9.</b>	Can residents of CCUs find “asylum” in the community? Some illustrative cases .....	pg. 66

<b>Chapter 3: Theoretical background of the research: Construction of the notion of “asylum” in the community through the exploration of Thirdspace</b> .....	pg. 70
3.1. The shifting meanings of “asylum”: How can we create community care services offering “asylum”? .....	pg. 70
3.2. The value of Thirdspace: Edward Soja's <i>Thirdspace</i> .....	pg. 73
3.2.1. Soja’s Discovery of Thirdspace through Lefebvre's work .....	pg. 74
3.2.2. Soja’s trialectic of space: The development of the notion of Thirdspace .....	pg. 77
3.2.3. The rationale for the choice of Soja’s Thirdspace as the theoretical framework of this research .....	pg. 79
3.2.4. Critiques and comments on Soja’s <i>Thirdspace</i> : The value of Thirdspace in this particular research .....	pg. 82
3.3. Importance of the research.....	pg. 84
3.4. Originality of the research, aims and objectives of the study .....	pg. 86
<b>METHODOLOGY</b> .....	pg. 90
<b>Chapter 4: Methodology of the research</b> .....	pg. 90
4.1. Choosing qualitative methods .....	pg. 90
4.2. Issues of epistemology .....	pg. 92
4.3. Choosing Klimaka and gaining access .....	pg. 95
4.4. Issues of reflexivity – Positionality of the researcher .....	pg. 96
4.5. Sampling issues .....	pg. 100
4.6. The use of semi-structured interviews in this research .....	pg.104
4.7. Ethical considerations .....	pg.109
4.8. Issues relating to transcription and translation of interviews .....	pg.112

4.9. Analysis of the data .....	pg.114
4.10. Ensuring rigour – Issues of reliability and validity .....	pg.119
4.11. Quality assessment .....	pg.123
<b>ANALYSIS .....</b>	<b>pg.124</b>
<b>Chapter 5: Circumstances that led to hospitalisation and daily life of residents while in mental health institutions .....</b>	<b>pg.124</b>
5.1. Reasons that led up to residents' hospitalisation .....	pg.124
5.2. The involuntary and traumatic commitment of residents to mental health institutions .....	pg.127
5.3. The varied degrees of communication residents had with their family.....	pg.130
5.4. Financial issues while in mental health institutions: Sources of income .....	pg.135
5.5. Daily schedule-routine of residents while in mental health institutions .....	pg.141
5.5.1. Personal care and hygiene of residents while in institutions .....	pg.142
5.5.2. Daily activities, routine and occupational therapy .....	pg.145
a) Residents who enjoyed the leisure activities and social character of the hospital .....	pg.145
b) Residents that participated in the occupational therapy programmes of mental health institutions .....	pg.149
5.6. The small number of friends and narrow social networks residents had while in mental health institutions .....	pg.153



**Chapter 6: Relationship with staff members and issues of treatment while in mental health institutions ..... pg.159**

- 6.1. The good, neutral or poor relationships residents had with the staff in mental health institutions ..... pg.159
- 6.2. Pharmacological treatment in mental health institutions: limited awareness concerning medication, but with trust In treatment .....pg.167
  - a) Residents who did not know what kind of treatment they were receiving while in mental health institutions ..... pg.168
  - b) Residents who knew which drugs they were receiving while in mental health institutions ..... pg.171
  - c) Side effects residents experienced because of the drug treatment while in mental health institutions .....pg.174
- 6.3. Residents who had experienced electroconvulsive therapy while in mental health institution .....pg.176
- 6.4. Limited to non-existent participation of residents in psychotherapy while in mental health institutions .....pg.179
- 6.5. Notion of temporary “asylum” while in mental health institution .....pg.182

**Chapter 7: Contact with family members and financial issues of residents while in the CCUs .....pg.188**

- 7.1. Varied degrees of contact residents had with their family members .....pg.188
- 7.2. Financial exploitation of the residents by their relatives after their deinstitutionalisation and their transfer into the community care unit .....pg.195
- 7.3. Financial issues concerning the residents while in the community care units .....pg.198
  - 7.3.1. Sources of income .....pg.198

7.3.2. Receiving the money and managing of the monthly income with the aid of staff members .....	pg.201
7.4. Financial concerns of residents on a microeconomic and macroeconomic scale .....	pg.204

**Chapter 8: Daily schedule and routine of residents while in CCUs .....**pg.210

8.1. Daily personal hygiene activities and taking vital signs .....	pg.210
8.2. Breakfast and “Community” .....	pg.212
8.3. Occupational therapy and work mostly for the younger residents .....	pg.213
8.4. Creative activities in groups .....	pg.221
8.5. Chores and structured daily programme while in the community care units: difficulties in adjusting to rules .....	pg.226
8.6. Enjoying leisure activities .....	pg.231

**Chapter 9: Friendships, social networks, degree of freedom and contact with the neighbourhood while in the community care units .....**pg.235

9.1. The increased number of friendships and broader social networks residents developed while in the community care units .....	pg.235
9.2. Greater degree of freedom while in the community care unit .....	pg.242
9.3. Increased contact with the neighbourhood and notion of stigma in the community .....	pg.246

<b>Chapter 10: Relationships with the staff, pharmaceutical treatment, religious aspects and notions of “asylum” while in the CCUs</b> .....	pg.259
<b>10.1.</b> Good relationships with the staff while in the CCUs .....	pg.259
<b>10.2.</b> Pharmaceutical treatment and psychotherapy while in the CCUs: increased awareness and participation to psychotherapy .....	pg.264
<b>10.3.</b> Religious aspects and therapeutic value of spirituality .....	pg.272
<b>10.4.</b> Community Care Units offering temporary and permanent asylum .....	pg.273
<b>10.4.1.</b> Notion of “asylum”: feeling safe and protected while in the CCU .....	pg.273
<b>10.4.2.</b> Where did participants feel at home while in the CCUs...	pg.275
 <b>DISCUSSION</b> .....	pg.284
 <b>Chapter 11: Discussion of results</b> .....	pg.284
<b>11.1.</b> Introduction .....	pg.284
<b>11.2.</b> Recommendations for mental health practice in Greece: Differential experiences of the notion of “asylum” ...	pg.284
<b>A.</b> Mental health institutions offering temporary asylum .....	pg.284
<b>B.</b> Community Care Units offering temporary and permanent asylum .....	pg.290
<b>11.3.</b> Recommendations for the practice of deinstitutionalisation in Greece: Non-contributory and contributory factors to a successful deinstitutionalisation .....	pg.297
<b>11.4.</b> Recommendations for future mental health policy implementation in Greece .....	pg.298

11.5. Recommendations for future mental health policy research in Greece .....	pg.301
<b>CONCLUSION</b> .....	pg.302
<b>Chapter 12: Conclusion of the thesis</b> .....	pg.302
12.1. Differential experiences of the notion of “asylum” and recommendations for mental health practice in Greece .....	pg.302
12.2. Reflections of the researcher .....	pg.304
12.3. Proposals for future mental health policy research .....	pg.305
<b>REFERENCES</b> .....	pg.307
<b>APPENDICES</b> .....	pg.338
Appendix I .....	pg.338
Appendix II .....	pg.341
Appendix III .....	pg.343
Appendix IV .....	pg.344
Appendix V .....	pg.346
Appendix VI .....	pg.347
Appendix VII .....	pg.349

## TABLES, DIAGRAMS AND FIGURES

### **Table 1:**

Studies with a before and after deinstitutionalisation approach ..... pg.9

### **Diagram 1:**

Mental health institutions providing temporary asylum .....pg.117

### **Diagram 2:**

Strong paternalistic approach of practicing psychiatry in mental health institutions ..... pg.118

### **Diagram 3:**

NIMBYism and Social Stigma as non-contributory factors to a successful deinstitutionalisation ..... pg.118

### **Figure 1:**

Notion of temporary asylum provided by institutions ..... .pg.286

### **Figure 2:**

Notion of temporary and permanent asylum provided by CCUs .....pg.292

### **Table 2:**

List of residents of Klimaka's four CCUs ..... pg.338

**Table 3:**

List of staff members of Klimaka's CCUs ..... pg.339

**Table 4:**

List of other participants ..... pg.340

**Table 5:**

Part 1: Themes concerning the period of institutional care ..... pg.347

**Table 6:**

Part 2: Themes concerning life in the community care unit .....pg.348

## INTRODUCTION

This research in the field of Health and Social Care, deals with the issue of deinstitutionalisation and transition to community care of individuals experiencing SMI, who have been deinstitutionalised from public mental health hospitals to community care units, run by Klimaka, a private, non-profit organisation in Athens, Greece. In this research, all residents and staff members of four community care units that Klimaka runs in the greater area of Athens were interviewed. In order to get a more complete picture on deinstitutionalisation of patients with SMI in Greece, the legal advisor of Klimaka, two staff members of Dromokaition Mental Health Hospital and two officers from the Greek Ministry of Health responsible for mental health services were also interviewed.

The first aim of this study was to explore the shifting meaning of “asylum” by privileging the voices of residents. The research aimed to discover what contributes to residents’ notion of “asylum” in the community care unit: while one dimension of “asylum” is that of a place offering shelter, safety and security, it is important to discover what particular aspects of residents’ everyday life in the community care unit offer this sense of safety and security, and what do not.

A second aim of the study was to compare and contrast residents’ life in the community care unit with their previous life in the mental health institution. This way, it became possible to discover which particular aspects of residents’ everyday life in the hospital used to offer this sense of safety and security, and which ones did not. Residents got a chance to compare and contrast, express their living preferences, and describe the changes that their placement in the community care unit has brought to their lives.

A third aim of the study was to identify what positive features of asylum might be recreated in the community, and what negative ones need to be avoided; also, what positive features of the notion of “asylum” in the community care unit need to be recreated on a larger scale in the

community and what negative ones need to be avoided. Identifying these features can facilitate a better understanding of residents' deinstitutionalisation experience. This understanding can offer valuable lessons of what factors and support mechanisms facilitate a successful transition to community care and what contribute to an unsuccessful one. This way, policy makers can find out what really works for residents of CCUs and reorganise community care services in order to offer true "asylum" to them.

In the Greek context there are very few studies of deinstitutionalisation. Those that do exist tend to focus only on staff or family carers, by using qualitative methods (Assimopoulos, 2006; Loukissa, 1996), or focus on experiences of ex-patients in the community only, but with the use of quantitative methods (Zisi et al, 2006). In the Greek context there is only one qualitative study with a "before and after" deinstitutionalisation approach (Lentis, 2008). Although the study offered valuable insights on the issue of deinstitutionalisation, it was limited by the fact that out of the original sample of 24 chronic patients from a public mental health institution, only 3 individuals had a successful transition to life in a community care unit at the time of the second interview (6-12 months after deinstitutionalisation) (Lentis, 2008). This meant that only they were in a position to talk about their life in a community care unit (Lentis, 2008). As a result, this was the very first time that a qualitative study explored on a larger scale the notion of "asylum" of residents in a community care unit run by the private sector, and gave at the same time the opportunity to participants to compare and contrast life in the community with their previous life in a mental health institution. The originality of this research lies in its context (studying transition to community care in Greece), in its setting (units run by the private sector), and in its methodological approach.

This research seeks to make a serious contribution to knowledge, by filling the gap that currently exists in the Greek context in the field of qualitative studies exploring the issues of deinstitutionalisation and care in



the community, based on residents' experiences. The lack of qualitative studies concerning psychiatric services in general in Greece stems from the fact that social sciences have been developing very slowly in Greece, and also from the fact that the traditional model of biological psychiatry still dominates in the field of mental health (Assimopoulos, 2008). The lack of knowledge of users' –residents' of CCUs - experiences based on qualitative data, may very well be a serious inhibitory factor for the successful transition from hospital based care to community care for people with SMI in Greece (Assimopoulos, 2008). As a result, this study can fill this gap in knowledge, by providing valuable information on residents' notion of "asylum" in a community care unit, in order to successfully recreate it on a larger scale in the community.

This research also serves a new international trend for the production of knowledge – evident also in the U.K. Department of Health's new Research and Development strategy – which can be understood as "...moving away from the traditional, university-based model of knowledge production towards a new one", that places – among other groups – patients at the centre of research (Scott and West, 2008, pg. 387).

The thesis is organised as follows: Chapter 1 addresses the meaning or meanings of the term "asylum", how the transition from institutional care to community care became a reality for people experiencing Severe Mental Illness (SMI), and what were the major driving forces behind the deinstitutionalisation movement. The chapter also explores how two countries with very different health systems, the U.S.A. with a predominately private health system and the U.K. with a national health system, proceeded with the deinstitutionalisation of people with SMI. The major differences between private health systems and national health systems, and the different ways their mental health services are organised, greatly affect patients' experiences concerning deinstitutionalisation (Fakhoury and Priebe, 2002). The U.S. and the U.K.

models offer important lessons to countries like Greece, that now proceed with deinstitutionalisation.

Chapter 2 presents how the transition from asylum care to community care became a reality and how community care services are organised in the Greek context. The chapter also addresses the main problems concerning the implementation of the deinstitutionalisation policy but also the positive side of the psychiatric reform in Greece. Chapter 2 also explores how the current financial crisis has been plaguing both state psychiatric hospitals and care in the community in Greece, greatly affecting the quality of care for people with SMI – patients and CCU residents - in the Greek context.

Chapter 3 presents the theoretical background of the research on the construction of "asylum" as a place offering safety and security. In particular it addresses the importance of exploring the "lived experience" of residents of CCUs in order to create community care services offering indeed "asylum", based on Edward Soja's theory of Thirdspace. The chapter analyses the great value of exploring Thirdspace, not only as a lived space located in the margins of society, but also as a site of radical openness, through which resistance to all forms of oppression can occur.

Chapter 4 addresses why qualitative methods, and in particular semi-structured interviews, were chosen as the best approach for this research. The chapter explores issues of epistemology, reflexivity and positionality of the researcher, along with issues of reliability and validity. The chapter also addresses sampling issues and ethical considerations concerning this research. The chapter also explains why thematic analysis was chosen as the best approach for the analysis of the data.

Chapters 5, 6, 7, 8, 9, and 10, are the substantive chapters of the thesis, where participants' views - residents and staff members of 4 Community Care Units (CCUs) run by Klimaka, the legal advisor of Klimaka, two staff members of Dromokaition Mental Health Hospital and two officers from the Greek Ministry of Health- concerning mental health care and deinstitutionalisation are presented. Chapters 5 and 6 in

particular, present participants' retrospective views and experiences of their life in mental health institutions, covering the following issues: involuntary commitment, communication with the family, financial issues, daily schedule, friends and social networks, relationship with staff, drug treatment and psychotherapy, and notion of "asylum" while in mental health institutions.

Chapters 7, 8, 9 and 10 explore the present life of residents of the CCUs, covering contact with family members, financial issues, friendships and social networks, contact with the neighbourhood, daily routine, relationship with staff, drug treatment and psychotherapy and notion of "asylum" while in the CCUs.

Chapter 11 – Discussion - draws together some of the cross-cutting themes that have emerged from participants' – residents' and staff members' - experiences, in an attempt to portray a wider picture of the key concerns of individuals with SMI who move into CCUs, along with their different experiences of "asylum". The chapter draws out specific proposals, based on participants' experiences for improving life both in institutions and CCUs. Lastly, the chapter addresses lessons for future implementation of mental health policy and deinstitutionalisation in Greece.

Chapter 12, Conclusion, presents a brief overview of the findings of the thesis, along with reflections and proposals for future mental health policy research.

As far as the group of Klimaka's residents that participated in this study is concerned, it should be mentioned that they have all been involuntary patients in public mental health institutions. A few had also been hospitalised for brief periods of time in private mental health hospitals as well. All residents of Klimaka according to the Greek Law, as it will become clear in Chapter 5, were involuntarily admitted to mental health institutions, after being examined by at least two psychiatrists according to the diagnostic criteria used at the time of the involuntary commitment (DSM-II, DSM-III, DSM-IV, and DSM-5). All residents at

Klimaka's CCUs had experienced a form of psychosis such as schizophrenia or bipolar disorder at the time they were hospitalised and - according to the staff members of Klimaka and some residents' own accounts - they were still receiving medication for schizophrenia or bipolar disorder at the time of the interviews. That is the reason why participants have been introduced - only at the beginning of the thesis - as people experiencing SMI.

Since all participants were Klimaka residents at the time they were interviewed, I decided to use the term "residents" in order to designate the group of participants throughout the thesis. On rare occasion, if in the same sentence the term "resident" needed to appear twice, the only alternative term used was "participants". It is also interesting to note that, although the usual term being used by staff members when referring to residents of Klimaka was "residents", in some instances the term "patients" was used by them, so in the respective quotes additional brackets have been used indicating that they referred to the "residents".

Lastly, I would like to mention that the term SMI has rarely been used in the Literature Review chapters, only in few cases where it has been mentioned by the authors of the respective sources in that section.

# LITERATURE REVIEW & IMPLICATIONS FOR RESEARCH

## Introduction

In overview, the literature search had three stages. The literature search of stage one dealt with the search of peer-reviewed articles, books, official reports and legislation relating to the issue of deinstitutionalisation and community care for people with SMI in the countries of USA, U.K., Greece and Italy. The stage two literature search dealt with studies concerning deinstitutionalisation with a “before and after” deinstitutionalisation approach. The stage three focused on the theoretical literature, concerning all literature relating to Soja’s Thirdspace, which I used for the theoretical background of my research. In the initial search phase, article titles and their abstracts were read for relevance, along with book summaries before a more rigorous assessment. Using this approach, in total 530 articles, books, reports and Laws were identified as potentially relevant. In the final document of my thesis, 267 sources have been included.

Stage one focused on identifying academic, peer-reviewed papers and books using a selection of databases including Google Scholar; NHS Evidence; Medline; Pubmed; Web of Science and Scopus. For the Greek literature review search, I had to search the electronic archives of major Greek journals relating to the issue of deinstitutionalisation, from the fields of Psychiatry, Nursing and Social Sciences, involving electronic search of the following scientific journals: Psychiatry (Ψυχιατρική), Nursing (Νοσηλευτική), Social Work (Κοινωνική Εργασία), and Notebooks of Psychiatry (Τετράδια Ψυχιατρικής), the main journals in Greece in this area. The search covered the years from 1950 to 2015. In the initial search phase, article titles and their abstracts were read for relevance, along with book summaries before a more rigorous assessment. Also, since Greece is one of the last European countries to proceed with deinstitutionalisation, and since this issue a) has not been studied to a great extent yet academically, and b) faces currently serious problems due

to the severe financial crisis plaguing Greece, I decided to also include sources derived from newspapers articles. These sources were searched with the aid of google.gr, and consequently through a thorough search of the electronic archives of all major Greek newspapers. Once duplications were removed, the final peer reviewed journal articles, books, reports and Greek newspaper articles with a potential for inclusion were identified. Through a thorough revision of these articles and reading of books, note cards were constructed for each source, with relevant sections that were going to be used on one side, and source on the other. The key words that have been used were: asylum; mental health policy in USA, UK, Italy and Greece; history of mental health policy in USA, UK, Italy, and Greece; community care for people with SMI in USA, UK, Italy and Greece; deinstitutionalisation in USA, UK, Italy and Greece; reinstitutionalisation in USA, UK, Italy and Greece; neoinstitutionalisation in USA, UK, Italy and Greece; transinstitutionalisation in USA, UK, Italy and Greece; stigma and SMI; NIMBYism; biomedical model of practicing psychiatry; medication as a psychiatric intervention. The Italian model of deinstitutionalisation was not included in my final thesis in order to allow for more depth to the analysis of the American and British models of deinstitutionalisation, and explore the differences between a private and a national health system.

Stage two focused on studies that had followed the “before and after” approach on deinstitutionalisation. This approach means following patients before and after their deinstitutionalisation from mental health institutions to community care units. I used a selection of databases including Google Scholar; NHS Evidence; Medline; Pubmed; Web of Science and Scopus. For the Greek literature review search, I had to search the electronic archives of major Greek journals relating to the issue of deinstitutionalisation, from the fields of Psychiatry, Nursing and Social Sciences, involving electronic search of the following scientific journals: Psychiatry (Ψυχιατρική), Social Work (Κοινωνική Εργασία), Notebooks of Psychiatry (Τετράδια Ψυχιατρικής), Psychology (Ψυχολογία), and Nursing (Νοσηλευτική). The search covered the years from 1990 to 2015. The

search revealed mainly British studies, one Swedish, one Canadian and one Greek, that were relevant to my “before and after deinstitutionalisation” strategy, but seven had a different methodological approach.

**Table 1: Studies with a before and after deinstitutionalisation approach**

<b>Author/ Date</b>	<b>Aim/s</b>	<b>Method</b>	<b>Findings</b>
Trieman, N. and Leff, J. (2002).TAPS Project 44	To study the long-term outcome of a group of 72 long-stay psychiatric in-patients, regarded as unsuitable for community placement.	Quantitative	A high proportion of patients with severe disabilities, designated as “difficult to place” in the community, could benefit from slow-stream rehabilitation within specialised facilities enabling them to move into ordinary community homes.
Leff, J. and Trieman, N. (2000). TAPS Project 46	To compare the quality of life of patients in two north London hospitals scheduled for closure, with that in the community homes to which they are discharged.	Quantitative	Community care has enhanced the quality of life of this group of patients, involved in a well-planned and adequately resourced provision programme.
Leff et al.,	To evaluate the	Quantitative	When the capital and

<p>(1996). (TAPS) Project 33</p>	<p>policy of closing psychiatric hospitals and replacing their functions with community-based services.</p>		<p>revenue resources of a psychiatric hospital are reinvested in community services, based on staffed houses, there are few problems with crime or homelessness. With such well-resourced services, the benefits greatly outweigh the disadvantages of both “old” and new long-stay patients.</p>
<p>Daysonet al., (1992). The TAPS project 16</p>	<p>To identify patients who could not be resettled in the community as part of the closure plans of two psychiatric hospitals and to determine their numbers and risk factors for failure.</p>	<p>Quantitative</p>	<p>Rehabilitation efforts should be focused on the characteristics of these patients that put them at risk of failing to succeed on community placements.</p>
<p>Thornicroft et al., (1992). The TAPS project 17</p>	<p>To identify risk factors which increase the likelihood of readmission for long stay psychiatric patients after</p>	<p>Quantitative</p>	<p>During the closure of psychiatric hospitals, facilities need to be preserved for acute relapses, among long-term, and especially younger,</p>



	discharge from hospital.		discharged patients. Staffed group homes may help prevent relapse and reduce the number of admission beds required.
Dencker, K. and Gottfries, C. (1991)	To study all patients in the long term unit of a large psychiatric hospital in Sweden, at an early stage of deinstitutionalisation.	Quantitative	12% of patients were discharged during that year, mostly to other institutions, and only 2 patients to their homes.
Lesage et al., (2000).	To study the relevance of deinstitutionalisation for long-stay inpatients with severe disabilities, from a Canadian mental health institution, and examine the risk that those discharged into the community may be abandoned.	Quantitative	Deinstitutionalisation in the largest Canadian psychiatric hospital did not lead to patient abandonment in the community.
Lentis, D., 2008	To study the deinstitutionalisation of 24 chronic patients from a public mental health institution in Greece.	Qualitative	From the original sample, only 3 individuals had a successful transition to life in a community care unit at the time

			of the second interview (6-12 months after deinstitutionalisation).
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Stage three focused on literature review for the theoretical background of my research. This search focused on literature relating to Soja's Thirdspace that would be of value for my thesis. I also had to read - although I eliminated these sources in the final document - the books of several writers which Soja used in order to build the notion of Thirdspace, i.e. bell hooks, Michael Foucault and Gillian Rose, amongst others. Note cards were constructed for these sources as well, and then were examined at the final document for relevance on contributing to the theoretical questions of my research. From the original list, several sources had to be eliminated, based on the fact of not contributing to the answering of the theoretical questions raised by my research.

The following Chapters 1, 2 and 3 present the Literature Review Chapters. In sub-sections 3.3 and 3.4., the importance of this research is presented, along with the originality of the research and aims and objectives of the study, based on the implications for research derived from the literature review.

## **Chapter 1: Shifting notions of “asylum” and two different models of mental health policy and deinstitutionalisation**

Chapter 1 examines the various meanings of the term “asylum”, drawing on the work of key theorists who have analysed the era of institutional care (Goffman, 1961) and the deinstitutionalisation movement (Scull, 1984). This chapter also examines how the transition from institutional care to community care became a reality for people experiencing Severe Mental Illness (SMI), and the variety of explanations concerning the driving forces behind the deinstitutionalisation movement. Lastly, the chapter presents the way two different countries – the United States and the United Kingdom – implemented mental health policy and proceeded with deinstitutionalisation. These two different models offer very important lessons for future policy implementation in countries like Greece, that are now proceeding with the deinstitutionalisation of people with SMI from mental health hospitals to community care units (CCUs).

### **1.1. The concept of “asylum”**

According to the Webster’s New World College Dictionary the term “asylum” means: “a place where one is safe and secure; refuge”. Different loci though, through the centuries, have been offering “asylum” to individuals experiencing SMI. In the eighteenth century individuals experiencing SMI were locked up in “madhouses”, where the treatment and care they received had very little to do with the original notion of “asylum” (Scull, 1996). “Madhouses” in the Victorian era (1837-1901) came to represent places of horror, where they were perceived as “more or less well-tended cemeteries for the still breathing” (Scull, 1996, pg. 7).

With the goal of offering better care and treatment for people experiencing SMI and improving their living conditions, many asylums – mental health institutions – were built in the United Kingdom, in the United States and in France. The founding of the asylum signaled a great shift in thinking, treatment and places within which that treatment occurred.

Asylum was related to “moral treatment”: people living with SMI were no longer thought of “animal” or “inhuman” but as people in need of a refuge, and a safe haven from the world, along with treatment (Edgerton, 1997, pg. 92). At the end of the eighteenth century, two asylums that introduced great reform were the Bicetre in Paris, under Dr. Philippe Pinel (1793), and the York Retreat founded by William Tuke in 1796 (Jones, 1972). Pinel and Tuke introduced “moral treatment”, that is psychological rather than physical treatment (Jones, 1972; Wing, 1990). Instead of blows and chains, they both introduced fresh air, light, cleanliness, workshops, areas for walking, but most of all: refuge and reparation (Jones, 1972; Wing, 1990). In Bicetre and Retreat, patients managed to find “asylum” in its original sense: they felt protected, sheltered, safe, being cared for by people with genuine compassion and kindness, and a great consideration for their wants and happiness (Jones, 1972; Wing, 1990). These two asylums pioneered great change in treatment of people experiencing SMI across Europe and in the United States (Jones, 1972). Mental health institutions were now responsible for offering “asylum” to patients, and this continued to be the case for the nineteenth century and for the first half of the twentieth century.

This means that up until 1950s – 1960s, the typical structure within which the functions of “asylum” were being carried out was the mental hospital estate (Wing, 1990). Wing provides a description of the functions of asylum within this context:

“The first function (refuge, shelter, retreat, sanctuary) included protection from: cruelty; exploitation; intolerable stress; competition (e.g. if unable to compete for housing or work on the open market, or unable to use ordinary amenities for recreation); pauperism (insufficiency of food, light, heat, clothing and basic personal possessions); social and intellectual poverty and isolation; and harming self or others, whether by self-neglect or violence. The second function, reparation, included: identification of the causes of social disablement, by skilled diagnosis and psychosocial assessment; treatment, within the limits of contemporary medical knowledge, of the physical and mental disorders responsible for admission; and provision, within the

limits of local social attitudes and facilities, of the means of rehabilitation and resettlement” (Wing, 1990, pg. 824).

These functions of asylum were being carried out sometimes very well by the standards of the time, but often not well enough (Wing, 1990). Under the principle of “*parens patriae*”, patients living with SMI within mental health institutions were able to find an orderly parental household, with kind attention, but this was not without a price to personal autonomy (Segal and Baumohl, 1988). Patients did not have to worry about where to find shelter, food and clothes, or about the need to pay the bills, but such a relationship assumed a great degree of dependence by the part of the patient, “...who by forfeiting his autonomy, could be assured of stability and security through the medium of ready-made home” (Segal and Baumohl, 1988, pg. 259).

Over time the number of patients in public mental health institutions in the U.S.A. and in European countries like Great Britain, constantly increased (Torrey, 1988). The very size of institutions (sometimes containing more than 2,000 patients) was contradictory to the domestic surroundings necessary for treatment on moral principles (Paterson, 2000; Jones, 1972). Many mental health institutions found it impossible to attract the necessary number of attendants required to “...manage disturbed patients without resorting to measures of restraint” (Paterson, 2000, pg. 7). Gradually, the system of treatment came to be seen as a system of control, that often resulted in extreme violations of patients’ personhood (Goffman, 1961).

For many chronic patients, environmental poverty inside mental health institutions was associated with the “clinical poverty syndrome”: The lack of contact with the outside world and the isolation that patients felt, along with stimulus deprivation during their long years of hospitalisation was seen as resulting in poverty of speech, flatness of affect, apathy, feelings of worthlessness and social withdrawal (Tomlinson, Carrier and Derton, 1996, pg. 117).

In the 1950s and 1960s, both in the United States and in European countries like Great Britain, mental health policy makers and others started to question whether the “classical system” – meaning one in which the hospital was the dominating feature – was appropriate (Isaac and Armat, 1990; Pilgrim and Rogers, 1993). Asylums were no longer offering an “asylum” in its original sense, but were just keeping patients isolated and away from the rest of community (Philo, 1987). As a result, they needed to be replaced with a new “modern” system that would help patients to “return” back to the everyday life of community: through a variety of services in the community individuals would have opportunities for social interactions, employment and becoming part of society. This notion gave birth to the deinstitutionalisation movement.

### **1.2. The deinstitutionalisation movement: Community care units offering “asylum”**

In the 1950s and 1960s a big breakthrough in the delivery of mental health services came with the deinstitutionalisation movement in the United States and in European countries like the United Kingdom and later Italy (late 1970s). Under the notion of care in the community, the state was no longer seen as an overseer of large, isolated “total institutions” (Goffman, 1961), but instead became a provider of community care services. Some of the explanations offered for the rise of the deinstitutionalisation movement include: a) the perception of deinstitutionalisation as a “cost-saving” policy by policy-makers, b) the discovery of anti-psychotic drugs, c) the “anti-psychiatry” movement, d) the community care movement and e) the ex-patient movement.

These driving forces contributed greatly to the implementation of deinstitutionalisation, and had a great impact in both the United States and in Europe. Although each country had its own health system and mental health policy and implemented deinstitutionalisation differently, the operation of these driving forces can be seen in all.

### **1.2.1. Driving forces behind the deinstitutionalisation movement:**

#### ***(a) The perception of deinstitutionalisation as a “cost-saving” policy by policy-makers***

The deinstitutionalisation movement was supported by a very strong economic imperative: policy makers in the United States and Europe viewed deinstitutionalisation as a policy of “cutting down the expenses” of institutional care. At that time, it was widely assumed that community-based care would be cheaper than hospital-based care (Lamb and Bachrach, 2001). Unfortunately, it took decades for policy-makers to realise that: “...if all the hidden costs associated with responsible programming are considered, it is generally not accurate to conclude that community services will result in substantial savings over hospital care” (Lamb and Bachrach, 2001). Back in the 1950s and 1960s though, deinstitutionalisation was often perceived or portrayed by policy-makers as a “cost-saving” policy and as the only practical solution to reducing the great costs associated with hospital care. This economic driver was particularly strong in the United States. In 1955 the census of the nation’s mental health hospitals reached its peak of 560,000 (Talbot, 2004). Policy-makers decided that the cost of dealing with mental illness through institutional care was too great to be borne: the state could no longer go on building and expanding mental health hospitals, because the burden upon tax payers was already becoming intolerable (Isaac and Armat, 1990). For policy-makers the deinstitutionalisation of patients to the community seemed the main solution to the problem of funding care.

At that time, the United Kingdom faced similar problems: Asylums in the U.K. during the first half of twentieth century became overcrowded, and the system slowly became overwhelmed by the number of patients that were admitted. As a result, there were very strong political pressures to keep costs down (Pilgrim and Rogers, 1993). Mental health hospitals had been very expensive to run, especially since the Second World War, mainly for two reasons: 1) the elimination of unpaid patient labour, and 2)

the increased cost of employees, due to the unionisation of labour (Pilgrim and Rogers, 1993). As a result, unit costs had been greatly increased. Again, deinstitutionalisation was seen as the best possible solution to the funding problem.

As a result, in both countries, large asylums had to be eliminated in order to save money. Scull (1984) offered a model in order to explain the policy change of closing down asylums. According to Scull, the main causes for the shift from asylums to community care were: 1) the increased costs of segregative control, meaning the increased cost of keeping people with SMI separated and isolated from the rest of society in large institutions, and 2) the fiscal crisis of the state. He writes that the deinstitutionalisation policy can be explained as follows:

“...In particular, it reflects the structural pressures to curtail sharply the costly system of segregative control once welfare payments, providing a subsistence existence for elements of the surplus population, make available a viable alternative to management in an institution. Such structural pressures are greatly intensified by the fiscal crisis encountered in varying degrees at different levels, of the state apparatus; a crisis engendered by advanced capitalism’s need to socialize more and more of the costs of production – the welfare system itself being one aspect of this process of socialization of costs” (Scull, 1984, pg. 152).

Scull, a Neo-Marxist theorist and one of the most prominent theorists of the deinstitutionalisation movement, has been very critical about the way economic pressures determined the reduction in or even abolition of mental health hospitals and the implementation of deinstitutionalisation as a mental health policy, primarily for cost-saving reasons. Scull believed that the community care movement was useful as “...ideological camouflage, allowing economy to masquerade as benevolence, and neglect as tolerance” (Scull, 1984, pg. 152).

### ***(b) The discovery of anti-psychotic drugs***

The “economic engine” of the deinstitutionalisation movement – described in the previous section – was rapidly “fueled” by the discovery of



anti-psychotic drugs. One of the most important pharmacological breakthroughs was the discovery of the major tranquillisers in the early 1950s, and by the mid 1950s chemical methods (drug therapy) rather than physical came to dominate psychiatric therapy. These anti-psychotic drugs did affect symptom reduction of SMIs, and in particular schizophrenia, but within certain limits (Johnson, 1990). That is, psychotropic drugs could alleviate symptoms, but not cure patients (Jones, 1972). Even in today's *Pharmacologie* scientists explain that the anti-psychotic drugs cannot cure schizophrenia, but they allow patients to function satisfactorily with the help of a supportive environment (Myceck et al., 2003). What anti-psychotic drugs offered primarily was a gain in symptom reduction.

By offering better control of the symptoms of schizophrenia, anti-psychotic drugs greatly helped a substantial number of former in-patients and increased their ability to function in the community (Isaac and Armat, 1990). Their use meant that people with schizophrenia could either remain in the community with support, but without having to go to hospital, or that they could spend only short periods in mental health hospitals for stabilisation and then return to the community (Jones, 1972). As a result, the use of anti-psychotic drugs greatly facilitated the deinstitutionalisation policy and the notion of care in the community.

### **(c) The “anti-psychiatry” movement**

A strong anti-psychiatry movement began to emerge in the 1960s in Europe and in the United States that also facilitated the process of deinstitutionalisation. In 1961, in the United States, Goffman published his highly influential book: *Asylums: Essays on Social Situation of Mental Patients and Other Inmates*. Goffman described life not only in mental health hospitals, but generally life in “total institutions”, such as orphanages and prisons.

According to Goffman, an individual experiencing SMI comes into the establishment with a conception of him/herself made possible by certain

stable social arrangements in his/her home world. But upon entrance he/she begins a series of humiliations and degradations of self:

“His self is systematically, if often unintentionally, mortified. He begins some radical shifts in his moral career, a career composed of the progressive changes that occur in the belief that he has concerning himself and significant others” (Goffman, 1961, pg. 24).

The writer also notes that a patient in a mental health institution finds him/herself in a position where he has to dress, eat and act like everyone else, following a very strict set of hospital rules; as a result he/she loses any sense of personal identity (Goffman, 1961).

Goffman notes that total institutions place a great barrier between an inmate and the wider world. An inmate’s separation from the wider world lasts around the clock and may continue for years; as a result, role dispossession occurs, meaning loss of prior socially valued roles, which give to a person self-esteem, psychological security and a valued identity. According to the writer, although some roles can be reestablished when he/she returns to the world, “...it is plain that other losses are irrevocable and may be painfully experienced as such” (Goffman, 1961, pg. 25). He also notes that a patient is considered to be “ready for liberty” only if he/she is a manageable person, very obedient, never expressing negative feelings against staff members or of life in hospital in general. But, if a patient fails to do so, then he/she is submitted to further treatment (Goffman, 1961). According to the writer, patients can find themselves “...crushed by the weight of a service ideal that eases life for the rest of us” (Goffman, 1961, pg. 336).

Goffman observed that in mental health institutions patients learned certain behaviours that helped them cope and live better in the inhumane environment of the hospital and he called these behaviours “secondary adjustments”. According to Goffman, these adjustments are non-symptomatic responses – meaning that they have nothing to do with SMI – but are referred to the institutional setting. Goffman (1961) believes that secondary adjustments are patients’ rational attempts to protect

themselves from the threatening and humiliating environment of institutions.

On the other hand, he expressed the view that most negative symptoms of SMI that patients expressed in institutional settings, such as apathy, poor speech and social withdrawal, were actually the result of long years of hospitalisation, lack of contact with the outside world, extreme isolation, and deprivation from any type of stimulus. According to Goffman, “institutionalism” or “institutionalitis” is developed in mental health institutions and other “total institutions” like prisons. As a result, according to the writer, mental health hospitals were responsible for most of symptoms of their patients (Goffman, 1961).

Goffman’s work was followed by the works of “labeling theorists”, perhaps most notably R.D. Laing and Thomas Szasz. According to these theorists, what gets defined as sickness does not always have a biological substrate. “Sickness” may be an individual’s “failure” to conform with wider social expectations, and as a result he/she gets labeled “sick” (Laing, 1967; Szasz, 1976).

Laing, a British psychiatrist, studied the effect that the family has on individuals experiencing SMI. He believed that it was the family of individuals experiencing schizophrenia that played a key role in the origins of mental illness. Both in his first book *The Divided Self*, published in 1960, and in his second book *The Politics of Experience*, published in 1967, Laing treated the behaviour of a person experiencing SMI as a rational strategy he/she uses in order to deal with a terrifying family environment: “...the experience and behaviour that gets labeled schizophrenic is a special strategy that a person invents in order to live in an unlivable situation” (Laing, 1967, pg. 114-115).

In his second book *The Politics of Experience* (1967) Laing became more radical, denying the existence of schizophrenia: “...There is no such “condition” as Schizophrenia, but the label is a social fact, and the social fact a political event” (Laing, 1967, pg. 121). Laing began progressively to

develop the idea of schizophrenia as a life-enhancing experience and a higher form of sanity (Laing, 1967).

Szasz also influenced the anti-psychiatry movement. In his book: *The Myth of Mental Illness* (1961), he argued that mental illnesses do not exist: the diagnoses associated with SMI are just “labels” that society uses for behaviours that are not acceptable. Szasz did not try to rationalise the perception of people experiencing SMI: for him there was no mental illness.

In *Liberty and Psychiatry* (1963), Szasz proposed the abolition of all involuntary hospitalisation, and encouraged individuals experiencing SMI to fight against psychiatry with the help of the legal profession (Szasz, 1963). For Szasz, schizophrenia was the invention of psychiatrists. In *Schizophrenia: The Sacred Symbol of Psychiatry* (1976), Szasz developed his argument, maintaining that: “...the identity of an individual as schizophrenic depends on the existence of the social system of (institutional) psychiatry. Hence, if psychiatry is abolished, schizophrenics disappear...” (Szasz, 1976, pg. 136).

The notion behind labeling theory was that family and society are the main causes of schizophrenia. For the labeling theorists mental illness was a socially constructed “label”, and the anti-psychiatry movement proposed the abolition of mental health hospitals (Szasz, 1976).

#### **(d) The community care movement and the ex-patient movement**

Along with the anti-psychiatry movement, in the late 1950s – early 1960s, the community care movement was born. The notion that psychiatric treatment in the community is far better than treatment in the asylum, was greatly influenced by Dr. Gerald Caplan, who in 1961 published his pioneer work: *An Approach to Community Mental Health*, and in 1964: *Principles of Preventive Psychiatry*. Caplan believed that hospitalisation in a mental health institution is an important cause of disability and that most of the symptoms of patients experiencing SMI are

produced not by the mental illness that led to their admission, but by the pathogenic environment of asylums (Caplan, 1964).

Caplan also believed in preventive psychiatry. Unsolved problems early in life create great stress, leading to neurosis or psychosis (like schizophrenia), but if there is primary prevention, then it is easier to detect and treat these cases before an individual develops mental illness (Caplan, 1964). The goals behind the community care movement were early intervention and prevention, to make hospitalisation either unnecessary or to make it necessary for a short period of time, and to provide that service in the community. The movement along with the use of neuroleptic drugs encouraged optimism that community care services could maintain former patients in the community.

In the late 1960s and early 1970s an alliance of ex-patients and some psychiatrists organised a movement against mental health institutions and all somatic treatments. In the U.S.A., U.K., Italy and in many other countries all over the world, ex-patients formed liberation groups for the inmates of mental health institutions; these groups on the one hand exposed the uncivilised and barbaric conditions that existed in institutions and on the other fought in order to protect inmates from abuse, mistreatment and neglect (Torrey, 1988; Isaac and Armat, 1990). The movement was greatly influenced by the human rights movement in the 1960s and aimed to abolish all somatic treatments – especially psychosurgery, electroconvulsive therapy and psychoactive drugs (Isaac and Armat, 1990).

The perception of deinstitutionalisation as a “cost-saving” policy by policy-makers, the discovery of anti-psychotic drugs, the “anti-psychiatry” movement, the community care movement and the ex-patient movement, all contributed to a shift of policy towards deinstitutionalisation.

### **1.3. Different models of mental health policy and deinstitutionalisation**

This section presents how two different countries – the United States and the United Kingdom, proceeded with the deinstitutionalisation of individuals experiencing SMI. Despite sharing many common experiences, countries may differ, because of their specific traditions, funding arrangements and socio-economic situations (Fakhoury and Priebe, 2002). It is also important to note that the way mental health services and the healthcare system in general are organised in each country, plays a crucial role in the way deinstitutionalisation becomes a reality. Two countries with very different health systems – U.S.A. with a private health system and U.K. with a national health system - proceeded very differently with the deinstitutionalisation of people with SMI. Of course, there are other countries with interesting models of deinstitutionalisation as well: for example, in Italy, deinstitutionalisation proceeded in a very radical way, under the initial guidance of Dr. Franco Basaglia, by abolishing in a very short period of time all mental health institutions. However, in order to present my argument about the differences between private health systems and national health systems, and the different ways their mental health services are organised, I decided to compare the history of deinstitutionalisation in the U.S.A. and U.K., and explore the U.S.A. versus the U.K. model of deinstitutionalisation.

The experience these countries have had on this issue could provide invaluable lessons for countries such as Greece that now proceed with deinstitutionalisation.

#### **1.3.1. The Deinstitutionalisation Movement and Mental Health Policy in the United States**

The United States has always had a system of private healthcare with the state providing only residual services for certain groups of very poor people (Torrey, 1988; Isaac and Armat, 1990). Traditionally, America's patients experiencing SMI have been cared for in state

psychiatric facilities (Talbot, 2004). By the late 1950s and 1960s though, mental health institutions came to be viewed not as medical treatment centres, but as “factories for the manufacture of madness” (Goldman and Morrissey, 1985), as well as a major item in state budgets (Goldman and Morrissey, 1985; Torrey, 1988).

In the 1950s, all forces mentioned in the previous section - cost-saving reasons, discovery of anti-psychotic drugs, anti-psychiatry movement, community care and ex-patient movement - were shaped into administrative policy by federal and state departments of mental health. The departments favoured the new trend for deinstitutionalisation, that involved mainly two elements: the discharge of existing state hospital patients to the community and a decrease in new admissions to state facilities (Torrey, 1988). In 1963, President John F. Kennedy signed into law the Community Mental Health Act - also known as the Mental Retardation and Community Mental Health Centres Construction Act of 1963 - which drastically changed the delivery of mental health services (thenationalcouncil.org, 2015). This law led to the establishment of community mental health centres throughout the country.

According to legislation, CMHCs had to offer five services: consultation and education services, outpatient services, emergency services and in-patient services (Torrey, 1988). The original intent was for CMHCs to receive federal funding for 4½ years, and then become self-sufficient (Ray and Kanapaux, 2002). Unfortunately, that expectation never became a reality, for two reasons: first, CMHCs had to treat a large number of patients who often arrived at the centres with no money to pay, and second, individuals with private insurance hesitated to receive treatment from a CMHC along with newly released patients from state mental health hospitals, mainly because of the stigma associated with mental illness (Ray and Kanapaux, 2002). So, CMHCs started relying on the states rather than federal funding. By the early 1970s, it became clear that without increased funding, efforts for care in the community would

become increasingly ineffective because of the financial problems CMHCs were experiencing (Talbot, 2004).

Although community care units were facing serious problems, the policy of deinstitutionalisation proceeded: by 1984, 80% of the beds occupied in 1955 in state hospitals were taken out of use (Torrey, 1988). This meant that a massive shift of patients took place from mental health institutions into the community. Since CMHCs were facing serious problems, thousands of chronic patients with SMI were transferred to nursing homes instead (Talbot, 2004). In fact, as of 1977, about half of the 1.3 million residents of nursing homes in the U.S. had a SMI, "...making nursing homes the single most commonly used psychiatric long-term care facility" (Goldman and Morrissey, 1985). Nursing homes though did not offer "asylum" in its original sense to these individuals, as living conditions in them became very difficult because of the overcrowding (Talbot, 2004).

The transfer of thousands of ex-patients to nursing homes has been viewed by certain theorists and analysts, as strong evidence that deinstitutionalisation in the United States was caused by the underlying economic trends of privatisation and corporate welfare, and this was intensified by the essentially private nature of the American health care system (Scull, 1984; Harman, 2002). Scull (1984) viewed deinstitutionalisation as "transinstitutionalisation": he believed that the Federal Community Care bill of 1965, rather than saving money, actually shifted money from state mental health hospitals to "for-profit" nursing homes, through the discharge of patients (Scull, 1984, pg. 151, 166). The shift of responsibilities of care for patients with SMI from the public to the private sector, with private units working under the capitation system – according to which agencies receive a fixed amount of money per patient – has led to fears of undertreatment, lower quality services, and/or reduced patient choice of treatment (Fakhoury and Priebe, 2002).

The situation in the U.S. was exacerbated in the 1980s, because the Department of Housing and Urban Development reduced incentives for



builders to create low-income housing units, and as a result, the number of these units decreased dramatically: in the period 1970-1982, 1,160,000 single room units disappeared (Torrey, 1988). But CMHCs were also facing an economic crisis, which became even greater in the 1990s: the states started refusing to give any additional funding; public officials suggested that only the strongest centres would survive (Ray and Kanapaux, 2002). In the 1990s the dream of CMHCs' financial independence dissolved for good.

For patients released from mental health institutions the consequences were serious. In many cases the "ghetto" or the streets replaced the mental health hospital in offering "asylum" (Dear and Wolch, 1987). In many North American cities, huge ghettos of discharged ex-patients were created in areas of low-cost housing, proprietary homes, in deteriorating neighbourhoods (Talbot, 2004). In these parts of the inner city, service providers found the least community opposition, along with cheap housing. In suburban areas and affluent city neighbourhoods on the other hand, mental health services were typically excluded, on the basis of the Not In My Backyard attitude, which stemmed from the fear of residents that the presence of individuals with SMI in their neighbourhood would jeopardise their sense of security (Dear and Wolch, 1987).

In many cities in the U.S.A. where ghettos were formed it was the ghetto that actually offered "asylum" to individuals experiencing SMI (Talbot, 2004). Even in the ghetto though, many individuals with SMI found it practically impossible to find affordable housing. Ex-patients who were unable to work had to rely on Supplemental Security Income (SSI), which could not cover the rent even for a one-room bedroom apartment (NRC, 2004, Question 1). As a result, thousands of former patients ended up homeless (NRC, 2004). As Goldman and Morrissey (1985, pg.729) noted: "Community mental health brought mental patients "home"; deinstitutionalisation left them homeless".

Statistics on the issue of homelessness in the U.S.A. have been alarming: in 1996, an estimated 2.1 million adults were homeless over the

course of a year, and people with SMI were over represented among this population (NRC, 2004). At that time, although only 4% of the U.S. population had a serious mental illness, five to six times as many people who were homeless (20-25%) had serious mental illness (NRC, 2004, Question 4, pg. 1). In the late 2000s and early 2010s, people with mental illness were still over-represented among the homeless, relative to the general population: a large survey that was performed in 2012 revealed that approximately 633,000 people are homeless on a given night in the U.S.A. and 26% of these people are experiencing severe mental illness at any given point in time (HUD, 2012; endhomelessness.org, 2015). Also, in a survey that was performed in 2008 by the U.S. Conference of Mayors, twenty five cities were asked for the main causes of homelessness in their communities, and 48% of the cities mentioned mental illness as the third largest cause of homelessness for single adults (National Coalition on Homelessness, 2009; endhomelessness.org, 2015).

Living on the streets, it can be difficult for people with SMI to keep taking their medication, and in such a case they usually start feeling extremely disorganised, fail to notify mental health services, stop receiving any form of treatment or social support, and in many cases get easier access to alcohol or street drugs (Lamb and Bachrach, 2001). Also, people experiencing SMI have greater difficulty exiting homelessness than the others, and they are "...twice as likely as other people who are homeless to be arrested or jailed mostly for misdemeanors" (NRC, 2004, Question 4, pg. 1, 2). As Greenberg and Rosenheck (2008) noted, homelessness combined with SMI and substance abuse, greatly increase the risk of incarceration in prisons (Greenberg and Rosenheck, 2008).

As a result, for many individuals released from mental health institutions, prisons and jails replaced mental health hospitals in offering "asylum". Individuals experiencing SMI who fell through the treatment gaps of the mental health care system, found themselves trapped in the "revolving prison door" cycle, going from acute hospitalisation to homelessness to arrest (Birmingham, 1999; Baillargeon et al, 2009). In

fact, the “epidemic” of psychiatric disorders in the U.S. prison system has been described as a national public health crisis: studies show that 15%-24% of U.S. inmates in prison have a SMI, and a recent report by the Bureau of Justice Statistics indicates that approximately half of inmates – which means more than 1 million individuals – have at least one mental health condition (Baillargeon, et al, 2009). As Lamb and Weinberger (2005, pg.532) noted: “It has now been left to the criminal justice system to provide the high-caliber and humane level of services that was once the domain of the mental health system”.

Lastly, it is important to note that it is difficult for ex-patients with SMI in the U.S.A. to find “asylum” in mental health hospitals during periods of relapses, due to the dramatic decrease in hospital beds: Over the past fifty years, there has been a 95 percent reduction in the country’s state hospital population (Fisher et al, 2009). The law in the U.S. has also made it very difficult for people with SMI to receive treatment in mental health hospitals for longer than a few days (Torrey, 1988). Patients spend fewer days in hospital every time they get admitted, but account for many more admissions and readmissions to a larger number of hospitals, resulting in the “revolving-door syndrome” (Talbot, 2004). Brief hospitalisations though may fail to stabilise escalating psychiatric symptoms and increase the risk of relapse (Baillargeon et al, 2009).

It is important however to note that besides the efforts to reduce their use and to close them, more than 200 state hospitals remain open, serving a declining but challenging population of patients suffering from severe medical conditions (respiratory problems, hypertension, heart disease, diabetes, epilepsy, blindness, deafness and in some cases cancer) and/or problematic behaviours (poor self-care or dangerousness to self or others) (Fisher et al, 2001; Fisher et al, 2009). Equally important is the fact that across the U.S.A. the decline in the state hospital population has stalled and for the first time since the 1950s it has shown an upturn in some states (Fisher et al, 2009). Although some states still plan to close their mental health hospitals, at the same time others have

recently built or plan to build new facilities, in order to provide “asylum” to people with SMI (Fisher et al, 2009).

From this analysis it appears that the deinstitutionalisation movement in the U.S.A. had some serious and unanticipated negative effects (Torrey, 1988; Isaac and Armat, 1990; Talbott, 2004). Lamb and Bachrach (2001) summarise the lessons that can be learned from the U.S. experience as follows: 1) that successful deinstitutionalisation involves more than simply changing the locus of care from mental health institution to community care units, as serious planning is needed before and during the process; 2) that there is a great need for individualised care for people with SMI, as they constitute a diverse and heterogeneous group of people; services should be tailored for individual needs; 3) that hospital care must be available to those individuals who need it, and for as long as they need it; 4) that people with SMI must be involved in service planning, in order for services to become effective to their needs; 5) that service systems must be open to changes and flexible; and 6) that continuity of care must be achieved, in order to ensure a “smooth” transition from mental health hospital to community care.

### **1.3.2. The Deinstitutionalisation Movement and Mental Health Policy in the United Kingdom**

One should keep in mind that there are important differences between the health care systems in the U.S.A. and the U.K. The health system in the U.K. is based on the NHS (National Health Service), which was set up in 1948, in order to provide healthcare for all citizens, based not on the ability to pay, but on need (NHS, 2006a). Its purpose was: "...to promote health, to prevent ill health, to treat illness and disease, and to care for those with long-term health needs" (Williamson, 2002). The core element of the philosophy behind the NHS is that the provision of care is free at the point of need, and is designed to meet the needs of all people (NHS, 2006b). As a result, mental health policy and the deinstitutionalisation movement have proceeded in the U.K. very differently from the United States.

The first attempts to develop community care services in the U.K. took place in the 1950s. In 1959, the Mental Health Act recommended a shift from asylum to community care; it also gave to local authorities the legal basis for the provision of preventive services, as well as the establishment of residential alternatives to hospitals, along with training and occupation centres (Welshman, 1999). However, lack of funding meant that progress was slow, and provision in most areas was poor (Welshman, 1999). Things changed a little in the late 1960s, due to a relaxation of the restriction on capital expenditure, and as a result many new junior and adult training centres and hostels were created, and more social workers were employed; however, progress was still slow and uneven (Welshman, 1999).

In 1971, a Government paper on *Hospital Services for the Mentally Ill*, proposed the complete abolition of the mental health hospital system, with all services being delivered by District General Hospital Units (DHSS, 1971), which were part of the general hospital, offering a therapeutic regime similar to that provided in mental health hospitals, but in a much more modern environment (Pilgrim and Rogers, 1993). The focus for

DGHUs was to organise psychiatric services, based on inpatient and outpatient facilities, within the hospital building (Killapsy, 2006). As a result, outpatient clinics became an integral part of psychiatric service provision (Killapsy, 2006).

Alongside these developments, in 1975 and in 1981 two government policies: *Better Services for the Mentally Ill* and *Care in the Community*, supported a greater shift towards community care, with the development of more community-based services for people with SMI such as supported housing and day services (DHSS 1975; DHSS, 1981). At the same time, the 1975 White Paper (DHSS, 1975) stressed the fact that there was still no standard level of provision for people experiencing SMI in the community, and that there were great variations among different areas of the country (DHSS, 1975; Welshman, 1999).

The most famous critique though on community care came from Richard Titmuss, who stressed the fact that community care was not cheaper than institutional care, and wrote that: “if community care is not to spell community irresponsibility, what is first needed is a definitive policy and legislation, then leadership, then a willingness to spend the money required” (Titmuss, 12/5/1959). Titmuss believed that the transformation of asylums to therapeutic institutions would be a very expensive procedure, and he urged policy-makers to give increased funding to community care services and increased grants to local authorities. He believed that by transferring patients from mental health institutions to community care, there would be a transformation of care and responsibility from trained staff (doctors, nurses, social workers, psychologists) to untrained staff or no staff at all. As a result, community care services needed more money in order to employ more social workers and mental health nurses, so that provision and care for people with SMI in the community would reach a satisfactory level (Titmuss, 1961). Because of the financial problems community care services were facing – which persisted in the 1970s – the 1983 Mental Health Act increased the support for care in the community for individuals with SMI (Payne, 1999).

It becomes clear from this analysis that during the first two decades of transition (1960s and 1970s) from institutional care to care in the community in the U.K., community care services were developed slowly, mainly because available funding was inadequate to meet the needs (Payne, 1999). The reduction in psychiatric beds in the U.K. during that period was not as dramatic as it was in the U.S.A., reflecting the fact that deinstitutionalisation in the U.K. was not as rapid or far-reaching as it was in the U.S.A. (Scull, 1984). In the years between the mid 1950s and mid 1970s the population of English hospitals was declining by a relatively modest average of 3% per year; overall, during that period the inpatient census of English mental health hospitals declined by one-half, whereas during the same period the American mental health hospital population fell to less than a quarter of what it was in the 1950s (Scull, 1984). Also, ex-patients in the U.K. did not have to go through the ordeal of “transinstitutionalisation” during the first two decades (mid 1950s - mid 1970s) as quickly or as dramatically as happened in the U.S.A. (Scull, 1984). This reflects on the one hand the lower number of chronic patients discharged, and on the other “...the more entrepreneurial character of American capitalism, and the greater legitimacy accorded to the process of privatization of state and welfare services” (Scull, 1984, pg. 168).

In the U.K. the national pace of dehospitalisation has been very slow, with no closures of a psychiatric hospital before the 1980s, perhaps due “...to the lack of centralised co-ordination and legislative commitment to mental health reforms by successive British governments” (Jones, 2000, pg. 183). The ideology of “New Right”, introduced into British politics by the Conservative government led by Margaret Thatcher in 1979, gave impetus to the pace of psychiatric hospital closure and shift to community care (Jones, 2000). This change in political context resulted in more effective state mechanisms, in order to enable the “top-down” implementation of national policies concerning care in the community at the local level (Jones, 2000).

In late 1980s – early 1990s, however, particular events created an increasing fear in the general public of people with SMI: the high profile case of Christopher Clunis for example, a man who was diagnosed as schizophrenic, who murdered Jonathan Zito in an unprovoked attack at Finsbury Park station in London, highlighted the potential for ex-patients with SMI in the community, living a “transitory” lifestyle, to lose contact with mental health services (Killaspy, 2006, pg. 250). Special programmes like the Care Programme Approach (CPA), were implemented in order to monitor more effectively ex-patients in the community and improve continuity of care for people with SMI (Department of Health, 1990). According to the CPA programme, individuals diagnosed with SMI should have an identified professional who coordinates their community care and constructs a package of services to meet their needs. The identified professional should arrange regular reviews of their care with other professionals, including their consultant psychiatrist (Department of Health, 1990; Killaspy, 2006). If an ex-patient or a person with SMI in general, moves to another geographical area, there has to be handover of this responsibility through a formal process, in order to minimise the chances of him/her becoming discharged from services (Department of Health 1990; Killaspy, 2006).

In 1999, the *National Service Framework for Mental Health* set targets for the implementation of specialist community mental health services across U.K., such as community mental health teams, assertive outreach teams, crisis resolution teams, and early intervention services (Department of Health, 1999a; Department of Health, 1999b; Department of Health, 2001 ). Community Mental Health Teams bring together health and social care professionals within an integrated management structure and in the U.K. context most mental health social workers in statutory settings work in CMHTs (Webber, 2011). When CMHTs are compared with non team standard care, the major and most consistent difference is lower hospital admission rates for people that receive CMHT care (Malone et al., 2007). However, many of the presumed benefits of CMHTs such as



greater user and carer satisfaction, improved social functioning and lower cost, have not been found through these trials (Malone et al., 2007; Webber, 2011).

Crisis resolution/ home treatment teams aim to provide an alternative to hospital admission for those experiencing acute mental health difficulties; in order to achieve this, the team stays intensively involved for as long as necessary for the crisis to be resolved (Onyett et al, 2008). Crisis resolution teams have been shown not only to reduce the likelihood of admission when compared with community mental health team care, but to also lead to improved patient satisfaction with services (Glover et al, 2006; Killaspy, 2006). Assertive community treatment (ACT) teams on the other hand, which target people with enduring SMI who are high users of in-patient care and have problems engaging with standard mental health services, have not been found to be able to reduce admissions in the U.K., despite the fact that they have been associated with improved client engagement (Killaspy et al, 2009).

Lastly, for early intervention teams, studies have shown that early intervention reduces the risk of a second relapse (Singh, 2010). A major benefit is that early intervention appears to be cost-effective in the short-medium term (McCrone et al., 2010). However, it appears that gains made while in the care of early intervention teams disappear when people move on to generic services (Gafoor et al., 2010; Weber, 2011). From this it becomes clear that more research studies and systematic reviews are needed in the U.K. context, in order to draw safe conclusions about the effectiveness of all these different approaches.

Although these teams have been central to English mental health policy since 1999 and many of them achieve great local impact, implementation is still variable: for example, a much greater number of CRHT teams that operate in urban areas seem to be fully set up when compared with suburban and rural teams; also, telephone support and out-of-hours access are more usual in urban locations (Onyett et al, 2008).

This fact though lends fuel to the debate over whether these teams and community care services in general offer an essentially urban solution.

Another important feature of deinstitutionalisation in the U.K. is that the establishment of community care units has not created so many serious problems in relationship to NIMBYism attitudes and reactions from local communities, as happened in many North American cities (Moon, 1988). It is common practice in England, for example, to inform neighbours in advance of a planned new community mental health service, with many meetings, in order to address neighbours' concerns (Thornicroft et al, 2008, a, b). Through extensive information-sharing and consultation, service providers try to foster good neighbourly relations between local residents and residents in the community care homes (Thornicroft et al, 2008, a, b). As a result, although suburban jurisdictions have been slow in the U.K. to provide services and facilities for ex-patients, and NIMBYism attitudes have been evident to a certain extent (Sibley, 1995), at the same time reactions from local communities have been milder than in the U.S.A.

Another very important factor contributing to the promotion of socially inclusive attitudes in the U.K. are the public campaigns that the government organises in order: 1) to reduce stigma and discrimination against people with mental health problems, and 2) to promote further existing legislation around equality (Killaspy, 2006). Governmental support for the promotion of such campaigns along with many socially inclusive practices for individuals with SMI have come from the Social Exclusion Unit of the Office of the Deputy Prime Minister's report on mental health (2004): this identifies the needs of people with SMI for improved access to job opportunities, education and leisure facilities, with a resulting reduced dependence on specialist institutions (such as day centres), and better social inclusion (Killaspy, 2006).

In general, dehospitalisation and deinstitutionalisation in the U.K. have proceeded slowly with careful planning, and without putting patients through the ordeal of discharging them into the community without adequate preparation and community care provision. The Team for the

Assessment of Psychiatric Services (TAPS) that was established in 1985 by the North East Thames Regional Health Authority (NETRHA) conducted several long term studies in order to follow up long-stay patients discharged from two psychiatric hospitals in north London, which were closed down (Leff and Trieman, 2000). The TAPS Project 33 revealed that out of the 737 patients discharged, only two went to prison and only seven patients were lost to follow up and were presumed to have become homeless – but no resident was lost from a staffed home, and there were no transient periods of homelessness for residents of these facilities (Leff et al, 1996). Discharged patients were very appreciative of their increased freedom, with 80% wishing to stay in their community homes; also, their social lives were enriched by an increase in friends, although there was a decrease in contact with relatives following discharge from hospital (Leff et al, 1996). Equally important was the finding that there was an increase in the number of ex-patients who viewed their medication as “helpful”, following deinstitutionalisation (Leff et al, 1996).

TAPS project 44, on the other hand, revealed that even a high proportion of patients with severe disabilities, often characterised as “difficult to place” in the community, could benefit from slow-stream rehabilitation within specialised facilities (such as “ward in the community”, “hospital hostel”, “special needs” unit, or “community care” ward), enabling them to later move into ordinary community homes (Trieman and Leff, 2002). Leff et al (1996, pg.1318) concluded that:

“When the capital and revenue resources of a psychiatric hospital are reinvested in community services, based on staffed houses, there are few problems with crime or homelessness. With such well-resourced services, the benefits greatly outweigh the disadvantages for both old and new long-stay patients”

It is also very important to note that while the number of homeless mentally ill people in the U.K. has been increasing, this phenomenon does not seem to have reached the same magnitude as in the U.S.A. (Leff et al,

1996). Still though, when compared with the general population, mental illness is overrepresented amongst homeless people, with most common mental health problems being depression, schizophrenia, drug-induced psychosis and anxiety states (Wood et al, 2001; Wright et al., 2004). Also, less than one third of homeless people with SMI actually receive treatment (Wright et al, 2004), because these individuals tend to be self-sufficient, mistrustful and mobile (Wood et al, 2001). In order to deal with this situation, the government decided at the beginning of 2000s to establish specialist services in the community, aiming to “assess” the mental health of homeless individuals through clinical interviews, achieve “brief contact” of these individuals with CPNs and/or psychiatrists, and promote “ongoing care”, i.e. long-term contact of patients with the homeless service or the local psychiatric services. In 2002 the government decided to increase funding through the Homelessness Act 2002, which gave to the English councils more than £13 million, in order to “...tackle and prevent homelessness” (communitycare.co.uk.,2002, pg. 1).

However the problem of homelessness became more intense in the following years, particularly after the 2008 banking crisis: In 2011/12 15,000 households in Wales and 45,000 households in Scotland applied to their local authority for homeless assistance, whereas in 2012/13 over 113,000 households applied to their local authority for homeless assistance in England (crisis.org.uk, 2013). Government statistics also show that 2,309 people in England slept rough on any night during 2012, and this represents a 31 per cent rise on 2010 (crisis.org.uk, 2013). The government decided to give 400 million pounds to local authorities and partners from the voluntary sector on homeless prevention between 2011 and 2015 in order to provide: 1) necessary deposits to help people rent properties in the private sector, and 2) mediation type of social services in order to help resolve family tensions in the home which might otherwise lead a family member to leave (gov.uk, 2011). An additional funding of 12,5 million pounds was also given to “Crisis”, a special programme that helps single homeless people – among which mental illness is

overrepresented - to find stable private rented accommodation (gov.uk., 2011). Additionally, the London pilot programme “No Second Night Out” is aimed at those new to rough sleeping in London, and operates a 24-hour phone line so that the public can report someone sleeping rough, who can then be referred to an assessment hub for help; this programme is now extended to 8 more areas across the country (gov.uk, 2011).

Another important parameter that one must consider when studying deinstitutionalisation in the U.K. is that research reveals that over the past twenty years there have not been excessive numbers of offenders with SMI in the prison system (Leff et al, 1996; Weich, 2008). Although there has been an increase in the general prison population in the last few decades, there is no evidence about how the proportion of prisoners with SMI among the prison population has changed over time (Priebe et al, 2005). Research findings also suggest that forensic admissions are made up mainly of patients already known to mental health services rather than “new” patients who have been diverted from the criminal justice system (Weich, 2008). As a result, the phenomenon of the criminal justice system providing services that were once the domain of the mental health system, which is evident in the U.S.A. context, seems to be considerably less evident in the U.K.

It is important though to note that although transition to community care has been carefully realised in the U.K., there will always be a proportion of ex-patients who cannot adjust well to life in community care units. TAPS project 16 revealed that 6% of the long-stay patients of the two London hospitals that were closed, were not successfully resettled in the community (Dayson et al, 1992). These patients were usually readmitted because of a deterioration of their mental state and aggressive behaviour, both of which made necessary their continuing stay in hospital, often in a locked ward (Dayson et al, 1992). Inpatient units though are very expensive to operate, and will probably always be unpopular among service users, as care there is most difficult to deliver (Weich, 2008). In such units – like acute psychiatric wards – there is evidence of violence,

substance misuse, sexual harassment, rapid turnover, low staff moral; also, patients seem to be critical of conditions on the ward and view life there as both unsafe and boring (Quirk and Lelliott, 2001).

For these “new long stay” patients, with the closure of asylums, besides provision in acute psychiatric wards, there has also been an increase in the provision of specialised housing by the private sector, the so called “virtual asylum”: these are non-statutory agencies, that provide housing, and include residential care homes, nursing homes, staffed hostels, and supported tenancies with staff on site (Killaspy, 2006). A problem associated with this though is that many health and social service localities find it difficult to provide sufficient residential and nursing home places for those leaving hospital, and as a result they outsource to facilities far away from the local area (Killaspy, 2006). There have been concerns about the quality and continuity of care for ex-patients placed in these “out of area treatments” (OATs), along with serious financial concerns, as the cost of the whole virtual asylum to the NHS alone has been estimated at £222 millions per year (Killaspy, 2006). As a result, the process of reinstitutionalisation that is evident in other European countries and in the U.S.A., is clearly evident in the U.K. as well (Priebe et al., 2005; Priebe et al, 2008).

In conclusion, the deinstitutionalisation movement in the U.K. has proceeded at a slower pace than in the United States, mainly because community care services were not ready early enough, due to limited resources. This means that in the U.K. patients were not discharged into the community without adequate community care provision, unlike what happened in the U.S.A. As a result, a more balanced approach was achieved, including both community and hospital services (Thornicroft and Tansella, 2004). As Weich (2008) indicates: “That service users welcome further reductions in bed numbers speaks volumes not only for the reprehensible state of many inpatient units, but also for users’ confidence in community services” (Weich, 2008, pg. 1561).

These two different models of deinstitutionalisation offer invaluable lessons for future implementation in other countries like Greece. In the U.S.A. there has been a much higher rate of deinstitutionalisation, and a much more rapid decline in mental health hospital populations, mainly for “cost-saving” reasons. In Great Britain deinstitutionalisation has proceeded at a much slower pace, mainly because community care services were not ready early enough. In both countries though, deinstitutionalisation became a reality. As this chapter has shown, this has not been a problem-free process: both in U.S.A. and in the U.K., ex-patients have been facing difficulties – to a greater or lesser extent – in finding true “asylum” in the community. In order to avoid a turn to reinstitutionalisation, neoinstitutionalisation, transinstitutionalisation, incarceration to prisons, homelessness or recreation of the total institution, we need to learn from these countries’ experience. This knowledge is valuable in helping countries to organise their mental health services in such way, as to truly provide “asylum” in the community for people with SMI.

## **Chapter 2: Mental Health Policy and Deinstitutionalisation Movement in Greece**

Chapter 2 presents how the transition from asylum care to community care became a reality, how community care services are organised in Greece, and addresses some of the problems experienced in implementing the policy of deinstitutionalisation, as well as positive aspects of the psychiatric reform in Greece. This chapter also explores how the current financial crisis has plagued both state psychiatric hospitals and care in the community, greatly affecting the quality of care for hospital patients and residents of CCUs in Greece.

### **2.1. The era of institutional care in Greece**

Chapter 1 aimed to help us understand how deinstitutionalisation became a reality in U.S.A. and U.K. These two models offer valuable insights and lessons for deinstitutionalisation in Greece.

Health care in Greece is under the provision of the National Health System (ESY), which was created in 1983, based on Law 1397/83 which decrees that the state has a responsibility to provide health care to all citizens, regardless of their financial or social status. The main objectives are: "...the equal distribution of health services, sufficient coverage of needs, improvement of quality and emphasis on each region separately" (Hellenic Republic, Secretariat General of Communications, 2004, pg.1). ESY has been divided into 17 autonomous and independent regional branches across Greece called PESY (Peripheral Health Care Systems).

Until 1992, mental health care in Greece, was under the provisions of two laws: Law ΨΜΒ/1862 "On the Organisation and Function of Psychiatric Institutions" and Circular 104/1973 "On Mental Health and Care of the Mentally-Ill Patients": these two laws placed great emphasis on the treatment of patients and sought to institute a system of caretaking within the walls of mental health institutions – both state and private (Law



ΨΜΒ/1862 and Circular 104/1973). As a result, the main form of treatment leaned towards institutional caretaking (Alevizos, 2000).

In 1838 the first mental health institution was established in Greece, on the island of Corfu. In 1887 the Dromokaition mental health hospital opened in Athens, and in 1905 the first university psychiatric clinic was established in Eginitio hospital in Athens (Yfantopoulos, 1994). In the early 1980s there were ten public psychiatric hospitals in Greece, nine for adults and one for children, and by 1982 their total capacity was 8,486 beds (Yfantopoulos, 1994).

Immediately after the Second World War, asylums in Greece became overcrowded and started facing serious problems (Kampylis, 2004; Dianellos, 1998; Lydaki, 1999). To find a solution, several psychiatrists and public officials proposed the creation of a State Psychiatric Hospital on the island of Leros, to relieve overcrowding elsewhere in Greece (Savvakis and Tzanakis, 2002). In 1958 the transfer of patients from other state psychiatric hospitals to the island of Leros began. The decision to transfer a patient to Leros was based on a simple criterion: if a patient had had no visits for over a year, then he/she was deemed suitable for transfer (Savvakis and Tzanakis, 2002). Each year, the number of patients institutionalised in Leros increased steadily, and by 1980 in-patients numbers reached 2,000, on an island with a total population of a mere 6,000 (Struti and Raumber, 1994; Savvakis and Tzanakis, 2002).

The development of the Leros Psychiatric Hospital can be seen as an example of socially excluding, completely marginalising and wholly incarcerating patients (Lydaki, 1999). During transfer of in-patients to Leros, a significant proportion of the files that dealt with patients' case histories and the objective data about their identities was lost, making it difficult if not impossible to tell with any certainty who these people "had once been": for the patients, their previous life confined to personal reminiscence and official indifference (Savvakis and Tzanakis, 2002). With their real names deleted or forgotten, patients were given new names by their caretakers that were "considered better suited to them [the patients]":

after all, most of the patients were unable to remember even their own name (Savvakis and Tzanakis, 2002, pg. 64).

In late 1970s a wave of protest erupted, starting with doctors doing their mandatory agrarian practicum at Leros, over the “unacceptable” conditions of life of in-patients and the deplorable way in which they were being treated. The “concealed” and “unwanted” patients were discovered, with some of them having stayed on the island for over twenty years (Savvakis and Tzanakis, 2002). The “purgatory of Leros” was described as a “place of torture” and a “daily Golgotha” for patients (Savvakis and Tzanakis, 2002, pg. 65). Public opinion rose against the deplorable conditions that prevailed in a “colony” where one psychiatrist with a skeleton nursing staff was obliged to tend 2,500 patients (Lydaki, 1999). In 1982 images of this disgrace emerged: articles appeared in the foreign press, and pictures of the Leros asylum with its naked human bodies and its inhuman living conditions even reached as far as the BBC in the U.K. (Dianellos, 1998). The world watched with horror as pictures of human beings stripped of all clothing and dignity, shackled, with vacant eyes or savage scowls, crawled through filth and faeces, while their wardens hosed them down (Lydaki, 1999).

The scandal of Leros provoked enormous criticism against psychiatric institutional care (Assimopoulos, 2006). Problems that plagued state mental health asylums in Greece came under close scrutiny and although the situation in most of these institutions was not as dramatic as in Leros, they were shown to be severely dysfunctional (Savvakis and Tzanakis, 2002). The need for radical reform within the mental health system in Greece had become of paramount importance (Assimopoulos, 2006). Thus, in 1983 under Law 1397/83, the first attempts at reforming the psychiatric system began (Strutti and Rauber, 1994). The driving force behind the new legislation was the need to transform the old “asylum-based” mental health care system into a modern “community-care” system for people with SMI (Kampylis, 2004). This was based on the principles of community mental health care, deinstitutionalisation, outpatient care,

sectorisation of services, primary care, psychosocial rehabilitation and protection of the legal rights of mentally-ill patients (Yfantopoulos, 1994; Alevizos, 2000). These principles were strongly recommended by the European Union, in 1984, in the form of Regulation 815/84, that concerned the development of community care, and also under the form of the “Recommendation of Ministers of the Council of Europe Committee” in 1993, concerning the “Legal Protection of Persons Suffering from Mental Disorders Placed as Involuntary Patients” (Regulation 815/84; Recommendation from the Council of Europe Committee, 1993). Since then, the European Union has supported this transformation through extensive funding via diverse programmes (Yfantopoulos, 1994; Matsa et al, 2002).

## **2.2. The transition to community care**

In 1992 the old laws concerning mental health care in Greece were replaced by Law 2071/1992 “Modernisation and Organisation of the Mental Health System”, which was supplemented in 1999 with the complementary law: Law 2716/1999 “Development and Modernisation of Mental Health Services, and other clauses”. Since then, these two laws established the framework for the mental health care in Greece. The new legislation stressed the importance of the creation of a wide network of mental health services, to meet the needs of individuals with SMI in the community. Also, the second new law, greatly emphasised the social rehabilitation of ex-patients and the creation of job opportunities through specialised occupational therapy workshops, business communities, etc (ΦΕΚ, Law 2716/99).

Mental Health Units in Greece are organised by both the public and the private sector. There is a variety of Mental Health Services that reflects the modern notion for psychiatric care, i.e. the shift from asylum to community care and social rehabilitation (ΦΕΚ, Law 2716/99). The goal behind this policy is early intervention and prevention, and to make

hospitalisation either unnecessary or make it necessary for a brief period of time, and then provide the service in the community.

The new policy emphasises primary, secondary and tertiary prevention (Madianos, 2000a). Primary prevention seeks to reduce factors that tend to produce mental and emotional disturbances, which may lead to mental illness, and it is achieved through key actions carried by Mental Health Centres. These include prenatal care, protection of pregnant women, diet control, family planning, consulting services, psychotherapy, genetic counseling (especially for mentally-ill patients or close relatives), outreach programmes, crisis intervention programmes, and educational programmes for the community in order to eliminate the stigma associated with mental illness (Madianos, 2000a).

Secondary prevention seeks early detection of mental illness and initiation of therapy as soon as possible. The basic principle behind it, is that Mental Health Units – and especially CMHCs that offer most community care services in Greece – must be readily accessible to patients (Trikkas and Mavreas, 2000). The goal of tertiary prevention on the other hand, is to diminish the negative effects of long-lasting and severe mental illness in the life of a patient, and help him/her deal with the illness on a long-term basis (Kontaxakis et al, 2000). This becomes a reality through rehabilitation programmes in the community, which focus on housing, job opportunities and psychosocial services (Kontaxakis et al, 2000).

In the Greek context, the non-hospital based mental health care units include Community Mental Health Centres and Housing Units such as boarding houses, supported apartments and foster families (Ploumpidis, 2000). Individuals with SMI can also participate in occupational therapy workshops, which provide pre-professional or pre-occupational training, professional training and supported labour (Economou, 2000; Ploumpidis, 2000).

### **2.3. Housing units and occupational therapy workshops**

People with SMI who are discharged from mental health institutions in Greece can seek “asylum” in various types of housing units in the community, such as boarding houses, hostels, supported apartments and foster families.

Boarding houses are usually (but not necessarily) located near hospital units and offer a structured everyday life programme to residents, with continuous care by psychiatrists, psychologists, social workers and psychiatric nurses; drug therapy is monitored, and psychotherapy and occupational therapy are available on a daily basis (Ploumpidis, 2000; Kontaxakis et al., 2000). In 2010, there were 126 boarding houses operating in Greece (Kazantzi, 2010).

Hostels on the other hand represent a more independent form of living. Each hostel has a capacity of 15-20 residents, which is considered to be the ideal number in order to create a family atmosphere. Residents usually stay in the hostel for six to twelve months, and they participate in social rehabilitation programmes and job training sessions; after that period and if they are willing and feel ready for such a change, they usually get transferred to supported apartments (Ploumpidis, 2000). In 2010, there were 103 hostels operating throughout Greece (Kazantzi, 2010).

Supported apartments represent the most independent form of living: residents assume a high level of responsibility with little help by nurses or social workers (Kondylis et al., 2002). Residents have responsibility for their own decision-making and the organisation of their day. In 2010 there were 233 supported apartments in many cities across the country (Kazantzi, 2010).

Lastly, there are foster families that help ex-patients in the community. Foster families offer room and board to ex-patients, and receive a payment from Mental Health Services for the service they offer (Ploumpidis, 2000).

In total today, there are 491 psychosocial rehabilitation units and programmes offering housing and care to ex-patients with SMI throughout Greece (Mpraoudakis, 2015).

Ex-patients can also participate in various occupational therapy workshops that offer their services (Kalogerakis et al, 2002). These services are divided into pre-professional or pre-occupational training, professional training and support labour, and all aim to help ex-patients gain skills and achieve a greater sense of control in their lives (Tomaras et al, 2002). Individuals experiencing SMI and their close relatives can also receive help by the Greek Organisation of Families for Mental Health, founded by family members of people with SMI (Economou, 2000). Family members and patients, can find there useful information about mental health units, support groups and new treatments (Armeniakou et al, 2002).

#### **2.4. The «Psychargos» Program for the return of patients with SMI to community**

Based on instructions from the European Community and on the new legislation, the Greek government has developed a programme with the name “Psychargos” (“Ψυχαργός”: ψυχή = soul + αργώ = return), meaning the return of individuals with SMI back to the community. The “Ψυχαργός” programme has three phases: the first one was from 1997-2001, the second one from 2002-2009, and the third one from 2011 to 2020 (psychargos.gov.gr).

The first phase was characterised by two goals: firstly, the main goal of the Ministry of Labour was to offer educational skills, occupation and employment to ex-patients, and secondly the goal of the Ministry of Health was to develop the first “pilot” supplementing residential accommodation units (boarding houses, hostels, private residential homes, shared apartments, etc). During the first phase, the Ministry of Labour financed the main part of the programme, and tried to achieve the best possible results as far as the preparation, education, occupation and

employment of ex-patients were concerned (Gournellis et al, 2002; Tsinia et al, 2002).

A series of serious problems occurred during the first phase of the programme: firstly, there were delays due to the fact that in many cases there was serious community opposition over the siting of the pilot housing facilities for ex-patients with SMI. Secondly, there were delays caused by failures of the public sector to release funds, and lack of knowledge of those implementing the programme, which resulted in poor outcomes for residents and for staff (Chondros, 2002). However, this author also reports some progress and positive developments, such as the establishment of occupational therapy workshops. Nevertheless, Chondros also points out that the training provided to ex-patients was for jobs not in great demand, and as result ex-patients faced difficulties in finding “real” jobs.

The second phase of the “Psychargos” programme had two main goals: a) to proceed with the great wave of deinstitutionalisation of patients with long-term SMI, and b) the full development of mental health units in the community (Giannoulatos, 2002). It was funded by the “3rd economic support programme” (Γ΄ Κοινοτικό Πλαίσιο Στήριξης), offered to Greece by the European Community (Giannoulatos, 2002). The European Community also consented (originally) to give additional funding to Greece for this programme through the “4th economic support programme” (Δ΄ Κοινοτικό Πλαίσιο Στήριξης) (Athanasίου, 2007a).

Originally the plan was to complete the deinstitutionalisation of 3,500 patients from all public mental health hospitals of Greece by the year of 2007, but as this was not realised, the goal was revised to complete the deinstitutionalisation of these patients by the year of 2010 (Kampylis, 2004). This however, did not become a reality either. The main reason for the delay was the fact that mental health units in the community were not fully developed (Giannoulatos, 2002; Athanasίου, 2008). The third phase of Psychargos (2011-2020) aims: firstly to develop more community care units in order to fully cover the needs of the Mental Health Sector, secondly to promote mental health in the general population and prevent

individuals from becoming mentally ill, and thirdly organise the Mental Health Sector through sectorisation, monitoring of services, evaluation, research and staff education (psychargos.gov.gr, 2015).

Progress however has been slow. The consistency of the third phase of the Psychargos programme with the economic and financial policy dictated by the Memorandum appears very low (Mpraoudakis et al, 2015). Because of severe lack of financial resources many community care units face very serious problems. Moreover, many mental health units that do operate in the community face serious difficulties because of stigma associated with mental illness and NIMBYism (Not In My Backyard) attitudes in the Greek context (Economou, 2008; Athanasiou, 2008).

### **2.5. Stigma and Severe Mental Illness in the Greek context**

In Greece, SMI is heavily associated with public [social] stigma (Economou, 2008). Dudley (2000) defines stigma as negative views or stereotypes attributed to an individual or a group of individuals in cases where their behaviors or characteristics are perceived as being different from or inferior to social norms. People with SMI go through periods during which they experience disruption of their normal thoughts and feelings, and this in turn interferes with their cognitive, emotional and social abilities; as a result, their behavior may be different than the norm (Hunter Institute of Mental Health, 2012). Another stereotype is that “madness” is linked to “badness”: people sometimes fear that those with SMI may become violent, so they are perceived as being “dangerous” (Moon, 2000).

Frequently these stereotypes concerning mental illness are endorsed by individuals in the general population, which consequently act in a discriminatory manner against people with SMI, resulting in public stigma (Corrigan and Bink, 2016). Under the notion of public [social] stigma, there is a belief held by a large fraction of society in which persons with the stigmatised condition of mental illness are perceived as being less equal or belonging to an inferior group (Ahmedani, 2011). In this context,



stigma can eventually lead to social exclusion and marginalisation (Nauert, 2010), as people with SMI are often denied opportunities to pursue their goals, work and/or live independently (Corrigan and Bink, 2016). Furthermore, people with SMI often experience structural stigma as well, which is defined as: “(1) policies of private or governmental institutions that intentionally restrict the opportunities of people with mental illnesses and (2) the policies of institutions that yield unintended consequences that limit options for people with mental illness” (Corrigan and Bink, 2016, pg. 231). Being the recipients of such unjust behaviours, people with SMI often internalise the discrimination that results from public and structural stigma, and this gradually leads to self-stigma (Corrigan and Bink, 2016). Self-stigma is experienced in the Greek culture not only by people with SMI, but by their family members as well, which often experience the same type of marginalisation (Lentis, 2008).

In the Greek context, it appears that public or social stigma is persistent and this stems from a culture that frequently does not respect people experiencing SMI, as it became clear in the previous sections. A study that was conducted in 2005 by the University Mental Health Research Institute (UMHRI) in Greece reviewing research findings supported that the social stigma accompanying schizophrenia in the Greek context remains very much alive, although it may have decreased over time (Mertika et al, 2006). A study that was conducted in 2005 by the University Mental Health Research Institute (UMHRI) in Greece reviewing research findings supported that the social stigma accompanying schizophrenia in the Greek context remains very much alive, although it may have decreased over time (Mertika et al, 2006). The promotion of the rights of minority groups, along with improvements in social conditions has led to a greater degree of tolerance towards individuals with SMI; nevertheless, cases of bias and prejudice continue (Mertika et al, 2006). The most significant finding of Mertika et al’s (2006) study was the great degree of social distance that study participants wished to keep from individuals with SMI: this was directly proportionate to the age of study

participants and in reverse proportion to their level of education and social class, while residents of rural or semi-urban areas, when compared to city residents, appeared to desire a greater social distance from individuals with schizophrenia.

The manner in which the mass media handle the issue of SMI plays a very crucial role for the development of stigmatising stereotypes (Tsalikoglou, 2001). A study of the depiction of mental illness in the Greek press found that schizophrenia appears to be the most stigmatised of all mental illnesses (Economou et al, 2005). In order to combat the discriminating social stigma that accompanies SMI and particularly schizophrenia in Greece, the University Mental Health Research Institute (UMHRI) has undertaken a programme that aims to inform and sensitise the public about mental disorders, by developing specific actions that will improve public attitudes, and decrease prejudice (Economou et al, 2006a). UMHRI's scientific programme is in research, education and communication (Economou et al., 2008). UMHRI has also conducted a series of interventions for high schools students, health care practitioners, patients and their families, as well as employers that are about to hire individuals with SMI, mass media representatives and police officers (Economou et al 2006b; Economou, 2008). It has also organised meetings at various municipality and community centres, with the purpose of educating the public (Economou et al, 2006a).

In the sector of communication, the programme cooperates with mass media spokespersons, publishes information material, organises seminars and conferences, maintains a website and operates a Telephone Line for Communication with the public (Economou, 2008). The "stigma stalkers", the programme's volunteers, play a very important role, as they are a network of sensitised citizens who react to the stigmatising depiction of mental illness across the mass media (Economou et al, 2006a). They alert the institute to the use of mass media language that may perpetuate stigma, with phrases such as "the schizo killer with the chainsaw", "weirdo", "psychopath", "paranoid", "schitz", "psycho", "loony bin", among

others (Kouklaki, 2003, pg. 1). The programme volunteers also strive to make the public aware of the stigmatising use of stereotypes in relation to mental illnesses (Economou et al, 2006a).

Besides the social stigma that people with SMI experience in Greece, care in the community is seriously affected by NIMBYism attitudes.

## **2.6. Negative attitudes to residents of CCUs as neighbours: NIMBYism in the Greek context**

As it became clear in Chapter 1, Not In My Backyard attitudes have been present both in the USA and UK context. Dear and Taylor (1982), in their landmark publication *Not on Our Street* described from a USA perspective, analysed how residents of suburban jurisdictions, although sympathetic in principle with the notion of community instead of institutional care for people with SMI, at the same time were resistant in practice to allow the establishment of a facility for people with SMI in their immediate neighbourhood (Dear and Taylor, 1982). Keeping distance became of paramount importance, as residents of those areas considered the establishment of a community care unit to pose danger to their own and family members' safety, along with possible devaluation of their property (Dear and Taylor, 1982). This was one of the main reasons why it became easier for community care facilities to develop in the ghettos of USA and Canadian inner cities, as there was the least community opposition, when compared to suburban jurisdictions (Dear and Wolch, 1987). The UK experience, as provided through cases such as the establishment of mental health hostel provision in Portsmouth, has shown that reactions can be milder (Moon, 1988), but this requires appropriate preparation through informing neighbours in advance for the establishment of a CCU, and successfully address their concerns (Thornicroft et al, 2008, a, b). Nevertheless, NIMBYism attitudes in the UK, although milder, have been rather persistent. Fears concerning safety and property devaluation behind the NIMBYism phenomenon appear to be universal in nature.

The phenomenon of NIMBYism, has not been confined to communities in the United States and Western Europe; research has shown that it appears very prominent in the Greek experience as well (Tsalikoglou, 2005; Lentis, 2008). Since the beginning of the deinstitutionalisation movement, NIMBYist attitudes have played a prominent role in the Greek context, making it very hard for ex-patients to find “asylum” in the community (Tsalikoglou, 2005). Moreover, there has been an alarming increase in the number of refusals from local societies as well as from Local Self-Government Authorities to allow the opening of community care units for the purpose of housing people who are experiencing SMI (Tsalikoglou, 2005).

One of the first hostels in Greece was on the Avlida beachfront on the island of Evia, and its development led to serious reactions from the local population. The hostel opened its doors in 1991 with the goal of housing a group of residents released from the Leros psychiatric hospital who had originally come from the island of Evia (Kampylis, 2004). Once the hostel opened, there was strong opposition from the nearby community. The staff working at the hostel reported to the police as well as to the media that the neighbours poisoned the hostel’s guard dogs and the chickens that were kept for the purpose of work therapy for the CCU’s residents (Kampylis, 2004). Closing the hostel became a daily item on the agenda of the local community. The main argument of the local residents—particularly summer visitors that maintained country homes there – was that the hostel’s operation would lead to devaluation of the area’s real estate (Kampylis, 2004). Reactions to the hostel were so severe, that after 5 years of operation, the hostel had to close and transfer to Chalkida, the island’s capital (Kouklaki, 2001).

In Chalkida, the hostel’s staff noted that the hostel no longer faced problems with local residents, mainly because there was a level of anonymity due to the greater size and population (Kouklaki, 2001). Hostel residents found no difficulties in dealing with the local residents in Chalkida: on the contrary, all of the CCU’s residents availed themselves of

the services the town had to offer, of the hospital, the mental health center, and the public sector services. Further, the elderly became members of the public Open Care Center for the Elderly (KAPI) (Kouklaki, 2001). During the years that the hostel has been in operation, only two of the CCU's residents have been in need of some light form of treatment and only for a brief period of time, while 3 female residents, who had initially been accommodated in the hostel, were eventually transferred to a semi-independent apartment (Kampylis, 2004; Kouklaki, 2001).

Another hostel, designed to offer accommodation to 12 residents, also met with strong opposition when it opened in early 2000s in the area of Nea Lampakos, in Evia (Kouklaki, 2001). Reactions began on the very first day of the hostel's operation and while the CCU's residents were being transferred there: it took the intervention of the district attorney and the presence of police to enable to enter the building since the crowd of local residents gathered outside blocked the entrance. Hostel's residents and staff remained within the hostel trapped and under siege for an entire week: area residents would allow neither food nor fuel to be transported inside the building. Moreover, for two entire days, the building was cut off from the area's main water supply (Kouklaki, 2001). A week went by before the district attorney intervened again, the siege ended, and life in the building went back to normal.

Local residents continued to oppose the hostel, arguing that the hostel's residents were "dangerous", and that all local residents were afraid of what might happen to their children who would go by the hostel every day on their way to school (Kouklaki, 2001). Quite soon, rumors in the form of "news" spread among the local residents that some of the hostel's residents had committed "crimes", although not one of those "news" items could be substantiated. The Prefect and the Municipal Council wrote a letter to the Prime Minister and the Minister of Health demanding that the hostel be removed to some other area (Kouklaki, 2001). However, the Ministry of Health ignored their demands and,

gradually, reactions from local residents subsided and the hostel continued to operate without further interruptions.

The argument that the opening of a community care unit would jeopardise the safety and security of children was also used by the Parents Association of an elementary school in Attica, who reacted against the opening of a boarding house next to their children's school (Kaldirimitzian, 2008). The Citizen's Council [a legal authority that reviews cases of citizens' protests against the government, municipalities, ministries and other state offices] reviewed the case and decided that neither Municipalities nor Prefectures can judge about whether a community care unit can start operation or not (Citizen's Council, 26/04/2005). Only the Ministries of Health and Finances can take responsibility for these decisions (Citizen's Council, 26/04/2005). The Citizen's Council also stressed the fact that boarding houses are highly structured units, with a high degree of supervision of CCU's residents by staff members. It also stressed the fact that SMI is heavily associated with social stigma in Greece, but this is a situation that needs to be changed: people with SMI should be able to live in the community, in a home where they will not be "hiding", but where they will actually be "belonging" (Citizen's Council, 26/04/2005).

Unfortunately, reactions to the opening of other CCUs did not have such a happy ending: Overall, during 2004-2005, half of the 55 Hostels and Boarding Houses programmed to begin operation in Greek communities within the framework of the «Psychargos» project, faced severe challenges; as a result, 20% of these community care units had their operation severely obstructed or even halted and were forced to move from those particular communities to other areas (Assimopoulos, 2006). The reactions of local communities seem to stem from collective anxiety and fears: fear that the local residents' personal safety will be severely restricted, that their children's safety is at stake, fear that burglaries and vandalism will rise, fear of potential sexual harassment and

abuse, anxiety over “bizarre” behavior, and serious concerns that real estate prices may decline (Assimopoulos, 2006).

Nevertheless, there have been cases where local communities have been more welcoming. The findings of a study conducted on the island of Mytilini on the attitudes of the local community relating to the operation of a hostel in a highly commercial area of the city of Mytilini (the island’s capital) have been encouraging (Zisi et al, 2006). The study showed that there has been a rather reserved and ostensibly accepting attitude towards the hostel and its residents by the community, in contrast to the attitudes exhibited by local residents in the communities already mentioned; the community discussed in the study appeared to be more receptive, thus indicating that areas with commercial establishments are less likely to exhibit intensely negative reactions (Zisi et al, 2006).

In conclusion, although in some cases reactions have been milder, in general NIMBYist attitudes appear to be strong in the Greek context. In order to solve this problem, researchers have proposed: 1) further educational programmes for the general public on issues concerning SMI, and 2) financial support by the State to Municipalities that agree to have a community care unit operating in their area (Kaldirimitzian, 2008). But, besides these measures and proposals, NIMBYist attitudes still create serious problems for people with SMI who try to find “asylum” in the community. These problems are further reinforced by the serious financial problems that plague psychiatric reform in Greece.

## **2.7. The impact of the financial crisis on community care units in Greece**

Psychiatric reform in Greece began with a very ambitious goal: the «Psychargos» programme represented a unique opportunity for the deinstitutionalisation of 4,000 patients and for the closing down (or downsizing) of all public psychiatric hospitals throughout the country. Mental health hospitals were to be replaced by a network of community care units, offering to ex-patients housing, shelter, medical care,

education, and employment as well as rehabilitation opportunities (Kampylis, 2005).

Serious financial difficulties though forced the «Psychargos» programme to fall behind schedule. Up until 2008, newly created community care units received initial funding from both the European Union and the state for 18 months. After that time period, their funding was to come from state funds alone (Kouklaki, 2007). It is during that second stage of funding that problems arise: the cost for maintaining each resident experiencing SMI in a boarding house, hostel or protected apartment is estimated at 3,000 Euros per month; once funding from the European Union ceased – after the initial 18 month period – the state was unable to continue footing the bill for these community care units (“TA NEA” Newspaper, 16/03/2007, front page). As a result, in 2006 the Units spent 30% less than they had spent in 2005, and in 2007 they received money from the state which barely covered 40% of the needs the Units actually had (Kouklaki, 2007). For 2008, the Units only received 41,000,000 Euros - 31,000,000 Euros less than their actual expenses (Matsa, 2008 a, b; Athanasiou, 2008).

In 2007, the Ministry of Finances persuaded the EU to give funding for the Psychargos Program through the “4th economic support programme” (Δ΄ Κοινωνικό Πλαίσιο Στήριξης) that would cover a period up until 2013 (Athanasiou, 2007b). The EU originally accepted this under the condition that the given money would be used in order to cover exclusively the needs of the Psychargos Programme (Athanasiou, 2007b). Unfortunately, at the beginning of 2009, once the EU discovered that the Greek government was using the money for different purposes, it ceased the funding (Matsa, 2008b; TA NEA, 27/03/2009). The situation has become even more difficult since 2010, because of the strict financial measures that the International Monetary Fund (IMF) imposed on the Greek government through the Memorandum. Moreover, as mentioned earlier, the consistency of the third phase of the Psychargos programme



with the economic and financial policy dictated by the Memorandum appears to be very low (Mpraoudakis et al, 2015).

Due to severe cutbacks in spending, some community care units particularly the ones run by the private sector – have already either closed down or are in danger of doing so. Residents of the units that close down have the ordeal of being transferred from one private community care unit to another, with serious consequences for their wellbeing (Athanasίου, 2007a). It is not though just the units under private supervision which are under threat of closure: public sector units are equally afflicted. For example, in 2006 one of the hostels run by the Attica Psychiatric Hospital (APH) in the area of Korythallos was forced to close down due to insolvency; as a result, residents had to “split up” and be transferred to other units (Kouklaki, 2007). Also, a hostel run by the ΕΠΙΨΥ (UMHRI), where 10 ex-patients from the Leros psychiatric institute over the age of 70 have been residing for several years, was forced to close (Athanasίου, 2008).

Community care units that manage to stay in operation also face very serious problems because of the financial crisis (Athanasίου, 2008). Many units are unable to pay not only the bills, but also the salaries and insurance coverage for the mental health professionals that work in these units; in many cases receipt of wages and salaries are subject to delay of many months (Matsa, 2008a). Many professionals have no other choice but to resign, and as a result many units operate with 22-45% fewer staff than what is required (Matsa, 2008b) [in fact, the hostel “Iris” in Athens, which was housing 8 children age 11-16 with SMI, had to close down because all staff members resigned, as they could no longer afford to work without payment (Athanasίου, 2008)]. The limited number of staff members in these units cannot offer the necessary quality of care; as a result, residents experience enormous stress that leads to very serious relapses, which may even put their lives in danger (Athanasίου, 2008). Even more surprisingly, the Special Commission for the Control of the Protection of Rights of People with Mental Disorders gave permission for

staff members in community care units (such as boarding houses) to restrain residents, if necessary by tying them down, a measure indicating the intentions of the Ministry of Health to operate units with minimum staff, and with as little expenditure as possible (Megaloeconomou, 2008).

The economic crisis has also had an impact on the «Psychargos» training programmes designed for ex-patients in the community. The programmes are now short, with an insecure future. The Ministry of Health along with the Ministry of Labor has taken measures through the years to combat the dramatic dearth of employment opportunities for ex-patients with SMI (Megaloeconomou, 2002; Lampakis et al, 2008). For example, Greece participates in a pilot way, in the European Programme EMILIA for the Empowerment of Mental Illness service users through Life Long Learning Integration and Action, in order to further help ex-patients [mainly residents of CCUs] through continuing educational programmes to socially reintegrate in the community; however, the rate of unemployment among ex-patients with SMI in Greece is still around 84% (Lampakis et al, 2008). In several cases, ex-patients that used to work in Occupational Therapy Workshops run by Mental Health Hospitals, found themselves – after the closure of these particular Workshops – having to participate in Business Communes, which face extremely serious problems because of lack of funding (Tovi, 2008). As a result, ex-patients that work there either do not get paid for several months, or are paid very little (Tovi, 2008).

These facts show that measures taken so far are simply not enough. For true social integration of ex-patients, it is imperative to implement active social policies along with employment opportunities that will ensure a stable and decent income for ex-patients (Megaloeconomou, 2002). If, however, deprivation of material goods and insecure living conditions continue to plague those with SMI in the community, then there is a danger that community care units will turn into “social exclusion areas” within the cities, instead of promoting the social rehabilitation of their residents. Should that happen, community care units are in danger of succumbing to the “neo-institutionalisation” phenomenon, as they continue

to manage through the same type of services the old model of psychiatric hospital provided, leading to the social exclusion of residents, and operating as “social ghettos” (Megaloeconomou, 2000 and 2008).

Another danger looming clear on the horizon is “reinstitutionalisation” of some residents of CCUs in the event that Mental Health Units within the community yield to financial pressures and are forced to close down (Matsa, 2002). Should that happen, some residents of CCUs would have to return to state psychiatric hospitals and begin life again under conditions of institutionalisation and social exclusion (Athanasίου, 2007a). Although the «Psychargos» programme has fallen behind schedule, seven out of the ten state psychiatric hospitals of the country have already closed down, with only three psychiatric hospitals remaining open, two in Attica and one in Central Macedonia (Mpraoudakis et al, 2015). If the situation does not improve, some residents of CCUs with no supportive family environment might find themselves released into the community with no appropriate support, many of them joining the ranks of homeless people (Theodorikakou et al., 2013).

Apart from the prospects of neoinstitutionalisation and reinstitutionalisation, ex-patients in the community are also being confronted by another danger, that of “transinstitutionalisation”, meaning the practice of transferring ex-patients to private clinics. In essence, the downsizing of public sector Mental Health Care is directly associated with moves towards the foundation of new private psychiatric clinics, something that Greece has not experienced in decades (Megaloeconomou, 2002). In 2008, the public sector had 1,038 psychiatric beds (698 in psychiatric hospitals and 340 in psychiatric sectors of general hospitals), while the private sector already had 4,418 beds (in private psychiatric clinics) (Matsa, 2008a). In total, in 2008 there were 20 private psychiatric clinics operating in Greece, offering a very “institutionalised” type of care, which is expensive (Matsa, 2008a). Today, there are 36 private psychiatric clinics throughout Greece, offering their services (Mpraoudakis, 2015). This indicates a tendency towards privatisation of Health Care, which seems to

be on a direct collision course with the principles behind the creation of the Greek National Health System, namely to provide healthcare to all citizens, regardless of their financial status.

In summary, the economic crisis has seriously affected community care units and their residents. The economic crisis though, has also affected state psychiatric hospitals, posing extremely serious problems in their operation, the daily routine of patients and the life of staff members.

## **2.8. The impact of the financial crisis on state psychiatric hospitals**

The financial crisis has affected not only community care units but state psychiatric hospitals as well. The serious debts of public institutions – which in some cases such as that of ΨΝΑ (Psychiatric Hospital of Attica) in 2008 exceeded the amount of 37 million euros – creates very difficult conditions both for patients and for staff (Matsa, 2008a). As a result, matters within the state hospitals have reached a very critical stage despite the efforts that are being made to further reduce the number of hospital beds available.

It is common practice for doctors, when admission beds are full, to admit the extra patients and give them the beds of patients who are on leave. Doctors have testified on many occasions that they have been forced by hospitals' management to use the beds of patients who are on a two-day leave and who are normally admitted in the brief hospitalisation wards (Vrathelis and Konstas, 2004). Once patients on leave are back, problems arise, and the doctors are forced to transfer the new admissions to wards reserved for patients with severe and long-term mental illnesses, although fully aware that this is not beneficial for patients (Vrathelis and Konstas, 2004).

In some mental health hospitals, among the long-term patients are also individuals with SMI that have committed serious crimes and have been convicted to five, ten or even twenty-year sentences. [In Dafni hospital for example, in 2007 there were 85 individuals among the chronic

patients that have committed murder (Athanasίου, 2007b)]. Since the small psychiatric ward of Korydallos prison is full, these patients serve their time in mental health hospitals, but unfortunately there is no special or secure wing for them; as a result, they occupy beds next to depressive or anorexic patients for example, who need in-patient care for only a brief period of time (Athanasίου, 2007b). This is a stressful situation for staff members as well, who find themselves having to not only practice their profession, but to also act as “warders” (Athanasίου, 2007b).

Because of this situation, patients that need treatment can get hospitalised in state psychiatric hospitals for only brief periods of time (Matsa, 2008). Such practices however, have exposed patients to hospitalisation periods that are inadequate in terms of time and quality and often lead to the revolving door phenomenon (Diallina, 2002; Matsa, 2008a).

The shortage of hospital beds has also forced state psychiatric hospitals to refuse admission to individuals who appear voluntarily for admission (Kouklaki, 2003). Individuals who are refused admission can apply to the district attorney’s office and return to the hospital with a court order for admission (Diallina, 2002). Consequently, a significant proportion of admissions to State Psychiatric Hospitals in Greece are involuntary (Matsa, 2008a). The only option mental health services have in trying to meet all of patients’ needs is the creation of more psychiatric clinics within general hospitals (Kouklaki, 2005). However this has been particularly difficult to implement, because of the closure of several general hospitals that has been announced by the Ministry of Health, due to the severe financial crisis that Greece has been experiencing the past few years (koutipandoras.gr, 21/07/2013).

Another problem in all state psychiatric hospitals in Greece is that the state does not appoint enough staff (Matsa, 2008a). Hospitals suffer from lack of specialised personnel, such as psychiatrists and nursing staff and even cleaning crews. This makes it difficult in practice to bring rehabilitation programmes for patients to fruition (Matsa, 2002; Vrathelis

and Konstas, 2004). This is particularly problematic where night shifts are concerned, where two members of the nursing staff can be responsible for as many as 35 to 50 patients, making it practically impossible to adequately supervise all (Vrathelis and Konstas, 2004). As a result, the night hours are the time of day when most suicides occur and some patients find the opportunity to temporarily “escape” from the institution; the hospital pronounces them “missing”, leaving the burden for finding their whereabouts on the police (Vrathelis and Konstas, 2004).

The economic crisis has also brought the reintroduction of practices that had been abandoned. Since the beginning of 2000s, staff shortages have resulted in many instances of nursing staff and psychiatrists tying down manic patients, keeping them restrained for days on end, despite the fact that such a practice is frowned on, or should be applied for a few hours only (Kouklaki, 2004). Such methods can be described at least as second-rate medical practice, causing patients tremendous grief, especially when they are in a manic stage, which subsides only through psychokinetic relief (Kouklaki, 2004). Even more worrying is the fact that the Special Commission for the Control and Protection of Rights of Individuals with Mental Illnesses has released special recommendations to staff members of mental health hospitals on how to proceed with the practice of restraining, instead of giving instructions on how to avoid doing so (Megaloeconomou, 2008).

The psychiatric community was also shocked by an order issued by the Ministry of Health in September 2007, calling for the immediate creation of “quiet rooms” for patients experiencing a severe episode. The rooms are to be all white, devoid of any furniture, with walls padded in soft materials and featuring surveillance cameras (City Press, 21/11/2007). Whilst in the eyes of the Ministry of Health this measure amounts to “psychiatric reform”, in the eyes of the psychiatric community it is tantamount to a return of the padded cell and an assault on the civilised world (City Press, 21/11/2007; Megaloeconomou, 2008). While such rooms exist in various psychiatric hospitals and clinics as well as in

general hospitals throughout Greece, it seems that the Ministry of Health wishes to turn the existence of the “quiet rooms” into a fixed regulation; in other words, instead of taking steps to train personnel to work effectively with patients, the Ministry is encouraging the wider use of “quiet rooms” to reduce the number of nurses needed per shift, one of whom monitors patients locked in isolation through the surveillance cameras (Giannouloupoulos, 2008; Megaloeconomou, 2008). The ministry of Health seems to give little consideration though to the fact that when a patient that experiences a severe episode – such as a manic one – gets “locked” in a quiet room, he/she may experience severe claustrophobia and deteriorate even further. Unfortunately, measures such as those described above, keep alive methods that are antiquated, exacerbating the condition of any patient undergoing an episode (Giannouloupoulos, 2008).

Measures like these make even more visible the dearth of appropriate trained personnel. Not only that, but in some cases, the limited staff members have to work under very dangerous conditions both for themselves and patients as well (Athanasίου, 2007c). In Dromokaition Mental Health Hospital for example, during the years 2004-2007, there had been nine fires from arson in patients’ rooms; during those fires, two female patients died and another five patients along with six staff members got serious burns and/or developed serious respiratory problems (Athanasίου, 2007c). These incidents happened because the hospital buildings did not have the necessary fire detection system, fire extinguishers and security lights (Athanasίου, 2007c).

Apart from the fact that hospital personnel (doctors and nursing staff alike) are required to work under adverse conditions, they do not have access, at least to the degree that they should, to the re-training so vital to their profession (Diallina, 2002). Under the “austerity policy” implemented by the Ministry of Health, appointments of suitably trained personnel to psychiatric hospitals have been kept to a minimum; such practices mean that psychiatric hospitals have to use their own limited staff and resources (Giannouloupoulos, 2008). It is little wonder that the quality of services

provided by psychiatric hospitals is low, causing problems in their daily operation. In 2014, the number of mental health professionals who participated in training rose to a small degree – compared to the number that participated in 2013 – but at the same time there were no new educational projects (Mpraoudakis, 2015). Another problem is that educational actions do not appear to be part of an integrated training scheme; as a result, a better design and implementation of educational programmes are needed for mental health professionals in Greece. This in turn, could result in better preparation of patients prior to their deinstitutionalisation.

## **2.9. Can residents of CCUs find “asylum” in the community?**

### **Some illustrative cases**

As the previous sections have demonstrated, for residents of CCUs to find “asylum” in the community has been a rather difficult task in the Greek context, because of stigma associated with mental illness, NIMBYist attitudes, and most importantly because of the financial problems that community care units are facing. Still though, no one can deny that in various cases there has been considerable progress in the deinstitutionalisation of patients.

For example – following the Leros scandal in 1985 – by the late 1990s the old institution of Leros was replaced by twenty small “apartments” throughout the island. Each apartment is a pretty detached house, with its own garden tended by tenants, housing 5 to 6 residents each (Lydaki, 1999). The nursing staff works in shifts during the day, while at night residents are left to their own devices (Lydaki, 1999). Meals are prepared and served in the canteen by residents themselves, while other tenants keep busy with working at the Institution’s Agricultural Co-op, sculpting, painting, embroidering or cleaning. Additionally, a hostel has been built for female residents in the larger area of the institution (Lydaki, 1999).



In 1998, Padraig Flynn, in his capacity as European Commissioner for Social Affairs and Employment, visited the Leros psychiatric facilities to survey the extent of the psychiatric reform that had taken place there, stating during a press conference at the time that he had been delighted with the result (Dianellos, 1998). The transformation of the Leros psychiatric hospital became the pilot for the transformation of all other Greek psychiatric hospitals, paving the way for the creation of community care units (Dianellos, 1998).

One of the first hostels created in 1993 within the framework of the psychiatric reform was “Thetis”, a community care unit in the area of Lower Chalandri in Athens, which accommodates several of the Leros ex-patients (Athanasίου, 2007a). The hostel supervisors have stated that after years of enormous effort and hard work on a daily basis, a number of residents that have been relocated to the hostel have been able to regain a measure of self and identity that had been lost to them, and to cultivate their inherent attributes and talents (Athanasίου, 2007a).

Residents accommodated at the 1<sup>st</sup> Hostel of Klimaka (a private, non-profit organisation) in Athens, have also shown marked improvements in their well-being (Kampylis, 2005). The hostel supervisors have reported that although it took years of caretaking, these residents have regained their full strength and have developed many new skills (Kampylis, 2005). Similarly, staff members of community care units that operate under the aegis of the Panhellenic Association for the Psychosocial Rehabilitation report that residents live for the first time in their lives under decent living conditions, with professional care and support respectful to their needs (Athanasίου, 2009).

In the island of Crete, 250 ex-patients that used to live under inhumane conditions in the Chania Mental Health Hospital (ΘΨΠΧ), now – after the closure of the institution – live in community care units throughout the island (Kokkinakos, 2008). As a result, in Crete there is psychiatric care without a mental health institution (Kokkinakos, 2008). Residents of CCUs in Crete learn various trades in the occupational therapy

workshops, and have started to reintegrate in the community (Konstas, 2009). When Vladimir Spilda, the Commissioner for Social Affairs and Employment of the European Union, visited the island of Crete in order to examine the progress of deinstitutionalisation in the island, an ex-patient [a CCU resident at that time] gave him as a present the belts which staff members of the Chania mental health institution used to use for tying him down, sometimes for periods of more than seven months (Konstas, 2009).

In conclusion, in various cases despite the serious financial problems units face, residents of CCUs have managed to experience a new life in community care units. A study using psychiatric statistical tools that was conducted at a boarding house in downtown Athens on the level of functionality, on the clinical picture and the psychopathological condition of the tenants, concluded that the residents showed marked improvement both in terms of their functionality and their psychopathological parameters (Chaidemenos et al, 2002). The study also showed that the more the residents remained within the community care unit, the more functionality increased (Chaidemenos et al, 2002).

All the above evidence shows that considerable progress has been made in the matter of deinstitutionalising patients and integrating them within the community, despite the serious problems in existence. Nevertheless, it is important to note that while the views of psychiatrists, psychologists and nursing staff involved, as well as those supervising the community care units are well heard, still there is a great need for the voices of the CCUs' residents experiencing SMI to be heard. People with SMI [hospital patients, ex-patients living on their own or residents of CCUs] in Greece have been slow to get mobilised politically (Megaloeconomou, 2002; Lentis, 2008). Yet, their involvement is crucial in understanding how deinstitutionalisation can be turned from ideology to successful practice. This study attempts to fill this gap by including the voice of individuals with SMI who are residents of CCUs: it is only by hearing their views and by working to address their expectations and their

own ideas about what the parameters of true “asylum” are, that progress can be made in creating a sense of “asylum” in the community.

## **Chapter 3: Theoretical background of the research: Construction of the notion of “asylum” in the community through the exploration of Thirdspace**

Chapter 3 presents the theoretical background of the research on the construction of "asylum" as a place offering safety and security. In particular it addresses the importance of exploring the "lived experience" of residents of CCUs in order to create community care services offering indeed "asylum", based on Edward Soja's theory of Thirdspace. The chapter analyses the great value of exploring Thirdspace, not only as a lived space located in the margins of society, but also as a site of radical openness, through which resistance to all forms of oppression can occur.

### **3.1. The shifting meanings of “asylum”: How can we create community care services offering “asylum”?**

Chapters 1 and 2 have clearly demonstrated that the deinstitutionalisation movement has been facing serious problems in the U.S.A., U.K. and Greece. From the previous discussion it is also clear that the notion of who is responsible for offering “asylum” to individuals with SMI has changed through the years, going from the mental health institutions to community care services and in many cases to the ghetto, or even prisons as it happened in the U.S.A. But no matter who is responsible for offering “asylum”, the notion of asylum for individuals with SMI always includes a social dimension that parallels refuge and a safe haven.

Wallcraft (1996), in one study in England, reported that survivors of mental health services considered “asylum” to have varying degrees of formality, covering a broad spectrum from informal to formal. At the informal end of the spectrum, “asylum” meant a safe house among friends; at the formal end of the spectrum, “asylum” referred to formal psychiatric services, but in a sense that individuals had freedom of choice, control

over their treatment, and confidence that no unwanted treatment would be forced on them, for instance being able to self-refer to an acute psychiatric unit (Wallcraft, 1996). In between the formal and informal end of the spectrum, “asylum” was described by individuals experiencing SMI as a crisis house with respect for individuality and a homely supportive atmosphere with availability of advice, counseling and information (Wallcraft, 1996). The various interpretations of the term “asylum” from service users suggest that there are different ways of interpreting the idea of “asylum”, beyond current professional knowing.

As the different models of deinstitutionalisation in the U.S.A., U.K. and Greece make clear, it has been a very difficult task for individuals with SMI to find “asylum” in the community. In many cases, instead of finding “asylum”, people have found themselves caught in the gaps between mental health services, not knowing where or how to find help, and trying to cope with what can be a very complicated system. As a result, a critical question is: what kind of place - or combination of places - could provide “asylum” in the community, without repeating the mistakes of the past?

In order to answer this question, besides taking lessons from other countries, we also need to listen carefully to the voices of individuals with SMI themselves. For patients’ and ex-patients’ voices to be heard though, is an extremely difficult task. The “mentally-ill” label seems to transform people from visible to invisible, silencing their voices (Parr, 1997). Despite centuries of stigmatisation however, during the past few decades the voices of psychiatric survivors in countries like U.K. are starting being heard and taken into serious consideration: In the U.K., government, professional and voluntary groups have started to consult ex-patients and report their findings (Parr, 1997). It is also important to note that several patient-led organisations have emerged in the last three decades: local-level politics of people with SMI started to gain momentum in the 1980s and early 1990s, with organisations of patients formally being established outside mental health hospitals (Parr, 1997). Also, charities like MIND

have been developed, which provide advice and support to empower anyone experiencing a mental health problem (mind.org.uk, 2015). These charities campaign to raise awareness, promote understanding and improve services for people with mental illnesses (mind.org.uk, 2015).

However, there are still large numbers of mentally-ill individuals who are not directly involved in user groups, or who do not have easy access to support networks; these people constitute a large proportion of the population of individuals with SMI, hence their voices are not represented at all. Users that usually participate in various forums along with policy-makers tend to be: "...articulate, informed and coherent. They are also predominantly white, middle aged, with no particular class bias, and male" (Parr, 1997, pg. 444). But what about all the ex-patients roaming the streets, parks and drop-in centres, who are usually afraid to participate to such forums, and whose usual resistance is to "escape" from places of medical care and treatment to spaces where they can just feel themselves? These people may have a very different notion of "asylum", and a place of refuge for them can simply be a bedroom, a park or a café, anywhere away from the "surveillance" of the state (Parr, 1997). For these people, the reality of any representation at all is highly unusual, and that is why research with individuals experiencing SMI is necessary, to ensure that their voices are heard and considered in the process of developing a sense of "asylum" in the community (Wright et al, 2004).

One of the main reasons why deinstitutionalisation has faced so many problems is that policy makers failed to take into consideration the views of mental health service users from the beginning. This resulted – in many cases – in community care services not offering true "asylum", but rather offering just similar medical services to mental health hospitals, but in a different setting. However, if we want community care services to work, and avoid a turn to reinstitutionalisation, neoinstitutionalisation, transinstitutionalisation, incarceration to prisons, homelessness or recreation of the total institution, it is our duty to explore ex-patients' notion of "asylum" and work hard in order to recreate it in the community.

In order to do so, we need to explore residents' of CCUs views and try to gain a knowledge which has been previously systematically hidden from mainstream human awareness and realisation; this is a “non-traditional” knowledge. Ex-patients in general and residents of CCUs in particular, in the Greek context, usually find themselves in the margins of society and if we want to have a clear picture of their views we need to explore their lived experience in the margins of society – or as Edward Soja defines it: the Thirdspace. Edward Soja, in his book: *Thirdspace: Journeys to Los Angeles and Other Real and Imagined Places* offers a new way of thinking about space, with a deep concern for human welfare being at the heart of his work.

### **3.2. The value of Thirdspace: Edward Soja's *Thirdspace***

Edward Soja was a Distinguished Professor Emeritus of Urban Planning at UCLA, in the U.S.A. He also taught courses in urban political economy and planning theory. Soja's work *Thirdspace* offers new ways of thinking about space: Soja is particularly interested in the way issues of class, race, gender and sexuality intersect with what he calls the spatiality of social life, and with the new cultural politics of difference and identity this generates (Soja, 1996).

Edward Soja's main objective in his book *Thirdspace* is to encourage the readers to “...think differently about the meanings and significance of space and those related concepts that compose and comprise the inherent *spatiality of human life*: place, location, locality, landscape, environment, home, city, region, territory and geography” (Soja, 1996, pg. 1). Soja believes that in order for us to achieve a better understanding of our contemporary life worlds at all scales, it is absolutely necessary to be strategically aware of our collectively created spatiality and its social consequences.

According to Soja, a growing community of citizens and scholars has, perhaps for the first time, begun to think not only about historicity and sociality, but also about the spatiality of human life. Soja is one of them,

and he tries to open up our spatial imaginations to ways of thinking and acting politically that respond to all binarisms, and to any attempt to confine thought and political action to only two alternatives. The writer believes that in order to understand our spatiality, Firstspace's and Secondspace's perspectives are not enough: Firstspace focuses on the "real" material world, and Secondspace interprets the reality through "imagined representations of spatiality" (Soja, 1996, pg. 6). These two perspectives though are not enough, and through his critical strategy of "thirling -as-Othering" the Thirdspace emerges as a place of radically open perspective. Soja introduces another set of choices, a critical "thirling": this way, the original binary choice is not dismissed entirely, but rather restructured in order to open new alternatives.

According to Soja, Thirdspace is located in the margins of society, and the invaluable knowledge people gain from exploring the thirdspace guides their search for emancipatory change and freedom from domination. Thirdspace is of critical importance for this particular research, because most CCUs' residents find themselves in the margins of society, the Thirdspace. In order to have a clear picture of residents' of CCUs views, the margin needs to be explored, and through the knowledge that is gained a better understanding of their notion of "asylum" can be achieved.

### **3.2.1. Soja's Discovery of Thirdspace through Lefebvre's work**

In his book *Thirdspace* Soja explores the notion of Thirdspace through the various works of intellectuals and academics like Michel Foucault, Gillian Rose and bell hooks among others, who have also studied the social meaning of different kinds of spaces. Soja however discovers the notion of Thirdspace through the work of Henri Lefebvre, a French Marxist philosopher and sociologist, best known for introducing the concepts of the right to the city and the production of social space (Lefebvre, 1991).



In the first part of his book, Soja engages with the extraordinary voyages of Henri Lefebvre, who has been an extremely influential scholar in exploring Thirdspace. Without ever using this specific term, he was the first to discover, describe and explore the Thirdspace. Through his work, he showed very clearly the way to the long hidden worlds of what he described as “l' espace vécu”, meaning the lived space (Lefebvre, 1991, pg. 39).

Lefebvre, in his book *The Production of Space*, was the first to introduce this notion of lived space (Lefebvre, 1991). According to Lefebvre, the “fields” we are concerned with are: “first, the *physical*-nature, the Cosmos; secondly, the *mental*, including logical and formal abstractions; and thirdly, the *social*” (Lefebvre, 1991, pg. 11-12). In other words, Lefebvre's triad is the physical space, the mental space and the social space.

Another way Lefebvre describes this trialectic is the following. According to the writer, first there is the materialised, socially produced empirical space, the *perceived* space, which is directly sensible and open – within limits - to accurate measurement and description (Lefebvre, 1991, pg. 38). Second, there is the *conceived* space, meaning the conceptualised space, which according to the writer is the dominant space in any society or mode of production (Lefebvre, 1991, pg. 38-39). The *conceived* space is tied to the relations of production and to the “order” which those relations impose, and “...hence to knowledge, to signs, to codes and to “frontal” relations” (Lefebvre, 1991, pg. 33). Third, there is the *lived* space, “...embodying complex symbolisms, sometimes coded, sometimes not, linked to the clandestine or underground side of social life” (Lefebvre, 1991, pg. 33). This is the space as directly experienced through its associated images and symbols, and as a result it is the space of “inhabitants” and “users” (Lefebvre, 1991, pg. 39). According to Lefebvre, the lived space overlays physical space, making symbolic use of its objects (Lefebvre, 1991, pg. 39). The lived space is the “dominated” - and

as a result the “passively experienced” space - which the imagination seeks to appropriate and change (Lefebvre, 1991, pg. 39).

Lefebvre believes that these lived spaces are the terrain for the generation of counterspaces, spaces of resistance to the dominant order arising precisely from the subordinate, peripheral or marginalised positioning. It is exactly on these margins of the homogenised sphere of our society, that differences endure or arise (Lefebvre, 1991, pg. 373). According to Lefebvre: “What is different is, to begin with, what is *excluded*” (Lefebvre, 1991, pg. 373). There is a “right to difference” though, that can be achieved only through practical action and effective struggle (Lefebvre, 1991, pg. 396).

This is certainly not easy: on the one hand the existing centre and the forces of homogenisation seek to absorb all such differences, and they will succeed if groups on the margins retain a defensive posture and no counterattack is mounted from their side (Lefebvre, 1991, pg. 373). On the other hand though, groups on the margins can fight back and challenge central power, and such resistance and counter-action will tend to strengthen their position:

“... Just as economic pressure from the base – and such pressure alone, in the shape of unions, the making of demands, striking, and so forth – is able to modify the *production* of surplus value, so pressure grounded in social practice is alone capable of modifying the apportionment of that surplus value – i.e. the distribution of the portion of social surplus production allotted to society's collective “interests”, the so-called social services” (Lefebvre, 1991, pg. 382, 383).

In conclusion, pressure from the margins has to confront the state in its role as organiser of space, in order for beneficial changes for “inhabitants” and “users” of the lived space to become a reality (Lefebvre, 1991, pg. 382, 383).

### **3.2.2. Soja's trialectic of space: The development of the notion of Thirdspace**

Soja, based on Lefebvre's work, evolved his own trialectic concerning space. The analogous concept to Lefebvre's perceived space is Soja's Firstspace: this is the material, physical space that can be empirically measurable (Soja, 1996, pg. 66). The physical space and actual building of an asylum or community care unit with rooms, walls, and facilities, for example, can be considered as Firstspace.

Analogous to Lefebvre's conceived space, is Soja's Secondspace: this is the space that is interpreted, mapped and controlled, and it represents the idealistic background on the basis of which the Firstspace is created. This mental space is tied to the relations of production, and particularly to the order or design that it imposes (Soja, 1996, pg. 67). This is the "dominating" space of regulatory and "ruly" discourse, and thus the representation of power and ideology, of surveillance and control (Soja, 1996, pg. 67). For example, the physical space (Firstspace) of asylum or community care unit is created according to some sort of idealism (Secondspace). The ideology (Secondspace) and the product of ideology (Firstspace) are not always distinct; these two spaces tend to collapse into each other (Soja, 1996).

Analogous to Lefebvre's lived space, is Soja's Thirdspace. This space is linked to the underground side of social life (Soja, 1996, pg. 68). Thirdspace is a strategic location, from which to understand and potentially transform all spaces simultaneously. It is the space of "lived experience" and "marginality", but also the chosen space for "...struggle, liberation, emancipation" (Soja, 1996, pg. 68). For example, Thirdspace represents the lived experience of individuals with SMI in mental health institutions or community care units.

According to Soja, Firstspace epistemologies and ways of thinking, have dominated the accumulation of spatial knowledge for centuries. They focus on a material and materialised "physical spatiality", that is "...directly comprehended in empirically measurable configurations" (Soja, 1996, pg.

74). Major sources for Firstspace knowledge are the human occupancy of the surface of the earth, the absolute and relative locations of things, sites, activities and situations, the relations between society and nature, the architectonics and geographies of the human “built environment” (Soja, 1996, pg. 75). Through these sources we come to the point of establishing concrete and mappable geographies of our world. Through Firstspace epistemologies, we arrive at “factual” knowledge about our world, and there is always a danger of not being able to avoid environmental or spatial determinism, i.e. the notion that the built environment sets limits to human social development (Soja, 1996, pg. 76, 77, 78).

Secondspace epistemologies have tended to arise as a reaction to the objectivity, excessive closure and determinism of Firstspace analysis. Secondspace epistemologies differ, because they concentrate on the *conceived* rather than the perceived space, and spatial knowledge is produced through “...discursively devised representations of space, through the workings of the mind” (Soja, 1996, pg. 79). Secondspace is mainly ideational, comprised by projections into the empirical world from imagined or conceived geographies. In other words, reality is comprehended through thought, and as a result explanation becomes more subjective, reflexive and individualised (Soja, 1996, pg. 79). In Secondspace, the image or representation defines reality, and this leads to the imagined geography becoming the “real” geography.

But Firstspace and Secondspace are not enough to understand reality. A notion of thirding -as- Othering arises, and it is designed not only to critique Firstspace and Secondspace modes of thinking, but to open new possibilities in exploring space and reality (Soja, 1996, pg. 81). According to Soja, Thirdspace is:

“...a limitless composition of lifeworlds that are radically open and openly radicalizable; that are all-inclusive and transdisciplinary in scope yet politically focused and susceptible to strategic choice; that are never completely knowable but whose knowledge none the less guides our search for emancipatory change and freedom from domination” (Soja, 1996, pg. 70).

For Soja, Thirdspace is a space of resistance, from which to redesign cityspace for all oppressed groups; it aims at an active and intentional “remapping” of the city as a strategic location for “...recovery and resistance, a meeting place where new and radical happenings can occur beyond the centered domain of the patriarchal urban order” (Soja, 1996, pg. 110). Choosing marginality for Soja translates into choosing a place for critical rethinking, re-envisioning, and for effective resistance to all forms of oppression and subordination (Soja, 1996, pg. 125).

This exploration of Thirdspace - which is located in the margins of society - is exactly the focus of this research. Thirdspace – analogous with Lefebvre’s lived space – is where residents of CCUs in the Greek context frequently find themselves located. As all groups in the margin, they often experience a sense of uncertainty, despair and of deep alienation. For marginalised groups, the cityspace is the “territory of their oppressors”, “powerful others” who control their lives and “map” the limits of who they are and can be (Soja, 1996). However, for residents of CCUs it is of great importance to find through mental health services, not only the Firstspace dimension of asylum, i.e. the physical space of a mental health institution or community care unit, but also to experience “asylum” in its original sense, as a safe haven, offering safety and security. Exploring the lived experience of CCUs’ residents concerning their notion of “asylum” is of critical importance in order to successfully reconstruct “asylum” in the community.

### **3.2.3. The rationale for the choice of Soja’s Thirdspace as the theoretical framework of this research**

In this section I wish to present my reasons behind choosing Soja’s Thirdspace as the theoretical framework for this research and how this took my exploration beyond the sociological concept of lived experience.

In my previous research, under an entirely different theoretical perspective, I had a limited opportunity to explore the views of only three patients that had been placed successfully in CCUs, while others had an

unsuccessful experience with deinstitutionalisation and had to return to the mental health hospital. I realised at the time that the lived experience of both patients in the mental health institution and of those individuals who were transferred to CCUs, was closely linked to the notion of space (Lentis, 2008). Soja's Thirdspace is a way of exploring residents' experience at three critical levels: at the CCU's space; at the neighbourhood surrounding the CCU; at the broader community. This allowed residents to compare their previous experiences in mental health institutions concerning these issues, with their new life in the community.

The exploration of the residents' lived experience concerning both the mental health institution and the CCU, gave me the opportunity to test in practice the differences between the notion of Firstspace, which represents the empirically measurable physical space, and the notion of Secondspace, which represents the "dominating" space of regulatory and "ruly" discourse, with the notion of Thirdspace, that represents their lived experience. This exploration revealed their views concerning space at the local, neighbourhood and broader community level.

At the CCUs' space level: in this research, residents underwent a major change of living, from the deteriorated and neglected buildings of large and impersonal asylums, to nicely and recently renovated community care units. This usually brings practical changes to the life of residents, as for example having to live with only one roommate instead of many people in a crowded wing, or having a personal closet and a bathroom en-suite, in comparison to the one bathroom per floor or per wing that used to exist in the institution. It was of great interest however to explore how these changes, that "we"- the outside world - perceive as a priori beneficial, were perceived by residents themselves. From my previous experience I had come to realise that these changes can be at times very stressful for some individuals and need careful planning (Lentis, 2008). It was also of great interest to explore relationships with staff and other individuals that had been developed in the two different settings and how these were perceived by residents.

At the immediate surroundings level: for the residents of this sample, there was a great change from living in large and secluded asylums, to community care units located either at the city centre or in the island of Aigina. This transition however can by no means be considered automatically beneficial: I have encountered in my previous research cases where the asylum acted as a “therapeutic landscape” with its large gardens and peaceful environment, no matter how deteriorated the actual buildings were (Lentis, 2008; Gesler, 1996). On the other hand, a nicely and recently decorated CCU in the city centre cannot automatically be perceived as a place providing safety and security, as a growing volume of Greek literature – as it became clear in Chapter 2 – indicates stigma in the community relating to SMI and NIMBYism attitudes, not only in smaller areas like in the island of Aigina, but in the city centre as well. Great caution was needed by my part, as to never make assumptions about the possible benefits of the change of scenery, in order to uncover the hidden reality of residents’ Thirdspace.

At the broader community level: due to occupational therapy activities in CCUs, which are usually located at different buildings or job opportunities that arise, a contact with the broader community starts to develop in cases of patients relocating to CCUs. From my previous experience, this can bring an increased degree of freedom, in a new environment, but once again it cannot be automatically perceived as being easy from the start. Questions arise about how a marginalised group in the city can find its space and place, with the ultimate goal of experiencing true “asylum”. Exploring residents’ lived experience with the broader community, can eventually lead to proposals for policy makers as to better plan mental health services for people with SMI in order to create spaces offering safety and security in the community. At the same time, it can also uncover new perspectives about the remapping of city space for marginalised groups in general: findings deriving from residents of CCUs can have broader applications to people that are homeless, immigrants, or

recently deinstitutionalised from other types of total institutions, such as prisons or drug rehabilitation clinics.

Soja's notion of Thirdspace, which comes in great contrast to Firstspace and Secondspace epistemologies, gave me the opportunity to do this journey, always with the ultimate goal of providing guidelines for the creation of safe havens for marginalised groups in the community. As Montgomery (2001) has indicated from a purely theoretical perspective, more research is needed in order to understand the meaning of asylum by those located in Thirdspace. This can reveal new ways of thinking, which can "... creatively expand the classic (First- and Secondspace) meanings of asylum" (Montgomery, 2001).

In conclusion, the link of the lived experience of residents to space was crucial, and a key determinant for choosing Soja's Thirdspace as the theoretical "lens" of my research. However, as it will become evident from my next section and the analysis chapters, although space critically affected the lives of residents, another crucial parameter was the way mental health services are organised in Greece. The exploration of participants' – both residents' and staff members' - lived experience in this research, uncovered weaknesses and serious imbalances that the recent austerity policy in the mental health sector has created. This is of great importance for Greece at the present period of serious financial crisis and limited government funding for mental health services, which has seriously affected the lives of both patients in mental health hospitals and residents of CCUs.

#### **3.2.4. Critiques and comments on Soja's *Thirdspace*: The value of Thirdspace in this particular research**

In his book, Soja tries to analyse the notion of Thirdspace as a space of radical openness and resistance to all forms of oppression. Soja's Thirdspace lies in the margins of society, and he believes that only by exploring Thirdspace can we improve the world in some significant way. At the heart of Soja's work lies a deep moral concern for human welfare, and



it is this concern that leads him to investigate all different forms of oppression in society and to consider appropriate political and resistance strategies in order to erase them. Soja's notion of Thirdspace has been used not only in the fields of sociology (Lin and Mele, 2005) and urban planning (Soja, 2010), but also in the fields of geography (Kuhlenbeck, 2010) and education (McIntosh, 2012) among others. And yet, while Soja's work is progressive, brilliant and inspiring, at the same time I have two critiques concerning his work.

My main critique through my first reading was that Soja at many instances emphasises the margin as a space that people can "choose": he speaks of choosing the margin as a space of radical openness, and this is true for many individuals who do so as a political act. But what about the marginality that is *imposed*? Through a very careful second reading though, I discovered that Soja, through his analysis of bell hooks' work - a black female intellectual - covers this issue as well, especially when he speaks about minorities and the imposed marginality that oppresses these people who do not have the opportunity to choose. The *choice* of marginality does not ignore the *imposed* marginality, and as Soja himself explains, it works for the reconstitution of a different type of margin; this margin holds the potential to act as a strategic space which promotes resistance and solidarity, instead of division and despair (Soja, 1996).

My second critique of Soja's work is that he places great emphasis on the way *space* affects human lives. However, for the group of people that I study in this research –residents of CCUs who have been deinstitutionalised from mental health institutions – space is not the only factor that affects their lives. They are also affected by the way *mental health services are organised*. These two concepts – organisation of health services and space – are interrelated, because the health system of a country greatly affects the way community care services are organised, and as a result, the way CCUs' residents experience such spaces as "rejecting" or "accepting" communities. In this study, my goal was to explore residents' of CCUs views in the margin – Thirdspace – concerning

mental health services. This notion of exploring residents' views in the margin concerning the way health services are organised and how their organisation affects their lives, was central to this work.

### **3.3. Importance of the research**

The focus of this research is the exploration of Thirdspace – the “lived experiences” – of residents in four community care units in Athens Greece, run by Klimaka, a non governmental organisation. As it became clear in the previous Chapters, the state has not been particularly successful in providing “asylum” to people with SMI in the community. In the Greek context, learning from other countries' experience is of great importance, but clearly something more is needed; the missing piece of the puzzle may very well be that individuals with SMI – patients in mental health institutions or residents of CCUs - have not had the chance so far to speak about their problems, and their voices could not be heard on a large scale. This happened first, because the users' movement has been very recently developed in Greece, and has not yet gained the necessary momentum, second because patients in mental health institutions or residents of CCUs are not involved in service planning, and third, because there is little or no patient-centred research. This means that the present study will be filling a gap in knowledge and could be of great value, because it is the first time that the voices of people who have been deinstitutionalised and transferred to CCUs have been heard in Greece.

As it became clear, in the previous chapters, care in the community for people with SMI has been facing very serious problems in most countries, and there is a great need on an international level for improvement in the *quality* of services (Weich, 2008). This can only happen if users' voices are heard and acted on (Weich, 2008). As Weich indicates from a British perspective: “...in our 21<sup>st</sup> century NHS, the necessary quantum leap is likely to depend less on the views of mental health professionals than on the actions of commissioners, and on their

willingness to engage in meaningful partnerships with users, carers, and service providers” (Weich, 2008).

A new system of mental health services has to be of high quality and be user-led (Appleby, 2000). As a result, there is a great need for involvement of individuals with SMI not only in the evaluation of services, but in service planning as well, to the fullest extent (Lamb and Bachrach, 2001). The views of people with SMI though cannot always become clear only through the users’ movement, because there are a great number of individuals with SMI that do not want or are not in a position to participate in users’ organisations (Parr, 1997). As a result, there is an urgent need for more patient involvement: “Ask the patient” is a guideline of critical importance for service planning of mental health services (Lamb and Bachrach, 2001).

In the U.K., since early 2000s, the Department of Health has been committed to involving patients in the NHS (Department of Health, 2001; Health and Social Care Act, 2001). The goal has been to put the patient at the centre of the NHS, and create patient-centred care, that can respond to patients’ needs and preferences (Staniszewska and West, 2004). The “status gap” that previously existed between professionals and patients, with commissioners or care pioneers having most power, has been challenged; it is now the patient that is considered the “expert” in order to provide: 1) valuable information about crucial aspects of the illness and treatment, along with 2) guidance for future service implementation and provision of care that would hopefully improve the patient experience at an individual, local and national level (Staniszewska and West, 2004).

In order to explore patients’ views, there is a growing requirement for more patient-centred research, exploring perceptions of quality of services (Currie et al, 2005). This is even more urgent for people with SMI, where patient involvement in research can help policy makers to identify gaps in the service and modify practice accordingly (Wright et al, 2004). This exploration of the “lived experiences” of residents of CCUs is exactly the focus of this research. This notion of exploring the Thirdspace,

is a way of giving to residents a "loud voice" that can influence not only their lives but hopefully future mental health policy as well. Through research like this study, the "margin" gets a chance to speak back to the "centre" and to press for beneficial changes in the field of mental health policy.

#### **3.4. Originality of the research, aims and objectives of the study**

The key aim of this study was to explore the shifting meaning of "asylum" by privileging the voices of residents of CCUs. The research aimed to discover what contributes to residents' notion of "asylum" in the community care unit: while one dimension of "asylum" is that of a place offering shelter, safety and security, it is important to discover what particular aspects of residents' everyday life in the community care unit offer this sense of safety and security, and what do not.

A second aim of the study was to compare and contrast residents' life in the community care unit with their previous life in the mental health institution in retrospective. This way, it is possible to discover which particular aspects of residents' everyday life in the hospital used to offer this sense of safety and security, and which ones did not. Residents got a chance to compare and contrast, express their living preferences, and describe the changes that their placement in the community care unit had brought to their lives.

Hence, a third aim of the study was to identify what positive features of asylum might be recreated in the community, and what negative ones need to be avoided; also, what positive features of the notion of "asylum" in the community care unit need to be recreated on a larger scale in the community and what negative ones need to be avoided. Identifying these features can facilitate a better understanding of residents' deinstitutionalisation experience and offer valuable lessons of what factors and support mechanisms facilitate a successful transition to community care and what contribute to an unsuccessful one. This way, policy makers can find out what really works for people with SMI in the

community and reorganise community care services in order to offer true “asylum” to them.

Since the early 1990s, on an international scale, there have been some studies on deinstitutionalisation, using the “before and after” approach in U.K., Canada and Sweden, but they were all quantitative (Leff et al, 1996; Dayson et al, 1992; Thornicroft et al, 1992; Trieman and Leff, 2002; Dencker and Gottfries, 1991; Lesage et al, 2000). In the U.K. in particular, the Team for the Assessment of Psychiatric Services (TAPS) has conducted various projects concerning deinstitutionalisation by following patients before and after their discharge from two psychiatric hospitals that were scheduled for closure (Leff et al, 1996; Dayson et al, 1992; Thornicroft et al, 1992; Trieman and Leff, 2002). It is important to note, however, that all these projects adopted standardised schedules and questionnaires for assessment that were then statistically analysed. Similar “before and after” studies were conducted in Sweden and Canada (Dencker and Gottfries, 1991; Lesage et al, 2000), but here too patients were rated using specific scales that were then statistically analysed. As a result, all previous studies adopted a quantitative methodological approach.

Although some qualitative studies have explored the lives of people with SMI in the community (Barham and Hayward, 1991; Parr, 1997; Pinfold, 2000), none have explored their experiences in relation to the concept of “asylum” in the community, nor did they give individuals the chance to compare and contrast life in the community with their previous life in a mental health institution.

In the Greek context there are extremely few studies concerning deinstitutionalisation. Those that do exist tend to focus only on staff or family carers, by using qualitative methods (Assimopoulos, 2006; Loukissa, 1996), or focus on experiences of ex-patients only, but with the use of quantitative methods (Zisi et al, 2006). In the Greek context there is only one qualitative study with a “before and after” deinstitutionalisation approach (Lentis, 2008). Although this study offered valuable insights on

the issue of deinstitutionalisation, it was limited by the fact that out of the original sample of 24 long-term patients from a public mental health institution, only 3 individuals had a successful transition to life in a community care unit at the time of the second interview (6-12 months after deinstitutionalisation) (Lentis, 2008). From the original sample, eight patients refused to be transferred to the community, eleven patients went back to their family home but had to return to the hospital, and two patients had an unsuccessful deinstitutionalisation to community care units and had to return to the hospital, because of serious relapses (Lentis, 2008). This meant that only the three patients that had the experience of a successful deinstitutionalisation were in a position to talk about their life in a community care unit (Lentis, 2008). The current study is the very first time that a qualitative study explores on a larger scale the notion of “asylum” of residents in community care units and gives at the same time the opportunity to participants to compare and contrast life in the community with their previous life in a mental health institution, in retrospective. As a result, the originality of this research lies in its context, in its setting (CCUs run by Klimaka), and in its methodological approach.

The potential for this study to make a contribution lies in the fact that there is a gap in knowledge in the Greek context in the field of qualitative studies exploring the issues of deinstitutionalisation and care in the community, based on residents’ experiences. The lack of qualitative studies concerning psychiatric services in general in Greece stems from the fact that social sciences have been developing very slowly in Greece, and also from the fact that the traditional model of biological psychiatry still dominates in the field of mental health (Assimopoulos, 2008). This lack of knowledge though of users’ experiences based on qualitative data, may very well be a serious inhibitory factor for the successful transition from hospital based care to community care for people with SMI in Greece (Assimopoulos, 2008). As a result, this study can fill this gap in knowledge, by providing valuable information on residents’ notion of

“asylum” in a community care unit, in order to successfully recreate it on a larger scale in the community.

This research also serves a new international trend for the production of knowledge – evident also in the U.K. Department of Health’s Research and Development strategy – which can be understood as “...moving away from the traditional, university-based model of knowledge production towards a new one”, that places – among other groups – patients at the centre of research (Scott and West, 2008, pg. 387).

# METHODOLOGY

## Chapter 4: Methodology of the research

This chapter addresses the rationale for choosing qualitative methods – and in particular semi-structured interviews – as the best approach for this research. The chapter explores sampling issues and ethical considerations related to my study. The chapter also considers how issues of reliability and validity were dealt with, and how the analysis of the data proceeded through thematic analysis. Finally, issues of quality assessment are presented at the end of the chapter.

### 4.1. Choosing qualitative methods

One of the main goals of this research was to explore residents' notion of "asylum" and whether or not they have been able to find "asylum" in the community; also, to discover – through participants' interviews – how "asylum" could be reconstructed in the community. In order to achieve these goals, qualitative methods were chosen as the most appropriate for this research.

Qualitative research presents the great advantage that it allows for the generation of rich data and the exploration of "day-to-day" experiences, enabling research participants to speak for themselves (Kuper et al, 2008a). In fact, proponents of qualitative research in the social sciences have argued that qualitative methods are the most appropriate for studying people, because they lead to a better understanding of social life in its "...naturally occurring, uncontrolled form" (Cohen and Crabtree, 2008, pg. 331).

Qualitative methods offer also the advantage that they can be used to explore variables that are not easily identifiable or that have not yet been identified, as well as investigating topics either unexplored or about which there is little previous research. In cases where a process or phenomenon is not well known or understood, qualitative research may



bring new and even unexpected knowledge to the fore (Morrow, 2007). In order to do so, a researcher has to collect information and learn about people's experiences, histories, beliefs and perspectives. Using language as a tool, a qualitative researcher is able to plumb the depth of subjective experiences in order to uncover meanings that are not otherwise observable and that cannot be gathered using surveys or other quantitative tools (Morrow, 2007).

Qualitative research has been recognised as making a valuable contribution to medical science (Collingridge and Gantt, 2008). Researchers in the field of health research have realised two very important elements: 1) that traditional quantitative research is limited in its ability to capture the meanings people attach to health care social phenomena, and 2) that understanding the experiential and interpretive elements that qualitative research is capable of providing is essential in order to enhance clinical knowledge and care (Collingridge and Gantt, 2008). Because of these reasons, qualitative methods' popularity will continue to grow steadily in the field of health sciences (Collingridge and Gantt, 2008).

Qualitative research is rooted in the interpretive perspectives found in the humanities and social sciences that emphasise the importance of understanding from the viewpoint of people involved, how individuals and/or groups interpret, experience and make sense of social phenomena, and what are *their* experiences of health services; this makes qualitative research particularly useful for research on health care and for unpacking some of the complex issues in quality improvement (Pope et al, 2002). As a result, qualitative methods can help researchers to gather information about the delivery – or not – of good quality health care, while explaining at the same time variations in health care provision.

Qualitative research methods are also very helpful when studying particular policy interventions in the field of health services [such as deinstitutionalisation and the transition to care in the community in the Greek context] (Starks and Brown Trinidad, 2007). Because of their

nature, qualitative research methods enable health science researchers to examine institutional and social practices and processes, identify barriers and facilitators to change, and discover the reasons for the success or failure of interventions (Starks and Brown Trinidad, 2007). In the field of mental health services, the National Institute of Mental Health (NIMH) in the U.S.A. for example, has repeatedly emphasised the importance of findings of qualitative research in order for policy-makers to determine what works, for whom, why, and under what circumstances (Robins et al, 2008). This is the case with this particular study, where the deinstitutionalisation policy in Greece and transition to community care is being examined.

Lastly, qualitative research presents another advantage: not only can it help decision makers understand the human consequences of their choices (Steiner, 2005), but it can propose and/or formulate interventions in organisations, as well as contribute to social change (Morrow, 2007). This was also one of the goals of this research – as it will become clear later on in this chapter – to enable the residents of CCUs to express their views on things that they would like to have been different in mental health institutions or that they would like to be different in their present life in community care units. This way, the findings of this research will formulate proposals for possible changes in the future. The views of residents of CCUs can be incorporated into policy and planning, in order to improve their prospect of finding true “asylum” in the community.

#### **4.2. Issues of epistemology**

As it became clear in Chapter 3, the main theoretical background of this research is based on the exploration of Thirdspace, as it is described and analysed in the works of post-modern theorists and philosophers such as Soja and Lefebvre. As Richardson (1991, pg. 177) indicates, researchers using postmodernism have unique opportunities to fulfill the promise of sociological imaginations: “...They can write the lives of individuals, groups, and collectives, grounding social theory in people’s

experiences and celebrating diversity, and multiplicity”. For this research I chose postmodernism as the main theoretical framework because I believe that it enabled me to explore and understand the meanings that oppressed people – residents of CCUs in Greece – make of their experiences concerning deinstitutionalisation and care in the community. As a postmodern qualitative researcher I acknowledge that there are multiple realities, and it is exactly these realities that I wanted to explore. The intention of this research was to give voice to people who had been traditionally marginalised, made invisible by the system and/or silenced.

For the epistemological stance of my research I chose that of interpretivism, which encompasses the theoretical framework of postmodernism (Kuper et al, 2008a). Interpretivism is the school of thought that emphasises the importance of interpretation in understanding the social world; consequently, it focuses more on the understanding of subjective experiences, instead of examining facts (Pope et al, 2002). The goal of interpretivism is to provide an understanding of a meaning behind human actions in a broader social context, based on a subject’s unique point of view. This was the main reason behind my choosing interpretivism as my epistemological stance: the fact that it places great emphasis on the interrelatedness of different aspects of people’s lives and recognises that psychological, social, historical, economic, political and cultural factors all play an important role in shaping people’s understanding of their world. Interpretivism provides a holistic understanding of research participants’ views and actions in the context of their lives overall (Snape and Spencer, 2003). This was particularly important for my research, as the political and economic context of Greece at the time of the research, resulted in serious cuts in funding of mental health services, resulting in a reshaping of mental health services, which affected participants’ lives.

Accepting interpretivism led me to value the importance of understanding people’s perspectives in the context of the conditions and circumstances of their lives (Pope et al, 2002). Because of this, I aimed to obtain thick description and as much detailed information as possible

about residents' lives from their own perspective, the staff members' perspective, the Klimaka's lawyer's perspective and the two mental health officers' perspectives, along with my own observations. It was also important to clearly delineate my interpretations from those of participants: in evolving my interpretations, I tried to adhere as closely as possible to participants' accounts, but I also acknowledged that deeper insights could and had to be obtained by synthesising, interlocking and comparing the accounts of a number of participants. Combining and comparing residents' and staff members' accounts was challenging and needed a clear headed strategy in order to clearly state in the analysis chapters the specific source of each account.

Another feature of interpretivism which needs special caution is the fact that the social world and the researcher impact on each other. In interpretivism the findings of a research study are usually influenced by the researcher's perspectives and values (Snape and Spencer, 2003). Because of this, what was needed by my part was to state my positionality as a researcher [provided in the relevant section 4.4.], and be transparent about any assumptions that were made, particularly through the process of the analysis of the data.

From an interpretivist approach, for my research there was also a great need to make the research findings accessible to mental health officers, policy makers and commissioners, along with staff members of mental health hospitals and CCUs, since they are all involved in the process of deinstitutionalisation. This meant that although my interpretation was based on the accounts of individual respondents, at the same time I had to employ language, categorisation and conceptualisation that had not been the residents'. Since my interpretations moved beyond the explicit data provided particularly by residents, I had to place great emphasis on ensuring that the building blocks used in arriving at interpretations were clearly visible to the reader. For this reason, in the analysis section, I included detailed examples about the way themes

derived from interviewee's accounts in order for the reader to understand their development.

In conclusion, I chose interpretivism as my epistemological stance because I considered it to be the best fit between the research questions that were posed through my research and the qualitative methods that I used.

### **4.3. Choosing Klimaka and gaining access**

This research aimed to explore residents' and staff members' of CCUs views on issues concerning transition to community care in Greece and reconstruction of the notion of "asylum" in the community. The reason for selecting units run by Klimaka, is because this Non Governmental Organisation is one of the largest providers of mental health services in Greece in the private sector. Klimaka provides mental health services in the community for people with SMI through nine psychosocial rehabilitation units (seven boarding houses, one hostel and one supported apartment), three day centres and one mobile unit for the islands of South East Cyclades ([klimaka.org.gr](http://klimaka.org.gr), 2015). Klimaka also provides shelter to homeless people and vulnerable groups like immigrants, and operates a special intervention phone line for suicide ([klimaka.org.gr](http://klimaka.org.gr), 2015).

From the nine psychosocial rehabilitation units that Klimaka operates throughout Greece, four units are located in the greater Attica area. As a result, I had access to units with a large total number of residents and staff members, in relatively close geographical proximity. Moreover, all residents in Klimaka had been previously institutionalised in public mental health institutions in Greece. As a result, their experience was valuable, as they could offer insight into problems – and prospects – of receiving care in public institutions, but in community care units run by the private sector as well. As it will become evident in the following chapters, although these units receive support by the Ministry of Health, at the same they experience problems because of the financial crisis that Greece has been experiencing since 2010, and the resulting cuts in funding.

In order to proceed with this research, I had to first gain access to Klimaka. Researchers conducting studies in medical settings often have to negotiate access with great care (Lewis, 2003). This was certainly the case with this study, where access had to be negotiated with Klimaka. I developed a good relationship with the directors of Klimaka, who really welcomed the opportunity to participate in this research, as they felt that it can make a very valuable contribution in the field of mental health research in Greece and possibly influence future mental health policy.

#### **4.4. Issues of reflexivity – Positionality of the researcher**

Reflexivity is extremely important within the qualitative paradigm (Kuper et al, 2008b; Yeh and Inman, 2007) and it refers to the recognition of the influence a researcher brings to the research process (Kuper et al, 2008b). Since researchers are positioned very centrally in qualitative research, they must be aware about how their own position and their a priori knowledge and assumptions impact upon all aspects of the research: from design, to data collection, to analysis and interpretation (Jaye, 2002), Particularly in the interpretivist paradigm that I used in this research, researcher values are assumed to exist, and are even embraced, and subjectivity is an integral part of the research process (Morrow, 2007; Yeh and Inman, 2007). As a result, research value biases are inevitable and should be discussed at length (Ponterotto and Grieger, 2007). Such a discussion should explain the experiences and/or motivations that led a researcher to undertake a particular investigation (Yardley, 2000), and what are his/her backgrounds, personal and professional experiences, and perspectives on the issues being explored (Malterud, 2001). This process then can shed light on the worldview of the researcher and on the lens through which he/she views the phenomenon of interest (Morrow, 2007).

As a qualitative researcher studying the issue of transition to community care for people with SMI in Greece, I have considerable experience on the topic: for my MPhil thesis, I studied the process of

deinstitutionalisation in Greece, and I conducted a large qualitative study following 24 long-term patients before and after their deinstitutionalisation from a public mental health institution. The experience I gained from my previous study though, made me proceed with this research with an open mind, mainly due to some very interesting findings which I had not expected at the time I conducted my previous research. One such finding was that there was a group of patients with long-term SMI who were older and who not only refused to become deinstitutionalised, but who also considered the mental health hospital to be their home. Patients in that group did not mind about the decrepit and drab buildings of the psychiatric hospital, nor the neglect of the interior décor. For those individuals the physical fabric of the place in which they resided was of far less importance to them than the social fabric of the place. As a result, an important lesson that I learnt was to always proceed with research with a very open mind and expect novel findings.

As I explained in section 3.3, my previous study faced two limitations: The first one was that at the time of the study, only 3 patients had been placed successfully to community care units from the original group of 24 patients [one group refused to get deinstitutionalised, another group had unsuccessful attempts at deinstitutionalisation and transfer to their parental home and had to return to hospital, and a third group had unsuccessful attempts of deinstitutionalisation to CCUs, but had to return to hospital due to serious relapses] (Lentis, 2008). At the end of my study I had indicated that an area for future research would be to undertake a study only with residents of CCUs that have been residing in the units for at least one to two years, in order to explore their views and experiences of transition to community care.

Another limitation of my research was that because of the design of the research, I could only interview patients, first at the mental health hospital, and then – for the ones that got transferred – in their respective community care units. However, in some instances it became clear that it would have been really interesting to explore staff's views as well (both in

mental health hospital and in community care units), because this would have given useful insights into the strengths and weaknesses of how mental health services are organised in Greece (Lentis, 2008).

This research comes to fill this gap by exploring residents' and staff members' of community care units views on issues concerning transition to community care in Greece and reconstruction of the notion of "asylum" in the community. The design of this study has been informed and influenced to a certain degree both by my previous experience and by the extensive literature review I have conducted. However, the purpose of this research is not to test previous hypotheses, but to develop new ones. Although I took into consideration findings of my previous research when organising the interview schedule, I did so with an open mind. My goal was to develop themes for the interview schedule that would allow for the exploration of new areas, instead of trying to later "fit data" into a pre-existing coding frame or analytic preconception (Braun and Clarke, 2006). I recognise through this self-reflective process my a priori knowledge and assumptions, but with the goal of attending to the participants' accounts with an open mind (Starks and Brown Trinidad, 2007). I agree with Braun and Clarke (2006, pg. 83) when they say that: "...researchers cannot free themselves of their theoretical and epistemological commitments" and that research cannot be conducted "...in an epistemological vacuum"; however, the goal of this research was to follow a mainly inductive approach, allowing meaning to emerge from the data (Kuper et al, 2008a). The semi-structured interview developed for this research was open-ended and discovery oriented, so that a variety of perceptions could be traced, and a broad spectrum of views could be collected.

As far as potential power relationships between myself and residents are concerned, in this research there was a great advantage: As an independent researcher, I did not have a doctor-resident or nurse-resident relationship with the participants that reside in the community care units; as a result, residents felt more comfortable to speak freely, because they did not have to give responses that would please doctors or nurses. I have



also explained in the Information Form, that their decision on participating would not affect their length of stay in the community care unit or their treatment in any way, nor would it affect or prejudice their future relations with the community care unit (Appendix II). It is important to note that both confidentiality and anonymity were offered to all participants in this research (Appendix II).

As far as my relationship with the staff members of these units was concerned, again, as an independent researcher who did not work in these units, I did not pose a “threat” to them, in any way. In fact, they understood that participating in this research anonymously, gave them the chance to speak freely about community care, and would not affect at all their position as staff members of these units (Appendix IV). Again, anonymity was provided to staff members, as it happened with residents (Appendix IV).

Moreover, in relation to my ontological characteristics, I recognise my positionality as a female researcher, educated and mentally “well”, but this is not necessarily problematic for a qualitative researcher if it is carefully managed and reduced. Reducing the impact of my positionality was realised through carefully placing participants at the centre: in this research, it was the “insiders”, the persons that were interviewed – residents and staff members – who were the “knowledgeable” ones. In this study, for me – the researcher – there was no dilemma of expert vs learner role, because I felt that I used my expert role to gain entry into the field, but I then relinquished the role of expert, in a collaborative pursuit of the participants’ meaning-making world, acting mainly as a “learner” (Morrow, 2007). Residents shared their insights and their experiences on community care, and I had to listen to their voices and their stories with an open mind, in order to understand their own reality, and study the interplay of multiple meanings about their social world (Leys, 2003).

The study was conducted in residents’ own “territory”, i.e. the community care units run by Klimaka, and the goal was to acquire a deeper understanding through a democratic form of communication - while

ensuring privacy and confidentiality - along with engagement, empathy and emotional involvement with participants' worlds (Morrow, 2007). My interest was mainly emancipatory in nature, and this is congruent with the social justice agendas that underpin the postmodern philosophy. This journey was an exploration of residents' Thirdspace, and revealed important lessons for future mental health policy implementation in Greece.

#### **4.5. Sampling issues**

One of the most critical decisions in a qualitative study is *whom* to include in the sample; as a result, sampling is a key aspect of social inquiry. As Kuper et al (2008b, pg. 687) indicate: "An understanding that qualitative research is based in experience and in the construction of meaning, combined with the specific research question should guide the sampling process". Participant sampling in qualitative research has to follow a well-defined rationale and fulfill a specific purpose, which is why qualitative sampling is often called purposive (Collingridge and Gantt, 2008). In short, purposive sampling refers to the process of selecting participants who serve a *specific purpose that is consistent with a study's main objective* (Collingridge and Gantt, 2008). As Ritchie et al (2003, pg. 78) indicate, in purposive sampling "...The sample units are chosen because they have particular features or characteristics which will enable detailed exploration and understanding of the central themes and puzzles which the researcher wishes to study".

A particular purposive sampling strategy is criterion sampling, where all cases that meet some predetermined criteria are studied, and this sampling strategy is very commonly used in studies that explore issues relating to quality improvement (Russell and Gregory, 2003). In this particular research, the sample was purposive in that all residents had the experience of deinstitutionalisation and transition to community care. The criterion was that all participants resided or worked in community care

units for people with SMI, run by Klimaka – a private, non-profit organisation – and were located in the greater area of the city of Athens.

Another important decision in qualitative research is not only *who* will be taking part in a study, but also *how many* individuals will be participating. The trade-off between breadth and depth in a research study affects the size of a sample. The aim of qualitative research is not to identify a statistically representative set of respondents or to produce numerical predictions, but rather to yield detailed and holistic views of the phenomena under study (Pope et al, 2002). While qualitative researchers aim to draw conclusions which can be “generalisable” to particular groups of people through studying particular examples, a qualitative researcher cannot study every single case (Silverman, 2002).

As a result, sample sizes are determined in part by “...the depth and duration required for each interview and how much it is feasible for a single researcher to undertake” (Britten, 2000, pg. 18), and in part by theoretical saturation. As Ritchie et al (2003, pg.107) noted: “There is a point of diminishing return, where increasing the sample size no longer contributes to the evidence”. Hence, in qualitative research, the researcher is mainly concerned with the richness of the data and reaching saturation, i.e. identifying all themes. The number of individuals needed is an important decision that a researcher has to make, depending on the goals and the purpose of the study (Starks and Brown Trinidad, 2007). For this research study, I made the decision to interview all residents and staff members of the four community care units for people with SMI that Klimaka operates in the greater Attica area. As a result, this was a *full* sample.

In total, I conducted 50 interviews with 30 residents and 20 staff members of the four community care units. Also, based on the suggestions of my supervisor Professor West, I additionally conducted 5 more interviews with the legal advisor of Klimaka, two mental health policy makers from the Ministry of Health, a psychologist from Dromokaition Mental Health Hospital, and a psychiatrist from Dromokaition Mental

Health Hospital, in order to gain a broader perspective on mental health policy and the problems that the deinstitutionalisation policy is facing in Greece. In total, I conducted 55 interviews. The sample size is large for a qualitative research, however I decided it was necessary, in order to gain a broad perspective on all major issues relating to deinstitutionalisation in Greece.

It is also important to note that, in all cases of purposive sampling besides ensuring that all parameters of relevance to the subject matter are covered, the sampling strategy also has to ensure that some diversity is included, so that the impact of the characteristic concerned can be explored (Ritchie et al, 2003). In this research study this was ensured by the fact that all participants had experience on the issue of deinstitutionalisation and transition to community care, but from different positions. The sample consisted of all residents and staff members of 4 community care units run by Klimaka: the first unit was a psychogeriatric boarding house; the second unit was a boarding house and the third one was a hostel – all three located in Athens. The fourth unit was a protected apartment on the island of Aegina which belongs to the greater Attica area. Residents of these units were both male and female, of a range of different ages. The sample also included all staff members of these units. It is very interesting to note that one staff member, a secretary at Klimaka, is an ex-resident who has gone through the transition from being to a mental health institution, then to a boarding house, to a hostel, to a protected apartment, to independent living. Her perspective on transition to community care was extremely interesting, because it offered a more complete view on the issues being examined. Also, the perspective of staff members – doctors, nurses, psychologists, social workers – was extremely important, and gave very useful insights to the study.

It should also be explained that the basis for comparing staff and resident perspectives, particularly in relation to experiences in the psychiatric institutions, was the fact that several CCUs staff members used to work in institutions the same period that many of the residents were

hospitalised at the same institutions, or have seen and regularly visited the residents in the hospitals during the period they were preparing them for the transition to the CCU. So in some cases, when expressing their views about care in mental health institutions, staff referred to some of the residents in this sample, who used to be patients in institutions the same period they were working there. Many residents have been institutionalised at Dromokaition Mental Health Hospital and/or Dafni, which are the two major mental health institutions in Attica, and these are also the hospitals that several staff members used to work. For methodological consistency, in cases where this applied and had been expressed by staff members, it was explained through additional comments. However, it should also be mentioned that some of the staff members did not have previous working experience in the same mental health institutions that most residents had been hospitalised, and this may explain disparities in reporting between residents and staff.

In order to have the opportunity to fully explore all themes, interviews lasted almost an hour, and in some cases participants were interviewed twice. In order to gain a broader perspective - as mentioned earlier - my sample also included the legal advisor of Klimaka, along with two staff members of Dromokaition Mental Health Hospital and two officers from the Greek Ministry of Health, responsible for the Mental Health Sector, who offered their insight from a different perspective.

All participants were given an information form (Appentix II for residents and Appentix IV for staff members), and had the opportunity to read it seven days prior to conducting the interview. From all residents of the four community care units, only four refused to participate, two from the hostel and two from the boarding house. All staff members on the other hand agreed to participate in the study. All participants signed consent forms (Appentixes III and V).

The full list of participants is included in Appendix I (Tables 2, 3 and 4). [The study started with three community care units, however due to an

internal restructuring and relocation of the boarding house Afaia, the units became four, always concerning the exact same sample of residents].

#### **4.6. The use of semi-structured interviews in this research**

For this particular research, semi-structured interviews have been selected as the best method for interviewing participants. Semi-structured interviews present many advantages. The first one is that they are typically based on a flexible topic guide that provides a loose structure of open-ended questions, in order to explore experiences and attitudes (Pope et al, 2002). These open-ended questions, on the one hand define the area to be explored, but on the other give the researcher and the interviewee the chance to diverge in order to explore a particular response or idea in more detail (Britten, 2000). As a result, in semi-structured interviews, the researcher has a set of themes to cover, but the nature of this type of interview allows for conversation and redirection if necessary (Britten, 2000). This means that with a semi-structured interview, the researcher can keep the agenda flexible.

This flexibility allows the researcher to go below the surface, explore participants' ideas, and possibly uncover new ideas or areas that one would not expect initially, and this is another major advantage of this type of interview. As Chenail (1992, pg. 2) argues: "...the margins of a project often provide some of the most interesting and informative patterns for investigators, if they include a curiosity for the exception in their work and a hesitancy to explain quickly that which might turn out to be unexplainable". As a result, with a semi-structured interview a researcher can ask probing questions in order to: i) encourage participants to elaborate on the details, ii) achieve clarity, and iii) stay close to the lived experience (Starks and Brown Trinidad, 2007).

Because of their nature, and in order to ensure that really detailed information is gathered, this type of interview requires experienced researchers, with the necessary ability and sensitivity to establish rapport with respondents, to use flexibly topic guides, and to follow up questions

and responses (Pope et al, 2002). With the great experience that I had from my previous research (Lentis, 2008), and with all the issues mentioned above taken into very serious consideration, in this research I presented myself to residents as a listener, and I asked them to give accounts of their lived experience (Starks and Brown Trinidad, 2007).

During interviews, I always tried to be friendly, polite and open. I was listening very carefully, both to the words being spoken by the residents but also to how they were being said and the emotional tone used. I paid particular attention to phrasing questions in such a way so that they were clear to the neutral and open-ended. I started the interview with questions that the residents could answer easily – such as questions relating to demographic or background detail – in order to make them feel more relaxed, and then proceeded to more sensitive or even difficult topics. From my experience, in most cases interviewees are willing to answer the questions and give the information or opinion they are asked.

Another important aspect concerning the use of semi-structured interviews in this research – as with any semi-structured interview – is that wordings cannot be standardised: in certain cases, I had to frame supplementary questions, in order to explore a particular idea or response in more detail, as new unexpected topic areas emerged, and in order to do so I had to use the interviewees' own vocabulary. Also, the use of semi-structured interviews gave me the flexibility to change the order in which questions were asked, depending on the course of each particular interview.

During interviews with residents, I made sure that the office where the interviews took place in each community care unit was quiet, with no outside interruptions, and no competing distractions. I made every possible effort to conduct the interviews at the interviewees' own pace, and I assured them that there was no reason to hurry. I used audio-taping as the way of recording the interviews, instead of notes written at the time of interview or notes written afterwards. Taking notes has certain disadvantages: writing notes at the time of the interview can interfere with

the process of interviewing, whereas notes written afterwards tend to miss out some details (Pope and Mays, 2000). I also assured participants that they could have the tape – after the transcription of the interview – and destroy it if they wanted to (Appendix II and IV).

In this particular research, the themes that were covered through the semi-structured interview are included in Appendix VI (Tables 5 and 6).

Part 1 themes concern the previous life of residents in the mental health hospital; as a result, they cover the period of institutional care. Part 2 themes concern the present life of residents in the community care units. All themes, from Part 1 and 2, were covered not only with the residents of the four CCUs, but also with the staff members of the community care units, the legal advisor of Klimaka, two staff members from Dromokaition Mental Health Hospital, and two Mental Health Officers from the Greek Ministry of Health, in order to have a more “complete picture” about deinstitutionalisation and transition to community care in Greece.

In this particular research, the semi-structured interview has been developed in such a way, in order to enable the participants to first of all express their views as far as deinstitutionalisation and transition to community care is concerned, and this was the first objective of the study. A second objective of this research was to enable residents to compare and contrast their previous life in a mental health institution with their current life in a community care unit. A third objective of this research was to discover what contributes residents’ notion of “asylum”. While “asylum” has a dimension of a place offering shelter, safety and security, it is crucial to discover what particular aspects of residents’ everyday life offer this sense of safety and security, and what does not. This can help policy makers to successfully recreate “asylum” in the community for people with SMI in the future.

The development of the themes that were covered in the interviews was informed by literature review, by my previous research and by the theoretical background of the research. Literature review was important for the development of the themes, as I investigated the areas covered by



studies on deinstitutionalisation on an international scale, using the “before and after” approach in U.K., Canada and Sweden (Leff et al, 1996; Dayson et al, 1992; Thornicroft et al, 1992; Trieman and Leff, 2002; Dencker and Gottfries, 1991; Lesage et al, 2000). Although all these projects adopted quantitative methodology, still the areas covered through them were of great interest for the development of the themes.

I also reviewed qualitative studies that have explored the lives of people with SMI in the community (Barham and Hayward, 1991; Parr, 1997; Pinfold, 2000). Although none have explored their experiences in relation to the concept of “asylum” in the community, nor did they give individuals the chance to compare and contrast life in the community with their previous life in a mental health institution, still were of interest for the development of the themes concerning life in the community. I also explored the areas covered by Greek studies: In the Greek context there are extremely few studies concerning deinstitutionalisation and those that do exist tend to focus only on staff or family carers, by using qualitative methods (Assimopoulos, 2006; Loukissa, 1996), or focus on experiences of ex-patients in the community only, but with the use of quantitative methods (Zisi et al, 2006). Still, the broader areas covered helped me to further shape my interview schedule. It is also important to note that the general literature review on deinstitutionalisation in Greece was helpful in highlighting areas that needed exploring through the interview, in relation to notion of “asylum”.

The development of the themes was also informed by my previous research, which is the only qualitative study with a “before and after” deinstitutionalisation approach in the Greek context (Lentis, 2008). Although that study faced the limitation that out of the original sample of 24 long-term patients from a public mental health institution, only 3 individuals had been successfully relocated to a CCU, still I had to develop for that research the necessary themes in order to explore the transition to community care (Lentis, 2008). What was important though for the development of the themes used in this research was to put all the

knowledge acquired from literature review and the experience gained through my previous research under a novel theoretical background that I used for the first time, that of Soja's Thirdspace. As a result the formulation of the themes aimed to uncover the lived experience of participants in relation to mental health institution and to the CCUs as places providing – or not – “asylum”, i.e. offering safety and security. The theoretical background of Thirdspace offered new lens under which the semi-structured interview schedule evolved. The interview schedule was discussed in depth with Professor West, Professor Meerabeau and Dr. Paterakis, and all agreed that the themes covered all necessary areas of participants' lives in order to explore notion of “asylum”.

It is also important to note, that although the semi-structured interview I have developed for this research was my primary method for data collection, I also used a secondary method for data collection, which was a diary. Throughout the study, I kept a research diary, in which I recorded important parameters concerning my research: impressions from the interviews, the relationship with the interviewees, and general comments concerning each interview. As Yeh and Inman (2007) note, using a diary in addition to another method for data collection is very useful, in order to separate the personal emotions and reactions of the researcher from the rest of the data (Yeh and Inman, 2007). I made sure that immediately after the end of each interview I wrote notes in my research diary. From my previous experience, this is very useful, because at the end of each interview impressions and feelings are very “fresh” in the mind of a researcher, whereas if even a few hours go by, a certain amount of detail can certainly be lost. Comments written in a diary are always very useful, particularly when the time of writing the final thesis comes, because they provide supplementary and valuable information that helps the researcher to establish a more complete view and present it as such to readers.

#### **4.7. Ethical considerations**

Ethical considerations are of great importance in all qualitative research studies. Conducting ethically sound research involves carrying out research that is honest, respectful, and that embodies the values of empathy, collaboration and service (Cohen and Crabtree, 2008). Researchers' responsibility to treat participants with high regard and respect is of paramount importance (Morrow, 2007). Respect must be shown both for participants' lives and for the complexity and ambiguity of the subject matter (Elliott et al, 1999).

One ethical consideration of great importance for this research – as in all mental health care research – is respect for the autonomy of participants, who in this case were residents of CCUs for people with SMI. This in essence means: "...the full regard for an ill individual's values, life experience, autonomy and dignity" (Roberts, 2002, pg. 2). Respecting people's autonomy has many implications: informed consent must be obtained from participants experiencing SMI, in order for a researcher to proceed with a research study. This is exactly what happened with this particular research: I provided residents with information about the purpose of the study, explaining what was involved, the likely duration of the interview, how the data would be used, what participation would require of them, and that participation was voluntary. I also stressed the fact that whether or not the residents participated, it would not affect their treatment. Also, residents were given assurances about confidentiality. All participants were given an information form and had the opportunity to read it seven days prior to conducting the interview.

I made sure that residents understood the given information, and this was achieved by providing information sheets written in residents' language. Also, a balance in the amount of detail given was carefully considered. Giving too much can deter interviewees, or curtail their spontaneous views by being over-specific. On the other hand, there is nothing to be gained from participants who are not adequately informed of what will be involved, and have no idea about the main topics that will be

covered during the interview. All these issues were given very careful consideration while developing the resident information form and consent form used in this particular research (provided in Appendix II and Appendix III). Similar information forms and consent forms were also developed for staff members, making clear to them that participating in this research would not affect at all their working relationship with the community care unit (provided in Appendix IV and Appendix V).

It is important to note that all residents in this study had the capacity to consent. Also, I made sure to obtain informed consent by all residents at the beginning of the research relationship, because as Morrow (2007) indicates, this is the best time to do so in a research. This helps participants anticipate their own reactions, ensures their ongoing consent during the process of the research, and keeps open the possibility of a participant withdrawing, if he or she feels that it is his or her best interest to do so (Morrow, 2007).

Particular thought was also given to the proposed conditions for anonymity and confidentiality. Anonymity means that "...the identity of those taking part not being known outside the research team" (Lewis, 2003, pg. 67). Confidentiality on the other hand means: "avoiding the attribution of comments, in reports or presentations, to identified participants, both direct attributions (if comments are linked to a name or a specific role) and indirect (by reference to a collection of characteristics that might identify an individual or small group) must be avoided" (Lewis, 2003, pg. 67). I took great consideration of these issues: all participants (residents and staff members) were given pseudonyms, so that no one would be able to identify them. Also, any comments or particular characteristics linked to a particular participant were avoided, so that no one would be able to identify a participant (resident or staff member) through his/her interview.

In all mental health care research studies, it is also important to give consideration to ways in which taking part may make participants feel uncomfortable, and as a result a researcher has to ensure ways of

protecting them from this. This is based on the moral principle of nonmaleficence, meaning: "...the duty to avoid and minimise harm" (Roberts, 2002, pg. 2). This issue arises most clearly in studies on sensitive topics – like this one – which may uncover painful experiences that an individual with SMI has never shared before. In such cases, a researcher has to provide mechanisms to mitigate potential distress to participants from sharing their personal stories (Kuper et al, 2008b). In this research, I took great consideration of this issue: first of all, I clearly informed all residents about the issues the study would address, before their actual participation. Also, I took care to always address sensitive topics through direct and clear questions. This is essential in order to ensure that the residents would not get drawn "...through ambiguity or confusion into subjects they would prefer to avoid" (Lewis, 2003, pg. 68, 69). I was alert to any signs of discomfort from residents and checked if they were willing to continue the interview or preferred to stop.

Another important issue that I had to take care of was the possibility that during the interview there could be indications that a resident was at risk of harming himself/herself. I dealt with this issue by clarifying to residents before the interview began, the circumstances under which information would have to be passed on. This aspect was mentioned in the resident information form that has been developed for this research. It is clearly stated that confidentiality would have to be broken under specific circumstances, like disclosure of abuse or risk of self-harm.

Another moral principle that had also been taken into very serious consideration in this research, was the principle of beneficence, which is the "...duty to do good by alleviating suffering and by working to enhance the life of the ill person" (Roberts, 2002, pg. 2). Clearly, the goal of this research was to give residents of CCUs the chance to express their views concerning deinstitutionalisation, transition to community care, and their views concerning their notion of "asylum"; this in turn can help officials in the future to plan better transition to community care, and also help to the successful reconstruction of "asylum" in the community. As a result, this

research can contribute to the concept of “empowerment” of participants, meaning “...doing things to help patients and clients to be more in control for their health and health care” (Gillon, 1994, pg. 4). It is possible though, that the residents that were interviewed in this research, may not receive personally any benefit from this study, but through their participation they can make a valuable contribution: the findings of the study will give officials the chance to plan better deinstitutionalisation for other hospital patients in the future, so that there can be a successful transition to community care and provision of true “asylum” in the community.

With respect for confidentiality and for the anonymity of residents and staff members of Klimaka through the development of the informed consent forms, along with respect for the moral principles of nonmaleficence and beneficence, I had to obtain first approval by Klimaka. This was necessary in order to gain access to residents and staff members of the CCUs that Klimaka runs for people with SMI in Attica. Also, because of the nature of the research, I had to consequently obtain ethical approval from the Ethics Committee of Greenwich University, which reviewed the research methodology in order to ensure i) the safety of participants in the research and ii) that ethical practices were being utilised in order to protect human rights. The approval letter from Klimaka that was submitted to the Ethics Committee of Greenwich University is presented on Appendix VII.

#### **4.8. Issues relating to transcription and translation of interviews**

In qualitative research, recording data objectively and comprehensively is important in order to ensure reliability and validity (Seale and Silverman, 1997). In order to record data objectively in this research, I tape recorded all interviews and then transcribed the audio-tapes in order to proceed with data analysis. Transcripts were checked for errors against the audio-tape of each interview, in order to ensure that accurate and authentic reproductions of participants’ accounts were made (Meehan et al, 2000).

However time consuming transcription is, it plays an extremely important role in the full tape-transcribe-code-interpret (TTCI) cycle (Lapadat and Lindsay, 1999). The full TTCI process presents many advantages: 1) it is more complete, accurate and unbiased for examining language data than alternative approaches; 2) it preserves the data in a more permanent, retrievable, flexible and examinable manner; and 3) it provides a researcher with an early sense of the data: through listening, re-listening, transcribing and reviewing, a researcher gets familiarised with the data, achieves a deeper understanding of hidden meanings, and starts interpreting the data (Lapadat and Lindsay, 1999; Tuckett, 2005).

It is also important to note that my transcriptions of audio-tapes also included elements of “paralanguage”, such as laughs or changes in the tone of voice of participants (Yeh and Inman, 2007). These are aspects that alter or emphasise what people say and do, and provide a depth to the emotions underlying a participant’s experience (Yeh and Inman, 2007).

After transcription was completed, then the process of translating the transcripts followed: in this research study, all transcripts from the participants’ interviews – which were in Greek – had to be translated in English. At this point it is important to note that language is more than just a means of communication: as Yeh and Inman indicate “...it is one of the main sources of transmitting cultural beliefs as well as traditions, perceptions, and emotions, and it serves as a source of identity and pride” (Yeh and Inman, 2007, pg. 379).

Translating transcripts from one language to another always raises the issue of “...achieving conceptual equivalence” and demands an engagement with the “politics of translation” (Jones, 2000, pg. 174). The difficulties of translating transcripts from one language to another mainly revolve around the issue that words may have multiple meanings and associations in one cultural and linguistic context that do not automatically occur in another, no matter how well translated (Smith, 1996). Smith (1996) argues that in such cases one needs to “disrupt” the “home” and “foreign” categories as the problematisation of language and meaning

applies to research in both “home” and “foreign” languages. Research in both cases requires interpretation and appropriation. As a result, through the process of translation “...differences, tensions and conflicts are explored, not as problems, but as spaces of conceptual and indeed political opportunities and negotiations” (Smith, 1996, pg. 165).

This approach was adopted in my own translation. As a Greek-American however, I was in the advantageous position of being able to conduct my research in Greek, my native language, and translate into English, which is also a native language for me. Nevertheless, from my previous experience I knew that there might be some instances where I would have to take great care with the translation in order to ensure that a conceptual equivalence would be achieved. When I came across a case like that, I made sure to discuss it with a bilingual translator, and examined the issue very thoroughly, until we reached consensus on the best possible interpretation based on cultural norms and practices (Yeh and Inman, 2007).

#### **4.9. Analysis of the data**

In order to derive conclusions, an extended analysis of the data has to proceed. The precise analysis of the detailed transcripts derived from the interviews is a long process that needs to be done extremely carefully (Pope et al, 2000). In this research I had to cope with the usual problem that qualitative research produces voluminous data (Pope et al, 2000), and requires a clear-headed management strategy.

For this research, I decided to use thematic analysis for the analysis of the data. Thematic analysis is a widely used qualitative analytic method for identifying, analysing and reporting patterns [themes] within data (Braun and Clarke, 2006). Basically, it focuses on identifiable themes and patterns of living and/or behavior (Aronson, 1994). Not only does it organise and describe a data set in detail, but it goes further than this, and interprets various aspects of the research topic (Braun and Clarke, 2006). Thematic analysis presents many advantages: 1) it is flexible, and a



relatively easy and quick method to learn and do; 2) it possesses theoretical freedom and is compatible with different epistemological paradigms; 3) results from thematic analysis are generally accessible to an educated general public; 4) it can usefully summarise key features of a large body of data, but at the same time it can offer a “thick description” of the data set; 5) it can highlight similarities and differences across the data set, and generate unanticipated insights; 6) it can be extremely useful for producing qualitative analyses suited to informing policy development (Braun and Clarke, 2006).

It is also important to note that thematic analysis can be inductive or theoretical, meaning that themes identified can be strongly linked to the data [inductive] or they can be driven by the researcher’s theoretical or analytic interest in the area of research [theoretical] (Braun and Clarke, 2006). For my research, I used an inductive approach, and this means that analytical categories and explanations were generated gradually from the data (Pope et al, 2002). As a result, I used a process of coding the data *without* trying to fit it into a pre-existing coding frame or my analytic preconceptions [although I cannot deny being informed by my previous experience, and I certainly cannot claim that data were coded in an “epistemological vacuum” (Braun and Clarke, 2006)].

In order to proceed with the process of data analysis, I did the following: First of all, I collected all data from recordings of transcribed interviews and notes from my diary [with a chronological account of the research process and my reflective notes made during the research]. Then, I familiarised myself with the data, through repeated reading of the data in an active way, searching for meanings and patterns. In my experience, this is always a very time consuming process, but it provides the bedrock for all the analysis. During this stage, I started taking notes and writing remarks, as a first attempt at coding the data (Tuckett, 2005).

After completing this stage, I proceeded with the actual coding process. Codes identify a feature of the data that appears interesting to the analyst, and refer to the most basic element of the data that can be

assessed in a meaningful way, regarding an experience or a phenomenon (Braun and Clarke, 2006). This means that codes were assigned to units of meaning in the text (Tuckett, 2005; Starks and Brown Trinidad, 2007). Through the coding procedure, I made sure to work systematically through the entire data set, giving full and equal attention to each data item. All actual data extracts were coded, and then collated together within each code. This practically involved photocopying extracts of printed data, and collating all items relating to a certain code together in a file.

The next step was to examine the codes for patterns/themes, and then reintegrate and organise the data around central themes and relationships drawn across all the cases and narratives (Starks and Brown Trinidad, 2007). This meant that I had to sort the different codes into potential themes, and then collated all the relevant coded data extracts within the identified themes. It is important to keep in mind that some initial codes ended up forming main themes, whereas others ended up forming sub-themes, and others still had to be discarded (Braun and Clarke, 2006). The goal was that data within a theme would cohere together meaningfully, while keeping a clear and identifiable distinction between themes. As a result, all the collated extracts of each theme needed to form a *coherent pattern*.

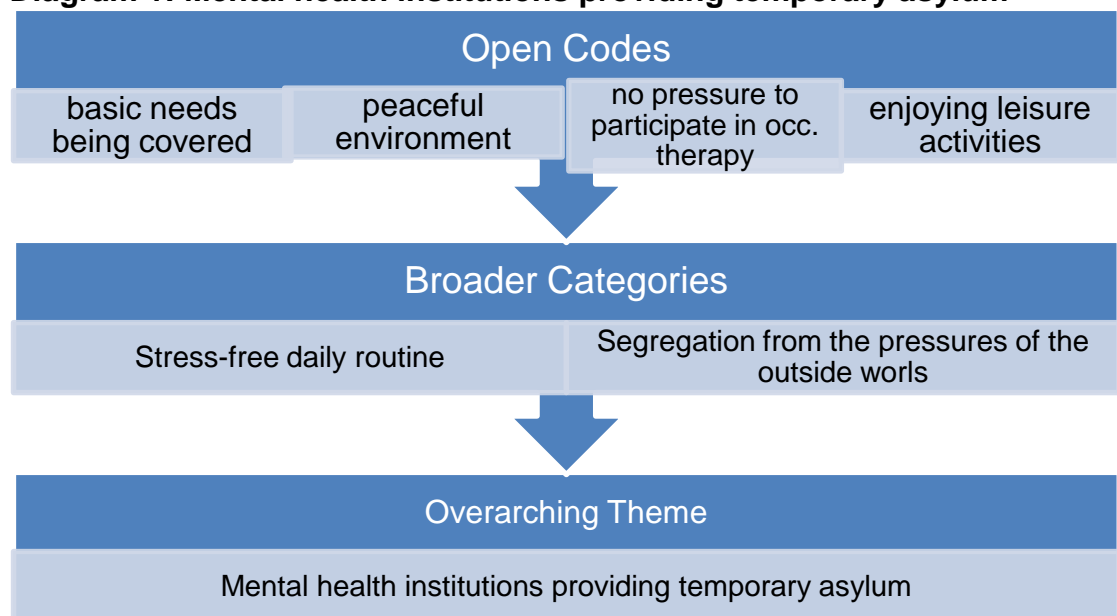
For each individual theme, I needed to conduct and write a detailed analysis. One theme for example that emerged from the data was the stigma residents of different CCUs experienced, particularly during the initial phase of transition to community, even in cases where units were located in inner-city areas, which are usually less rejecting than suburban jurisdictions [as it became clear in Chapters 1 and 2]. It was important not only to identify the “story” that each theme tells, but also how it fits into the broader overall “story” I would be telling about the data, in relation to the research question or questions. After this interpretation of the data, I developed analytic claims, illustrated by the relevant extracts. I made sure to provide sufficient evidence of the themes within the data, i.e. enough data extracts, to demonstrate the prevalence of a theme; this was

necessary in order to substantiate the organisation and saturation of themes (Braun and Clarke, 2006; Ponterotto and Grieger, 2007). I also made sure that deviant cases were identified and explained.

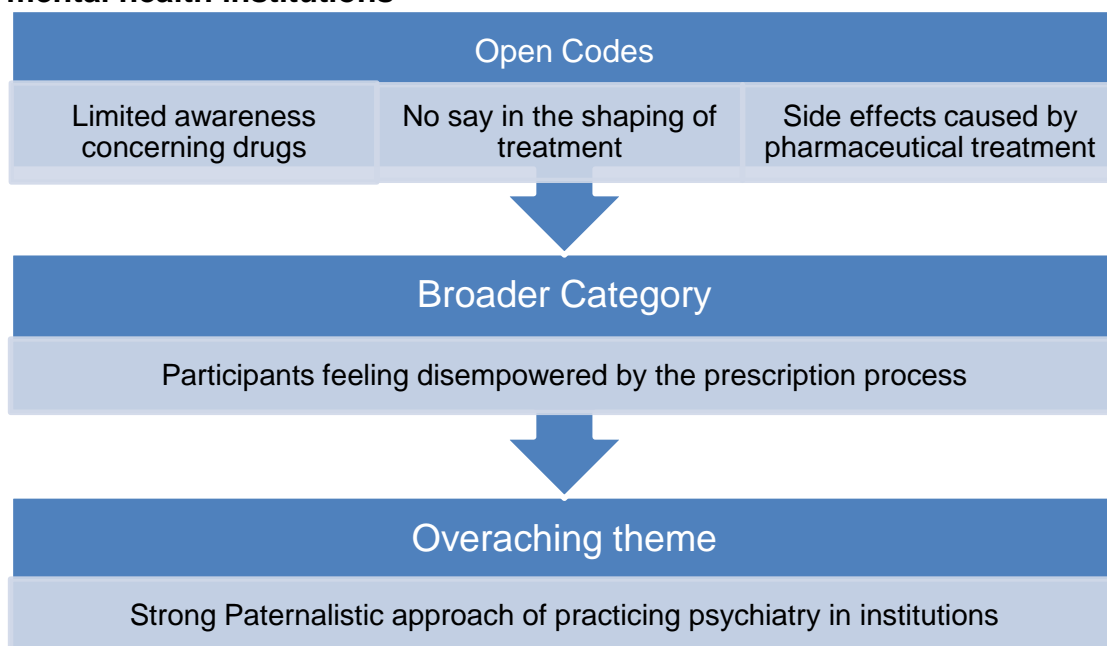
My goal was that the final report would provide a concise, coherent, logical, non-repetitive and interesting account of the story the data told. The aim was to provide “thick description” to the readers, meaning integration of descriptive and interpretive commentary when presenting findings (Ponterotto and Grieger, 2007). In order to do so, I made sure that my analytic narrative went beyond description, and made an argument in relation to my research questions.

In order to provide an “audit trail” for the validity of analysis, I have used examples illustrating the initial codes and the stages through which these were categorised and grouped within themes. Diagrams 1, 2 and 3 give examples of the direction of the analysis from open codes, to broader categories, to overarching themes:

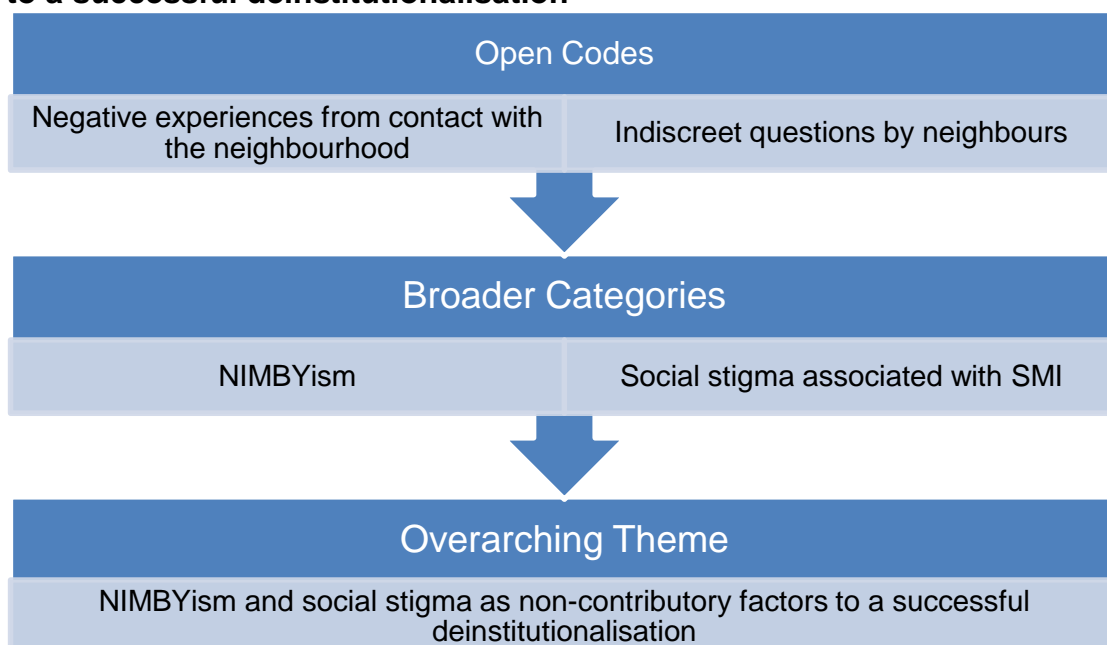
**Diagram 1: Mental health institutions providing temporary asylum**



**Diagram 2: Strong paternalistic approach of practicing psychiatry in mental health institutions**



**Diagram 3: NIMBYism and Social Stigma as non-contributory factors to a successful deinstitutionalisation**



#### **4.10. Ensuring rigour – Issues of reliability and validity**

In qualitative research, rigour refers to the resulting completeness of the data collection and analysis (Yardley, 2000). This depends firstly on the *adequacy of the sample*, not only in terms of size (Yeh and Inman, 2007), but also in terms of being able to supply all the necessary information that is required in order to receive a comprehensive analysis (Yardley, 2000). One way of ensuring credibility is data triangulation, meaning the use of multiple data sources in a research study, in order to produce a better understanding of the issues being explored (Cohen and Crabtree, 2008). As Yeh and Inman indicate, data triangulation helps a researcher to achieve multidimensionality to a data set (Yeh and Inman, 2007). In this research, I used three data sources, by interviewing residents and staff members of community care units, along with 2 mental health officers from the Greek Ministry of Health and Klimaka's legal advisor in order to gain a more complete picture of the issues being investigated. Another way of ensuring rigour, is to *record data objectively* (Seale and Silverman, 1997). In my research this was ensured by audiotaping all interviews, which greatly helped the process of transcription, and subsequently the analysis of the data (Seale and Silverman, 1997).

Once data has been collected in qualitative research, an issue of concern that arises is the issue of reliability. As it was mentioned earlier, qualitative research is stronger on long descriptive narratives than on statistical tables (Silverman, 2002). A problem then arises that concerns reliability: how such a researcher goes about categorising the activities or events described, and in general the data. This is known as the problem of reliability, and one way of dealing with it is through *inter-rater reliability*.

In qualitative research, a single researcher tends to carry out indexing the data and developing analytical categories. However, many qualitative researchers have given great emphasis to the fact that qualitative research analyses may carry greater weight when they are consistent between researchers (Pope et al., 2000). In many cases, it can

be useful to involve another researcher in the analytical process to code the data independently; this way, coding is examined in order to assess if the researcher has stayed close to the data (Pope et al, 2002; Yeh and Inman, 2007). Additionally, peer debriefing is useful because it also allows the researcher to discuss with a peer emerging themes and categories, and to try to reach consensus about the interpretation of the data (Pope et al, 2002). Although there has been an argument that a qualitative researcher has unique insights to the data which cannot be checked straight-forwardly by other researchers, still inter-rater agreement and reliability is one of the stronger ways in qualitative research to ensure reliability (Pope et al., 2000). As a result, if there is consistency among different qualitative researchers in their accounts of the same qualitative data, then this is a strong criterion to characterise qualitative research as reliable.

In this research, the issue of inter-rater reliability was addressed through peer review of the data and analysis. Once the data collection and analysis were completed, then Dr. Paterakis and Professor West reviewed the interviews, and arrived at certain key themes. Dr. Paterakis' and Professor West's key themes were compared with my main themes, and there was an agreement between the themes, with no differences, so that was indicative of consistency among us, in our account of the data. The only suggestion by Professor West was to further stress the element of segregation from the pressures of the outside world, [which derived through participants' accounts] as a novel dimension for the term "asylum". It appeared that most residents actually *enjoyed* and *liked* the relaxing everyday life in mental health institutions, with not so many stimuli, constituting a stress-free daily routine that did not put any pressure on to them. As a result, a novel dimension for the term "asylum" is that of segregation from the pressures of the outside world in a peaceful environment – not necessarily modern or new - which managed to offer the opportunity to the residents to follow their own schedule, without being pressured to participate in any activities they did not wish to. This element

of segregation was stressed at the end of Chapters 5 and 6, and was also stressed on the final Discussion of the thesis.

Another key criterion through which one can assess a research study is validity. As Silverman indicates: “The issue of validity is usually posed in terms of what constitutes a credible claim to truth” (Silverman, 2002, pg. 91). In qualitative methods, validation strategies used include the process of feeding the findings back to participants, in order to check if they agree with them, as being reasonable accounts of their experiences (Pope and Mays, 1995). This technique – often called “respondent validation” or “member checking” – provides participants an opportunity to make judgments on the resonance of findings with their own experience (Kuper et al, 2008b). Through respondent validation: “...the investigator’s account is compared with the accounts of those who have been investigated, in order to establish a level of correspondence between the two sets” (Pope and Mays, 2000, pg. 94, 95).

One should not neglect, though, the fact that there are certain limitations in this technique. The researcher’s account cannot be identical with the subject’s account, because they play two different roles in the study. Also, one should not forget that the researcher’s account is designed for a large audience, whereas the subject’s is not; as a result, one should think of respondent validation more as part of an error reduction process (Pope and Mays, 2000; Lincoln and Guba, 1985). Even so, respondent validation is one of the strongest ways to check the credibility of a qualitative research (Lincoln and Guba, 1985; Kuper et al, 2008, a, b).

In this research, respondent validation – i.e. returning themes from the data to the participants for verification – was one way of ensuring scientific validity. The participants were contacted a few months after the interview, and during a second meeting they were asked if they agreed with my key themes, derived from the data. This gave me the opportunity to: 1) enquire whether participants’ viewpoints had been faithfully interpreted; 2) determine whether there were gross errors of fact; 3) make

sure that data accurately represented the reality of the participants (Russel and Gregory, 2003; Yeh and Inman, 2007).

The themes returned to the participants were the preliminary themes that derived from the first level of coding, based on descriptive codes. The reason behind this is that I did not want to confuse participants with the final stage themes emerged from analytical coding, as this type evolved from a second level of coding that came after much reflection on descriptive codes and a return to the theoretical literature. Giving too much detail, particularly at a theoretical level could possibly confuse participants. As a result, a brief overview of the themes derived from descriptive coding was given to participants, and they all agreed with the themes provided to them. Based on the participants' response, I did not have to proceed with any amendments to the analysis.

A final way of ensuring validity in this study was through *clear exposition of methods of data collection and analysis*. Through an analytical exposition, the readers should be in position to judge whether the data adequately support the interpretation. As Pope and Mays (2000, pg. 95) indicate: "By the end of the study, it should be possible to provide a clear account of how early, simpler systems of classification evolved into clearly defined concepts and explanations of the data collected". In this study, I made sure that there were sufficient data included in the written account, in order to allow the reader to judge whether the interpretation is adequately supported by the data. I made sure that data analysis is *grounded in examples*, and this helped me to illustrate both the analytic procedures used and the understanding developed in the light of them (Elliott et al, 1999). Additionally, grounding in examples will help the readers decide if claims have been supported by sufficient evidence (Dixon-Woods et al, 2004). Finally, I made sure to indicate and analyse *negative – or deviant – cases*; this will help readers better understand the great complexity of the issues being examined in this study (Yeh and Inman, 2007).



#### **4.11. Quality assessment**

Qualitative researchers have established some general evaluative criteria in order to assess the quality of qualitative research. Cohen and Crabtree (2008) have identified published journal articles and books discussing criteria for rigorous qualitative research particularly in the field of health care, and they have concluded that there is general agreement on 7 criteria, important for the evaluation of qualitative research: 1) carrying out ethical research; 2) importance of the research; 3) clarity and coherence of the research report; 4) use of appropriate and rigorous methods; 5) importance of reflexivity or attending to research bias; 6) importance of establishing validity or credibility; and 7) importance of verification or reliability (Cohen and Crabtree, 2008, pg. 331). As it became clear in the previous sections, I have considered very carefully each and every one of these criteria, and I followed specific strategies in order to fulfill them. I believe that this study can make a very useful contribution and advance the current knowledge base on the issues of deinstitutionalisation, transition to community care, and reconstruction of the notion of “asylum” in community in the Greek context.

In conclusion, qualitative methods were chosen as the best approach for this research. The epistemological stance of my research was based on interpretivism. The sample was a full, purposive sample in that all participants had the experience of deinstitutionalisation and transition to community care, and consisted of all residents and staff members of the four CCUs for people with SMI that Klimaka operates in the greater Attica area. Information forms and consent forms were developed for participants ensuring confidentiality and anonymity, and ethical approval was granted by University of Greenwich. Semi-structured interviews were developed and used as the main data collection method. Thematic analysis was used for the analysis of the data. Reliability and validity were ensured through the use of data triangulation, peer review, respondent validation and clear exposition of methods and data collection and analysis.

## ANALYSIS

### Chapter 5: Circumstances that led to hospitalisation and daily life of residents while in mental health institutions

Chapter 5 explores the circumstances that led up to residents' hospitalisation along with the process of their involuntary commitment to mental health institutions. The Chapter also explores in retrospective the type of communication the residents had with their family while in mental health institution, financial issues, daily schedule and routine, along with friends and social networks they had while in hospital.

#### 5.1. Reasons that led up to residents' hospitalisation

Participants in this research study had all been hospitalised in mental health institutions with symptoms of SMI, before their being transferred to community care units. Their length of stay in mental health institutions varied, from a few months to one year for younger residents, up to five decades for older residents.

A very interesting finding of this study is that the residents often mentioned as the main reason behind their first hospitalisation a stressful event that led to the expression of SMI, and not SMI itself. This was probably happening either because the residents did not believe that they suffered from a SMI, or because they did not want to accept this fact at a conscious level. It is also possible that this might have helped them make sense of what happened to them, as it does seem logical that there usually are early warning signs in the life of an individual with SMI, before a severe first episode. Lastly, this could be portraying their experiences retrospectively in a positive light. Mr. Kerkyraios (42), a resident of the psycho-geriatric boarding house, gave a typical explanation:

**R:** We discuss with the psychologist that came from France. I explained to her the situation, that I got infected by a sexually

transmitted virus, by a microbe, and the infection was extremely serious, my whole body was infected, and I was in an emergency state, so I had to take too many drugs together, while I was in Kerkyra ... I don't know what kind of disease that was. I had been infected by multiple and difficult to diagnose diseases, but I don't know which one.

In one case, the stressful event which triggered the resident's first psychotic episode was the death of a close relative. Mrs. Kostaki (72), a resident of the psycho-geriatric boarding house, believed that this was the main reason behind her hospitalisation:

**R:** My mother died, and I got very upset, and they took me to Dafni [Mental Health Institution]. She was my weak spot. She was divorced from my father and I was very fond of her. I got admitted to Dafni because of my feeling upset after my mother's death.

For another resident of the psycho-geriatric boarding house, Mrs. Chatzichristou (84), the stressful event that triggered her first psychotic episode was an abortion that she had at a very young age, while she was 4 months pregnant. This was an extremely traumatic experience for her:

**R:** Thanasis the doctor put tincture at my genitals in order to burn my pussy, so that the baby would die.

After this traumatic experience, Mrs. Chatzichristou expressed schizophrenia for the first time, and she stayed at Dafni Mental Health Institution for more than 55 years. Even 60 years after her having the abortion, her mind kept returning to that painful event.

For another participant, Mr. Dimoulas (53), a resident of the boarding house "Afaia" in Athens, the main reason behind his first admittance to Dromokaition Mental Health Hospital was the depression he experienced after his divorce:

**R:** Listen: I was married, I got divorced, and that made me feel depressed, a little bit depressed. That's why I went to

Dromokaition, and I stayed there for a month and a half.

From all this it becomes clear that most residents did not recognise SMI as the main reason behind their first hospitalisation, but identified the environmental factor that psychologically triggered their first psychotic episode. This is an issue that emerged in my previous research as well (Lentis, 2008). This may be happening because most residents in this sample refuse to accept at a conscious level that they are suffering from SMI, because SMI is heavily associated with stigma, and stigma acts as a key barrier to successful treatment engagement, including seeking and sustaining participation in services (Ahmedani, 2011). In earlier times (from 1950s to late 1980s), it could also be that mental health services were ways of managing perceived “deviance”.

In some cases, a few participants mentioned as the main reason behind their first hospitalisation and later on for their transfer to CCU, a factor that had no association neither with SMI nor with a stressful event that could have triggered a first psychotic episode. Mrs. Kostaki (72) for example, a resident of the boarding house “Afaia” in Athens, mentioned that she got admitted to mental health hospital in order to quit smoking.

Similarly for Mrs. Maragaki (58), a resident of the boarding house “Afaia” in Athens, the main reason behind her first admittance to a mental health institution was just to have a regular check-up:

**R:** I stayed at Dromokaition Mental Health Hospital for 2 years, maybe even longer ... I didn't suffer from anything. I was not sick ... I got in there in order to have a blood test, a simple test. A check-up, something like that.

In this study, only 5 participants stated that they had to be admitted to a mental health hospital because of SMI. One resident of the psycho-geriatric boarding house stated that the reason behind his first hospitalisation was “alcoholic psychosis”, whereas another resident of the psycho-geriatric boarding house in his late 40s described that he got “sick psychologically” in his early 20s, after suffering a first serious episode of

multiple sclerosis in his teenage years. Another resident of the psycho-geriatric boarding house stated that he “got sick psychologically” after experiencing continuing stress at his work environment. So in these cases, residents could distinguish between the psychological trigger and SMI itself.

Only two residents out of the five fully explained their experiencing schizophrenia and the severity of their first psychotic episode which included serious delusions that even led to a suicide attempt. Mr. Poulakis (47), a resident of the hostel, described in a very analytical way the delirium of persecution that he experienced after a painful romantic breakdown from his girlfriend, understanding at the same time that the rejection he felt was only the trigger, not the cause of his SMI:

**R:** At the beginning I was living in a delirium ... I had a romantic breakdown, and I was thinking at the time that that girl would come back, that she owns ships and stuff like that, that she transferred me some of her ships, that I am a ship owner... I thought that I was a ship owner. At some point they gave me drugs after the delirium and I saw crystal clear that I went for the first time through a delirium, and I said: “How did this happen to me? It is not possible!” I couldn’t accept it. And I was suicidal ... the 1<sup>st</sup> time I got hospitalised for this at Galini, a private clinic. As soon as I gained full consciousness and I understood what had happened and that I experienced a delirium, it was then that I got hospitalised for the first time.

All participants in this study were unable to receive care in the community and were involuntarily committed to mental health institutions.

## **5.2. The involuntary and traumatic commitment of residents to mental health institutions**

All residents that participated in this study were involuntarily admitted to mental health institutions. What is striking is that most residents in this study did not mention at all their involuntary commitment to a mental health institution. Most probably, it was a terrifying experience for them, and they want to erase it from their memory. Only two participants

described the scene of their involuntary commitment and in both cases it was an extremely traumatic event. It should be mentioned that both of these residents are of older age and got admitted for the first time in psychiatric hospitals in the 1970s, before 1992, when the new Law was passed in order to secure patients' rights on involuntary hospitalisation. Mrs Iraklidou (70), a resident of the psycho-geriatric boarding house, got admitted for the first time in her twenties. She described a scene from Crete, the day of the involuntary commitment:

- R:** I was sitting in the vineyard. I had an orchard, which was full of watermelons. I was sitting there quietly, and I saw from far away Helen coming towards me. At that time the ship "PREVELI" came at the harbour and at the same time they were fixing my hair in a bun... And they took me by force, and I was sticking my nails so deeply to the bones, and I was screaming.
- I:** With the ship "PREVELI" you came from Crete to Athens, when they took you to Dafni?
- R:** Yes. That day they gave me something with cinnamon, I guess it was watermelon. Watermelon with cinnamon.

In the case of another participant, Mrs Ioannou, now resident of the boarding house "Afaia", her refusal for her commitment was expressed through an aggressive behaviour, including slapping the doctor:

- R:** Police officers cuffed me. They took me with a jeep. I was seeing mountains outside the window, I was seeing everything, and I said to myself: "Oh! What is going to happen to me now? Are these terrorists? Are these terrorists kidnapping me?" I was seeing them there, and I shouted: "Bastards". They were not talking at all; they were just looking at me. When we arrived at the hospital, the doctor came towards us, and he said: "What have you done here?" As soon as he said that, he took the handcuffs off my hands and I gave him **one** slap, where did I find all this strength?...I slapped him. I made his head spin and he saw stars because of my slap.

Only one resident, Mr Kerkyraios, described his involuntary commitment happening in a rather calm way, without giving details. It should be mentioned at this point that this resident got hospitalised for the first time after 1992, so his case represents a post-1992 example. Mr

Kerkyraios (42), a resident of the psycho-geriatric boarding house described:

**R:** Some men came to my house, some men with regular clothes, they were not policemen, I don't know who they were, anyway, and they told me to follow them to the police station.

From there, Mr Kerkyraios was led to the mental health institution, where they took his blood, they ran all necessary tests, and consequently they gave him a pharmaceutical treatment with which he felt that he "...got over the danger". At this point it should be clarified that in the Greek context when policemen commit a psychiatric patient involuntarily, they never wear their uniform, so that they can approach the patient and come to close proximity, without him/her recognising them as police officers. It is also common practice to cuff patients in order to take them to the police station ([mentalhealthlawblogspot.gr](http://mentalhealthlawblogspot.gr), 18/05/2011). Although Mr Kerkyraios' account appears milder than the description of the two older female residents, still the post 1992 experience is not indicative of serious changes in the field of involuntary commitment or of complying with the Law: Although a psychiatric patient has to be committed by qualified and experienced psychiatric nursing staff (Law 1992), still because of lack of staff, it is common practice for police to proceed with such interventions ([mentalhealthlawblogspot.gr](http://mentalhealthlawblogspot.gr), 18/05/2011). However, police interventions should only occur under extreme cases.

In sum, most residents did not mention at all the procedure of their involuntary commitment. For older residents who were committed in previous decades this is not surprising because involuntary commitment was a rather violent act; that is the main reason why the Law of 1992 was passed, in order to secure patients' rights on involuntary hospitalisation, determining in an explicit way the way this involuntary hospitalisation should be implemented so as to ensure the necessary respect for human decency (Law 1992, Article 47).

The law explicitly lays down that a patient must be examined by two psychiatrists and in the event of disagreement between the diagnoses,

then there should be a third examination. If involuntary hospitalisation is judged as necessary according to the diagnosis, this should be carried by qualified psychiatric staff (Law 1992, Article 47). In practice, however, it has been found that serious violations have been occurred for the last 23 years. According to the Hellenic Psychiatric Association (EPSE), while police interventions should only occur under extreme cases, in reality these interventions have become common practice, with serious side-effects for patients (mentalhealthlawblogspot.gr, 18/05/2011). It appears from the accounts of the few participants who discussed the matter, that within the Greek context some fundamental changes concerning the issue of involuntary hospitalisation, still need to take place.

In conclusion, participants in this study were all involuntarily committed to psychiatric institutions. For the older residents this led to long-term hospitalisation, which in certain cases lasted for up to five decades; for the younger ones this involved hospitalisation which lasted from a few months to a year. The parameters of their lives in mental health institutions are discussed in the following sections of this chapter.

### **5.3. The varied degrees of communication residents had with their family**

For those residents who participated in this research the kind of communication they maintained with their families during their hospitalisation in the psychiatric clinic varies. On one hand there were residents who kept close communication with their families, while on the other hand there were those whose family bonds were completely severed.

This closeness of contact is usually translated into the frequency of the visits, except for some cases where due to geographical distances relatives' access to mental health institutions was not easy. Therefore, there are varied resident categories.



For a small group of five residents, their contact with their family was quite frequent, usually with their parents and their siblings. Mr. Louloudis (39), a resident of the boarding house “Afaia” stated:

**R:** My parents would come every day and visit me in the military hospital [he was serving his mandatory military service of two years at the time]. My mother would come to Dromokaition Institution - meanwhile my father had died. I also have a younger brother, who I had a regular contact with during that time.

In such cases, for as long as the parents lived, the visitations would be frequent, and this is something that I encountered in my previous research as well (Lentis, 2008). In the course of events and after the death of the parents, the siblings could not maintain the same frequency of visits due to their own increased family and professional obligations. Thus, after the death of their parents, visits to the psychiatric clinic became less frequent. A typical example is Mr. Papadopoulos (49), a resident of the psycho-geriatric boarding house:

**R:** While I was in Aiginition Hospital both my father and mother lived and they used to take me home. Now they are dead. They died when I went to Dafni and from then on, I only had my brother. He is married, and ....

There were only two instances where residents from this group had contact not with the parents but with the spouse. Mrs. Bebekou (36), a resident of the hostel, while she was in the mental health institution maintained contact with her husband and her parents-in-law, but not with her parents on grounds of age and geographical distance that made their visitations impossible.

A similar experience is that of Mrs. Karamouza (52), a resident of the boarding house “Afaia”, who kept a very close contact with her husband, during her one-month stay in Dromokaition Institution. Actually, her husband got a job in a pizza restaurant close to Dromokaition Institution so as to see her daily:

**R:** My husband would come and see me. He would bring coffee, cheese pie...he would come and see me every day at Dromokaition.

Thus for this group of residents, their family was close to them with frequent and regular visits, at first, especially from their parents. Over time, however, and after the death of the parents the contact with the rest of the relatives - usually the siblings - became less frequent in the psychiatric clinic.

According to Mrs. Koubaraki, a psychologist in Dromokaition, this gradual distancing of family is due to the negative impact that the institution has on both a patient's psychology and his/her family. Many relatives perhaps feel that through this gradual detachment and distancing their relative could adjust better to the daily routine of the asylum, immersing him/herself into a daily program that would help him/her even at a therapeutic level. Mrs. Koubaraki described:

**R:** When people find themselves in the asylum and start spending time in it, their relationship with their family is gradually fading away. The reason of why that is happening is that the patients [the general population of hospital patients] themselves are absorbed by the daily routine of the asylum and they start to distance themselves or they feel abandoned from their family. This happens from both sides: the family is gradually disconnecting itself from the patient: they feel that the problem will be solved in this way, and therefore this arrangement makes it easier for everybody.

For most of the residents who took part in this research, visits from the relatives were not that frequent. This can be explained by the fact that in many cases, either the family environment was problematic and could not accept the problem or there were no relatives at all.

In two cases, the residents appeared to be very angry about the involuntary commitment that had happened to them, feeling deep inside them that their relatives were responsible for not being able to help them and prevent their commitment. Mrs. Chrysalis (67), a resident of the

psycho-geriatric boarding house, was taken to the hospital under a prosecutor's order after she had been evicted by her landlord and found herself in the streets. She lost all contact with her two brothers, who live in Canada, because she felt they were responsible for her commitment up to a certain extent, since they did not help her financially during that difficult period of her life. Mrs. Chrysalis stated:

**R:** At that time – before my hospitalisation – I desperately needed money in order to keep my house. My brothers however did not help me... After a while – when I got admitted to the institution - I stopped keeping contact with them.

Mrs. Aggelopoulou (30), a resident in the boarding house, took a long time before she got over the shock that her own relatives locked her in the psychiatric hospital:

**R:** Not right away, but gradually I started calling them, and I was the one who called them, not they. I would call them, not they.

In many cases however, the kind of disconnection was such that although there were attempts by the residents' side to connect again with their family when they were on a leave from the hospital, they were unsuccessful. This was due to the fact that the family had established a new pattern that excluded the resident. Thus, any attempt that was made for the resident to return home, even for a few days, would set off a storm of controversy, thus resurfacing all those memories from the difficult cohabitation between the residents and the relatives under the same roof. Mrs. Dimitraki, a nurse at the hostel with an extensive work experience in public psychiatric hospitals the same period that some of the residents were in the institutions, talked about the leave some of the residents took from the psychiatric hospital:

**R:** They felt abandoned, deserted and they would say to us that they didn't want to return to the family. Others wanted to go to their family but when a first step was initiated with the family

so as to get them back, they would stay for a couple of days, got into fights and returned to us. Although patients [residents of this sample] requested to go out on leave, the family could not support them most of the times. We should not forget that relatives too had problems so the family needed a lot of support as well. The family itself was in need of a supportive scheme.

The above evidence shows that there were families caring for residents, which needed additional support and aid from the State. As this type of help was not available in previous decades (Kollias et al., 2002) some family members experienced a lack of assistance and support and as a result, they may have felt unable to cope, resulting in great difficulty in any attempt for communication with their ill relative. This eventually led to some residents being disconnected from the family environment.

Older residents who were hospitalised for 3 or even 4 decades in the psychiatric hospital, over those decades between their initial commitment and their deinstitutionalisation, had often cut themselves off their family so much that there were cases where some family members had died or new members had been added in the family and they were unaware of this. Mrs. Boukala, a nurse in the hostel, with lengthy experience in working in mental health institutions, reported:

**R:** There were also those people who had lost complete contact with their relatives... They had children, grandchildren who did not know, dead siblings who they were not aware of. An absolute disconnection from the family.

In conclusion, therefore, some residents in the sample appear to have had good relationships with their family while in the psychiatric hospital, especially with their parents. After the parents' death, the visitations from their siblings became less frequent due to increasing family and professional obligations. Many residents in the sample however, rarely contacted their family if at all while they were hospitalised in the psychiatric hospital. As it will become evident in the following

chapters, this is a parameter of their life that in some cases considerably changed in the community care units.

#### **5.4. Financial issues while in mental health institutions: Sources of income**

In Greece, most people are covered in terms of health insurance and consequently receive pensions from two institutes. The Social Insurance Institute-General Employees' Insurance Fund, known as IKA-ETAM is the largest employees' social security organisation, which covers most of population: It insures workers in the public and private sector who are employed under a private-law contract (ec.europa.eu, 2012). Farmers and other agricultural workers on the other hand, are covered by the Agricultural Insurance Organisation, OGA. All institutes give pensions at the age of 65, but for serious health issues like SMI, pensions can be issued at a much younger age, even for the children of parents who are covered by these institutes (ec.europa.eu, 2012).

In this research, while the residents were in mental health institutions, several of them had already received a kind of pension upon their hospitalisation either because some residents had worked for some time before their hospitalisation, or because they had managed to receive a pension before this. Mr. Voskopoulos (71), a resident of the psychogeriatric boarding house for example, had already received a pension before his commitment to the psychiatric hospital, since he had worked as a science teacher. The pension received was usually quite high according to the Greek standards and it usually covered all the expenses of the resident in the psychiatric hospital.

Another participant, Mrs. Maragaki (58), a resident of the boarding house "Afaia" had been receiving a pension long before she was committed to the psychiatric hospital and with this she could cover her personal expenses within the psychiatric hospital. She stated:

**R:** I had, I had [money, while in hospital]... from my IKA pension... With that money I would treat my female and male

friends. I would buy them - it depends - either a cheese pie or a coffee and we would chat. My lady friends would treat me too, of course.

Unfortunately, however, in the majority of cases, the residents had neither a pension nor any kind of benefit when they were committed to the psychiatric hospital. The positive thing however - as far as their finances are concerned - was that when they were committed to the psychiatric hospital, social services were mobilised so that a pension was granted. As Mrs Amygdalou, psychologist in Klimaka, pointed out, this is an exceptionally time-consuming and complex procedure in Greece, since for someone to be granted a pension from the Social Welfare he/she is caught up in a maze of bureaucratic procedures.

For the majority of the residents who were admitted to the psychiatric hospital, while the procedure for the issue of a pension or a welfare benefit had already been initiated, a long time passed before they could receive the money or in most cases they would receive it long after they had been transferred to community care units. Therefore, during their hospitalisation in the psychiatric hospital, what would usually happen was that their expenses would be covered by the family. In many cases, this money would be enough to cover the residents' needs inside the psychiatric hospital. Mr. Kerkyraios (42), a resident of the psycho-geriatric boarding house, pointed out:

**R:** My sister would help me, she would come regularly and would help me, and we would go out [in Corfu] and would go to the square, to town for a coffee. She would bring me cigarettes and money and this money was enough.

Another participant, Mr. Poulakis (47), a hostel resident, worked before his hospitalisation as an EKAB ambulance driver. During his last hospitalisation and while waiting for his pension to be issued, he would depend on the money his siblings would bring to him in the psychiatric hospital, which was enough for him to buy coffee and cigarettes.

Finally, in the case of two female residents, their relatives did not bring them money, but instead they bought them the personal items they needed and would bring them to the hospital.

Within the sample of residents that took part in this research there were several residents who felt that the money brought by their parents (or their pension) in the hospital was inadequate. This could be attributed to 3 reasons: a) the dire financial situation that the family of the resident might have been in, b) the lack of management skills of the resident and c) thefts that have been reported to have taken place within the psychiatric hospital. The first reason - the family's financial weakness that is - is clear. Most of the times, these people were financially exhausted from the multiple hospitalisations of their relative, which in many cases took place in private clinics, so they would then turn to public psychiatric hospitals (Lentis, 2008). Within this severe economic crisis that the country has been facing, along with the high unemployment rates, it becomes quite clear that these cases with families facing dire economic difficulties will increase further, and that in return will affect the amount of money given to a relative in a mental health institution for his/her personal expenses. An example of this is that of Mr. Louloudis (39), a resident of the boarding house "Afaia":

**R:** ...the first time when my mother took me to the psychiatric hospital, she had no money to give me, she would bring me little things, painting items, brushes and stuff like that [because he likes painting] but we didn't have a lot of money at that time...I would like to have some money, to buy some things but my mother would come and help me. She would bring what I wanted. She could give me 10 cents to buy a coffee from the canteen over there.

The second reason was the residents' difficulty in efficiently managing their money. A typical example of this is that of Mr. Kalos (54), a resident who would avoid having a coffee with his friends at the psychiatric hospital because he felt obliged to treat all the clinic patients: "How can you treat them all? We were 300 people in the clinic". So, while the money

was enough for his personal expenses, he, however, felt it was not enough to treat all these people, as he could not draw boundaries between friends and other patients. This weakness in management skills along with a lack of full understanding of the value of money appears to be connected with SMI. Dr. Kastrinakis, head of Klimaka, offered his viewpoint on the issue, which derives from his clinical experience at the psychiatric hospitals:

**R:** Even if they brought a patient 100 euros or 100 drachmas, this made no difference to the patient. Either he would just buy cigarettes or he would treat everybody that same day and he would run out of money. What would have been helpful was the presence of a social worker or an occupational therapist, who would teach patients about the value of money and help them acquire money management skills. But because there was no one to help patients with this matter, you would see a person one day to buy 4 packs of cigarettes and then the next day that same person would ask for a cigarette etc. Therefore money played absolutely no role and nobody would save any.

From Dr Kastrinakis' comments, it becomes clear that there is a great need to teach patients the value of money and techniques for managing their monthly income while in mental health institutions, because this is one of the key domains of community functioning (Wallace et al, 1992). In my previous study (Lentis, 2008), it was clear that the hospital provided several educational social skills programmes, where one of the topics being covered was management of money. In those programmes, social workers taught patients the value of various items from the supermarket in euros, compared to their monthly income, in order to enable them to understand how much they could spend every month and on which items. Because of the extremely difficult financial situation currently in Greece though, resulting in serious cuts in mental health funding, these programmes cannot be intensified or even realised in some cases in mental health hospitals nowadays.

A third reason for some of the residents to barely make ends meet with the income they had per month is due to their money being very



possibly stolen by other patients. This is an issue that has emerged in my previous study as well: some patients had complained that their money, which they frequently kept in a drawer in their room, was being stolen very possibly by other inmates, usually during night time, when patients were heavily asleep from the drugs they were receiving (Lentis, 2008). Surely, concentrating patients with little money in one institution exacerbates the issue too. This issue though made patients feel very insecure, and certainly did not contribute to their feeling “safe and protected” in the mental health institution, - on the contrary they felt threatened and helpless, powerless to react (Lentis, 2008). As Mrs. Vlichá - general duty staff member of the psychiatric boarding house – mentioned [from her experience in working in public mental health institutions the same period that some of the residents were in the institutions], this forced a lot of patients in mental health institutions to spend all their money within the same day they received it, in order to avoid theft from the other patients:

**R:** ...either they would lose it [the money], or they would spend all their money the same day to avoid being stolen from them by other patients ...

Another source of income for a few residents, besides their pension/benefit and the money brought to them by their relatives was a small fee they would get while in the psychiatric clinic from their engagement in occupational therapy programmes. In a case of a female resident this had helped her family, since she felt that the money she received from this programme was more than enough. Mrs. Aggelopoulou (30), a resident in the hostel, said about it:

**R:** [While I was in the psychiatric hospital] my family would bring me money but when I started the occupational therapy programme, the person in charge would give me an allowance. With this money, I would go with Mrs. Stefanou (a member of the hospital's staff) I would go to the open market. I would buy clothes and slippers. I would go there every Monday.... of course it was enough [the money], it was more than enough.

The problem is that now with Greece suffering from the economic crisis the Ministry of Health has introduced a ban on money allocated to occupational therapy programmes for the hospital. As Dr. Starlis, head psychiatrist of the rehabilitation hostel which operates within Dromokaition, reports, patients who were in Dromokaition and took part in those occupational therapy programmes would be paid 130 euros per month while outpatients who took part in those programmes would get paid 170 euros per month. The Ministry of Health, however, banned this money allocation arguing that in many cases patients' relatives would profit from this money:

**R:** Money allocation was banned [money for the occupational therapy programmes.] And this is an argument expressed from the Secretary of the Ministry of Health, who claims that: "Instead of relatives profiting the money, we should keep it". No. We, the services, must find ways so as the *patients* take the money and neither the relatives, nor the Ministry.

The consequences of the cuts are threefold: First, it disconnects the occupational therapy programme from the payment, thus removing a strong motivation from patients who would like to be involved but lack the motivation to do it without a payment. This in turn deprives them of both the therapeutic value of the occupational therapy programme and the perspective of being involved in a craft that might prove useful once they are deinstitutionalised and be transferred to community care units. It also deprives patients of the reward effect of the payment which could serve as a positive feedback in order to continue participating in occupational therapy.

Some participants in this study had no income at all – no pension or benefit, no money from their family and no payment from their participation in occupational therapy programmes. A solution found by one such resident was to do little favours and run small errands for other clinic patients and they in turn would give her a small amount of pocket money. Mrs. Chrysalis (67), a resident of the psycho-geriatric boarding house referred to this:

**R:** I would go and buy things for them: I would get them coffee, I would get them cigarettes and they would give me an allowance so I would get my stuff too.

These small types of favour in exchange for a fee fall within the framework of secondary adjustments which Goffman in 1961 describes for patients in mental health institutions. Goffman observed that in mental health institutions patients learned certain behaviours and performed certain duties for other inmates that helped them cope and live better in the inhumane environment of the hospital (Goffman, 1961). However, what Goffman described 50 years ago, was still alive in the Greek context a few years ago, during some of the residents' last hospitalisation period. As Mrs. Koubaraki, psychologist of Dromokaition commented, this phenomenon still exists in mental health institutions:

**R:** ...you might find people here who can do these kind of chores for others within this framework of black market that exists in the mental health institution... and these usually are part of some sort of exchange for some small privileges, the asylum privileges so to speak.

In sum, for the residents in this research, financial issues while in mental health institutions were covered by various sources, but in some cases only up to a certain degree, that is why for some of them it was difficult to make ends meet.

### **5.5. Daily schedule-routine of residents while in mental health institutions**

This section explores the daily schedule of the residents while in institutions. In particular, it explores issues of personal care and hygiene, daily activities, routine and occupational therapy while in mental health institutions.

### **5.5.1. Personal care and hygiene of residents while in institutions**

This research focuses on residents' experiences. In this section I decided to present the staff's views along with the residents' on the issue of hygiene, as participants did not mention much on the matter, and even if they did, they did not mention it always in a very negative way. The only reason I decided this, was because I wanted to stress the difference between the lived experience of the residents and the perception of staff members.

One problem that the residents in this study faced when they were in mental health institutions was that of personal care and hygiene. Showering for instance took place only once or twice a week. Mr. Stonakis (30), a resident of the boarding house Afaia, mentioned that: "we used to shower every 7 days, every Tuesday [while in mental health institution]". Another participant, Mr. Leonidopoulos (64), a resident of the psycho-geriatric boarding house, mentioned that he had to wash his clothes by himself because there was no laundry machine in the mental health institution.

From my observations during my visits in public mental health institutions, I have seen that showering of patients takes place only once a week, usually with cold water, and usually with the aid of one nurse. What is striking though in this research and in my previous research as well (Lentis, 2008), is that the residents themselves did not mention this situation in a negative way: when they talked in retrospect about the time they had spent in hospital, this issue of personal hygiene did not appear to bother them.

Apart from the issue of personal hygiene, there were other serious problems concerning the general cleanliness and hygiene in the old and deteriorating buildings of public mental health institutions. These problems were mainly because of the skeleton staff working in these institutions, along with the unacceptable hygienic conditions that used to exist in the wards. The old toilets for example were just holes in the floor, and in many

cases patients could not understand that they had to defecate in there. As a result, there used to be faeces all over the place. Mrs. Vlichá, a general duties staff member of the psycho-geriatric boarding house, having worked for many years in the two public mental health institutions in Athens – Dafni and Dromokaition – mentioned on the matter:

**R:** The cleaning ladies used to get in the wards, with huge water hoses, and cleaned all the faeces, because patients used to defecate inside the wards. Each ward had toilets, but the toilets were of the old type, just holes in the floor, and patients couldn't understand that they had to defecate there. Most patients were naked, because they used to take off and rip their clothes ...

The appalling sanitary conditions were inevitably creating major sources of contamination and infection, attracting usually hordes of lice. Even nowadays – and I have seen this with my very own eyes during the course of my previous research – some patients in institutions have so many lice on their heads, that you can actually see them moving on their scalp while talking to them. Ten to fifteen years ago however, the situation was even worse, because the lice were so many, that in many cases they used to spread across the wards. Mrs. Vlichá stated on the matter:

**R:** I remember this: I was in one of the old buildings in Dafni, and there were so many lice on the wall that the wall had turned black, and I said: “What is this?” but something was moving, and it was the lice. And I remember saying to myself: “What am I doing in here?” That is why staff members were not coming very close, they used to ask patients to come out in the hall; they had a great difficulty entering the ward.

What is striking again however is that none of the residents mentioned anything about these issues. This research focuses on residents' experiences and aims to give voice to participants. In this section however I decided to include the very different perceptions that staff members had from their previous working experience in mental health hospitals for the following reason: the striking difference in perception proves that the notion of Thirdspace – the lived experience of

residents – can be very different from the perception of either visitors or staff members. It appears that the physical fabric of the institution – the Firstspace – is of far less importance for residents than the notion of Thirdspace, meaning their own lived experience.

Going back to the years that residents spent in institutions, staff members reported few more serious problems. Because of the fact that most residents were hospitalised in wards which did not have enough closets for all patients, this practically meant that they did not have a secure place to keep their clothes and their personal belongings. This led them to take extreme measures in order to deal with the situation. Mrs. Vlichá, staff member of the psychogeriatric unit, from her experience in working in public mental health institutions the same period that some of the residents were in the institutions, explained:

**R:** Each patient was watching his/her personal belongings as this was his/her entire fortune, because in the mental health institution there were many thefts [one patient was stealing the other patient's items]. In order to avoid this, patients used to wear *all* their clothes all together at the same time, so that no one would be able to steal them or they used to put all their clothes in a plastic bag, and then tie the bag on their bed, in order to not lose their personal belongings, their things.

As it becomes clear from this analysis, Greek mental health services have a long road to go in order to reach the point of offering decent living conditions to patients that get hospitalised in public mental health institutions. However, what is important to mention is that the residents themselves rarely mentioned any of these issues in a negative way. This tends to suggest that the notion of “asylum” as a place offering safety and security entails some characteristics which are novel and unexpected, and become clearer in the following sections.

### **5.5.2. Daily activities, routine and occupational therapy**

In the present study two groups of residents were identified with regards to daily activities in mental health institutions: 1) residents who mainly enjoyed the leisure activities and social character of the hospital and 2) residents that participated in the occupational therapy programmes of mental health institutions.

#### **a) Residents who enjoyed the leisure activities and social character of the hospital**

The first group of residents described a rather monotonous repetitious everyday schedule in mental health hospital. Mrs. Marouli (62), for example, who used to be a hostel resident, living independently at the time of the interview, really enjoyed her daily walk every morning and afternoon in the hospital's gardens, along with a friend whom she had met in the hospital. This going out was something she would not miss for any reason:

**R:** We used to take a regular breakfast and then we used to go out for a walk, and after that we used to take our pills. At noon, we used to have lunch at their dining hall ... In the afternoon we used to go for a walk again, *every day*, and we returned around 9.30 – 1.00 at night. They used to give us our pills, and then we went to bed.

**I:** Did you participate in any occupation therapy programmes while you were in Dromokaition?

**R:** No, no.

What these residents seemed to enjoy the most was the social character of the hospital. These findings support those obtained from previous research (Kinard, 1981; Lentis, 2008), that is, that social and leisure activities in the hospital are highly important to patients. Most of all, it was the daily activity of going to the hospital's coffee shop, that these residents did not want to miss, not even for a single day. Mrs. Vlicha, general duties staff of the psycho-geriatric boarding house stated on the

matter [from her experience in working in public mental health institutions the same period that some of the residents were in the institutions]:

**R:** They [patients in institutions, among which were some of the residents] used to go out, to the hospital's coffee shop. As they were, even though some of them looked like a mess ... whether they were properly dressed or not, they would go. I remember going to work, and I used to see them running down the hill, in order to go to the coffee shop and drink their coffee, even if they looked like a mess, even if their appearance was awful – some of them were even barefooted. However, to them it was very important and they really enjoyed going to the coffee shop for a cup of coffee.

From staff members' and the residents' descriptions it seems that residents were used to the specific environment that mental health institutions offer: Despite the fact that most hospitals' buildings are rather old, they are built in very large green areas with a number of places within the hospitals' grounds that a patient can visit. Both Dafni and Dromokaition [the two public mental health institutions in Athens] offer outdoor spaces and areas to walk in quiet, green environments, and these may act in many cases as therapeutic landscapes (Gesler, 1996). As a result, a novel dimension for the term "asylum" is that of segregation from the pressures of the outside world in a peaceful environment, which managed to offer the opportunity to the residents to follow their own schedule, without being bothered or pressured to work or to participate in any activities they did not wish to.

For all residents, both the ones that could take long walks in the hospital's outdoor spaces, but even more for those who were not allowed to go outside – not even to their ward courtyard – an integral part of their everyday life was watching TV. For Mrs. Ioannou (62), a resident of the boarding house "Afaia", who was not allowed to go out not even to the hospital's courtyard because of her repeated attempts to escape, watching TV was a major part of her everyday life, and practically the only way she



had to keep in contact with the outside world: “I did not do anything else all day long, I was just watching TV”.

For many residents the activity of watching TV was associated with the social character of mental health institutions. In Greek mental health institutions there are no TVs available in patients’ rooms. As a result, there is only one TV set available in the main lounge of each ward. This means that watching TV gave residents [while in hospital] a good reason to socialise with each other: TV usually had several music and dancing programmes. According to Mrs. Vlichá, staff member of the psycho-geriatric unit [from her experience in working in public mental health institutions the same period that some of the residents were in the institutions], residents took advantage of that and *created* an opportunity to have fun.

An important finding from this group is that none of these residents visited the Occupational Therapy Department, and they had no desire to participate in any such activity. Some mentioned that there were no such programmes available – something that is possible for the residents who got hospitalised in previous decades, before the 90s – while others mentioned that they were aware about the Occupational Therapy Programme that the hospital was offering, but they simply were not interested in participating. Mr. Dimoulas (53), a resident of the boarding house “Afaia”, stated:

**R:** There were occupational therapy programmes available [in the mental health institution], but I was not interested in them, nothing really moved me, that’s why.

What is very interesting in this group however, is that most of them did not mention the hospital’s everyday life schedule in a negative way, but rather as a daily routine to which they had become accustomed. Though studies on life in mental health institution often describe psychiatric hospitalisation as a negative, demoralising and in some cases dehumanising experience (Goffman, 1961; Rosenhan, 1973), as the residents from this group have demonstrated, there are also some positive

aspects of life in the hospital. A very interesting point is that most residents in this group actually *enjoyed* and *liked* this relaxing everyday life, with not so many stimuli, constituting a stress-free daily routine that did not put any pressure on to them. Mrs. Bebekou (36), a resident of the hostel, mentioned that her daily schedule while in the institution was: "...relaxing, more relaxing".

Mrs. Bebekou's comment shows that during their hospitalisation, these residents got used to a particular way of life and a daily routine that was relaxing and offered them a sense of stability. For some residents, this stress-free daily routine, this life style may very well meet their needs. For these individuals the hospital may provide a place where they find reasonable comfort and an undemanding life with dignity (Lamb and Peele, 1984; Lentis, 2008). As a result, the mental health institution offers a "temporary asylum" from life's pressuring circumstances (Lentis, 2008). Mr. Lyritzis, psychologist of the psychogeriatric boarding house, who regularly visits mental health institutions in order to evaluate and prepare patients prior to their transfer to CCUs, explained:

**R:** Look, this could possibly appeal to a patient, who because of his/her symptoms, and mainly because of serious depressive feelings, he may be withdrawn and feel within such an everyday life and daily schedule a certain security, calmness, and that he/she is not pressured by many different stimuli, and that he/she is not asked to do something which he/she does not want to do.

Although this stress-free daily routine appealed to residents, for some individuals, long-term living in an institution under such circumstances may act as an impediment to any possible improvement: According to Dr. Starlis, psychiatrist at Dromokaition Mental Health Institution, long exposure to such an environment "...creates a serious disturbance in space – where there is no sense of privacy, and in time – where in most cases is empty, and in relationships". Disturbance at all these three levels for a long time "...can seriously aggregate the disease course, and create even more serious problems to patients". According to Dr. Starlis – just as

Goffman noted in 1961 – “...mental health institutions are themselves pathogenic” (Goffman, 1961). This again shows that the perception of the residents about the daily routine in hospital is very different than what staff members believe. Residents in this group while in the institution felt rather calm and experienced a stress-free daily routine, which appealed to them, since it did not pressure them.

In conclusion, for a group of residents in this research study, the mental health institution offered a stress-free daily routine, and while they were there they did not participate in any organised activities. That daily routine with not so many stimuli, possibly offered them a temporary asylum from the pressures of the outside world, but in the long run it is an element that can further promote institutionalisation and create difficulties to their later transfer to community care units. Residents in this group were disconnected from ordinary day-to-day life, with very little stimulation. Hence, they were probably likely to report their few activities, like TV and walking, positively.

#### **b) Residents that participated in the occupational therapy programmes of mental health institutions**

A second group of residents in this study also mentioned having a daily schedule in the hospital that enabled them to go for walks in the hospital grounds, watch TV and go for a coffee, while at the same time they participated in the occupational therapy programmes that mental health institutions offered. Mrs. Chrysalis (67), a resident of the psychogeriatric boarding house, for example, mentioned that she participated in the painting workshop, after the hospital’s staff members motivated her to do so:

**R:** I participated in the painting workshop. But to tell you the truth, I don’t know how to paint. I told them: “I don’t know how to paint”. And they said to me: “Do whatever you can”.

Another participant, Mr. Papadopoulos (49), a resident of the psychogeriatric boarding house, participated in the construction, painting

and carpentry workshop, and his participating there was also associated with his sharing a cup of coffee with the occupational therapist. However, only the one mental health institution out of the three where he had been hospitalised, offered such programmes.

For one resident in this group, his participating in the painting workshop was very important for him, because it enabled him to keep practicing painting – being a cartoonist himself prior to his hospitalisation. Mr. Louloudis (39), a resident of the boarding house “Afaia”, stated:

**R:** I used to go to the occupational therapy department every day, around 10.00 o'clock in the morning. I participated in the painting workshop ... I liked that very much... My job used to be cartoonist, sketcher. Not painter, sketcher, in magazines, newspapers, in TV ... I have worked in known magazines... I have also done some video clips for TV cartoons.

Although Mr. Louloudis was not receiving any payment at all during the period he participated in the hospital's occupational therapy programme, still he was very happy at that time to participate in the painting workshop, since it was a really fulfilling activity for him:

**R:** ... it was something that pleased me very much: I did not feel so anxious and nervous, because I had something to relieve my energy, and I stopped thinking negatively, I stopped having all these melancholic thoughts. It was very helpful... it greatly helped me psychologically, it helped my very much psychologically, because it was something really nice. It is the same thing now: I always like to draw, sketch and paint, so I don't have in my mind negative thoughts.

Clearly, for Mr. Louloudis, participating in the occupational therapy programme gave him a sense of purpose. Purposeful participation in activity has been known to have a health-promoting value. As Blair and Hume (2000, pg.19) indicate, "through 'doing', people are confronted with the evidence of their ability to function completely and take control of their lives as far as they are able".

However, it is interesting to note that most residents in this group, although they liked being engaged in the activities offered at the

occupational therapy centre, wanted to do this from time to time, without undertaking commitments on a daily basis or the obligations of a more stable form of work. Even two female residents who were getting paid for their participating in the occupational therapy programmes did not wish to commit themselves and feel obliged to participate on a regular basis. This way, they enjoyed a more informal type of activity, which did not create any feelings of oppression to them. Mrs. Maragaki (58), a resident of the boarding house “Afaia”, stated:

**R:** I participated in the occupational therapy programme, in the embroidery workshop...not every day. I worked for a while and made some money... Well the money was not stable, because the one day I would be absent, so another patient would have to replace me, and this way the money was getting reduced, it was getting less and less.

These comments show though a very important element: that patients [in mental health institutions] sometimes may not wish to – or may not be able to - deal with the demands of a regular job. As Lamb and Peele indicate with respect to some long-term patients with SMI, competitive employment may not be a realistic goal; for this group just maintaining their present level of functioning should be considered a success (Lamb and Peele, 1984, pg. 779-780).

All this means that mental health policy makers need to consider two very important issues: 1) that there is a need to *better prepare* these patients [like the residents in this group who had participated in occupational therapy while in hospital and got deinstitutionalised] for the routine required of wider work in society, and 2) that there is a need for creation of job opportunities of more flexible, relaxed and versatile nature that will match patients' needs.

It is also important to mention that in this research study in two cases, the hospital's social workers tried not to integrate residents in the conventional occupational therapy programmes that the hospitals offered, but instead they encouraged the residents to cultivate their special abilities and talents. In the case of Mr. Leonidopoulos (64), resident of the psycho-

geriatric boarding house, the hospital's social worker pushed him and motivated him to cultivate his main talent, which was writing.

This shows that in some cases hospital's staff not only had the insight to recognise that the conventional occupational therapy programmes that the hospital offered did not match the particular residents' interests, but they also took the initiative to lead the particular residents to cultivate their real talents. This way, participating in the occupational therapy was not a *boring passtime*, but rather a *creative engagement* for them.

In conclusion, in the accounts of staff and residents, it seems that there were three parameters determining whether a resident would participate in the occupational therapy programmes while in the mental health institution. One was whether the resident had an innate desire for work, which would also be expressed as a willingness to participate in the occupational therapy programmes. The second parameter was whether the resident would find the psychological strength to cope within the institution's environment, and the courage to develop the necessary relationships with staff members, who would then in turn motivate and mobilise the resident to participate in the programmes. According to Mrs. Koubaraki, psychologist at Dromokaition Mental Health Hospital, that is "not something easy to happen within the pathogenic environment of the institution, which on the one hand tends to lead staff members feeling institutionalised as well, and on the other hand, increases a patient's tendency for withdrawal in many cases". The third parameter was the quality of staff, which in some cases not only encouraged the residents to participate in the programmes, but to also cultivate their special abilities and talents.

Lastly, it should be mentioned that while in the mental health institution, two residents preferred to help with the hospital's daily chores as an activity, or they did this in addition to their participating in occupational therapy.

## **5.6. The small number of friends and narrow social networks residents had while in mental health institutions**

Several residents during the period they spent in the mental health institution had not created any friendships with other patients, several had created rather superficial friendships in order to just keep company with the other patients, whereas only a small number of individuals had established close friendships.

Several residents had no friends while in mental health institution, not even companions to just spend some time together. They led a very lonely life, not wanting to have any contact with the other patients, and being rather withdrawn. Mr. Voskopoulos (71), a resident of the psychogeriatric boarding house, gave as an explanation to this the fact that he did not want to be there and he wanted from the beginning to leave:

**R:** I had no relationship with the other patients ... I didn't want to be in Dafni ... Even if I went for a cup of coffee, I went by myself.

Another participant, Mr. Stonakis (30), a resident of the boarding house "Afaia", stated that: "... we didn't use to talk much to each other [in the hospital]. I didn't have any friend there". However that did not seem to bother them. Mr. Dimoulas (53), for example, resident of "Afaia", stated:

**R:** I had no friends in Dromokaition, I was ... I was living by myself, alone, I didn't have any contacts with other people ... I used to go for a cup of coffee, but that was it. Afterwards, everyone went his own way, and lived his own life.

The reasons that possibly led these residents to live a rather lonely life while they were in the mental health institution have to do with: 1) the very nature of SMI, 2) the environment of the mental health hospital, and 3) the fact that their only option for socialising was with other patients experiencing SMI. As far as the nature of SMI is concerned and particularly schizophrenia, it is known that schizophrenia manifests itself in many different forms, and in some of them the symptoms of apathy and

withdrawal prevail (Myceck et al, 2003). According to Dr. Kastrinakis, psychiatrist, head of Klimaka, there are always some individuals who predominantly express these symptoms of schizophrenia:

**R:** There also exist those particular forms of schizophrenia that made a person apathetic, not speaking at all, sitting in a corner for years, with complete withdrawal.

Another reason that led these residents to express this type of behaviour, could very possibly be the environment within the mental health institution, that in many cases exacerbated the disturbance associated with SMI. The compulsory stay of residents in the mental health institutions (in the Greek context admission to a mental health institution is always compulsory) removed from them the option to create their own social networks. Dr. Starlis, psychiatrist at Dromokaition, stated on the matter:

**R:** To start with, we need to say that the mental health institution is a space of virtual reality, sort to say, right? It greatly differs from the community, where anyone can *freely* choose his/her friends, has his/her own relatives, has the persons he/she wants close to him/her. Here [in the mental health institution] it is a *compulsory* stay, a *mandatory* stay, and an obligatory symbiosis, the patient [the general population of patients] cannot choose the people he/she lives with, he/she is not able to choose... the mental health institution is a disturbed space. I mean that is a *pathogenic* space. Because in principle it is a military space...

The degree of isolation that these residents - while in mental health institutions- experienced was such, that even individuals who lived in the same ward within the institution did not know each other. According to Dr. Starlis, many years ago, when several psychiatrists started making serious attempts in order to “organise the chaos” in Dromokaition, he and his team organised small “get together” groups of patients, with some psychotherapeutic elements. Over there, the staff members discovered that patients who slept in adjoining beds, next to each other, had never



exchanged not even a single word, and did not know the name of their fellow inmate.

For another group of several residents, the relationships that they developed while in the mental health institution were rather *superficial*, more at the level of companionship. Mr. Barbarigos' comments (43), resident of the psycho-geriatric boarding house, were typical for this group:

**R:** [The people I interacted with in the mental health institution were] acquaintances, acquaintances. I was talking friendly with everyone ... it was not the type of a close friendship, it was more at the level of keeping company to each other ... We used to go to the coffee shop, and drink our coffee...”.

One reason behind the superficiality of these relationships was the great *insecurity* that - according to staff members - these residents experienced while in the institution, which was so dominant among the feelings they had, that did not enable them to establish close friendships. Mr. Lyritzis, psychologist at the psycho-geriatric boarding house [who regularly visits mental health institutions in order to evaluate and prepare patients prior to their transfer to CCUs], stated:

**R:** I don't believe that any particularly close friendships existed [in the institution]. The mental health institution is a place with incarcerated people, and you know, from what I have seen so far, when people are incarcerated they may come close to each other, but the insecurity they experience is so deep and the deprivation of their freedom so intense, that they are simply not able to develop themselves to the degree to bond closely to another patient.

One should also keep in mind that, according to the DSM-IV and the newest DSM-5 diagnostic criteria, in some cases of SMI, particularly paranoid personality disorder and paranoid schizophrenia, insecurity is intensified by paranoia (Behavenet.com, 2000; American Psychiatric Association, 2013). Individuals with paranoid personality disorder or paranoid schizophrenia express suspiciousness and generalised mistrust

of others (Behavenet.com, 2000; American Psychiatric Association, 2013). These expressions of SMI however can make it even more difficult for patients in mental health institutions to form close friendships.

Another reason behind of the superficiality of relationships was the fact that some residents did not view themselves as being as seriously ill as some of the other patients in the asylum, and this made them to avoid establishing close friendships. The comments of Mr. Kerkyraios (42), resident of the psychogeriatric boarding house are very characteristic:

**R:** I had five to six friends, but they were in a much worse state than me. They were much worse off, they were in a very bad condition.

Lastly, a small group of residents – only four to five individuals – managed to establish close friendships while in the asylum. Mr. Vlastos mentioned that he had rather close friendships with the patients he used to share a cup of coffee and his cigarettes, and with whom he had developed “... a special dialect for talking and communicating”. Only one participant, Mrs. Marouli (62), a previous hostel resident, who lived independently at the time of the interview, mentioned a particular friend, with whom she used to spend a lot of time and share many activities in the hospital. She believes that this friendship helped her greatly to cope with all the difficulties she faced during her hospitalisation. She stated:

**R:** I had a close friendship [in the mental health institution]. With my friend we used to go for coffee every evening or every afternoon. We had to sign a paper first – I signed it for both of us – and after that we were able to go out. We used to go to a coffee shop right across the street from the mental health hospital, and we used to order pizzas and then take them back to the hospital and eat them. We used to also make coffee in our room, smoke, and then drink our coffee in the living room. After that, we would go to sleep, together... We had a very good relationship with my friend, and that was something that kept me together. It greatly helped me to pull myself together.

It becomes clear that for Mrs. Marouli, her friendship with the other lady was vital. It is generally known that providing help and support to a

friend is very important, as it contributes to an individual's own sense of self and well-being. This stands true not only for the general population, but for people with SMI as well: the Mental Health Foundation Report in 2001 revealed that people experiencing mental distress find great support among a network of friends; the most common unprompted response of individuals with mental illness was the need to stay as friends, keep in touch and spend time together (Mental Health Foundation Report, 2001). As my previous research has shown (Lentis, 2008) *when* such friendships exist – usually among women – they play a crucial role in a person's sense of well being within the hospital.

Lastly, as far as residents' contact with the neighborhood is concerned while in the hospital, that was simply non-existent in most cases. Only one female participant mentioned that she was able to go to the coffee shop that was across the street from Dromokaition. Also, only 2 residents who got institutionalised at the mental health hospital in Kerkyra (Corfu) mentioned that they were able to take the local bus and go to town every day to have a cup of coffee. Other than that, all the other residents led a rather *isolated* life while in mental health institutions, with no other social contacts other than the visits of their relatives.

In conclusion, participants in this research had all been hospitalised in mental health institutions before their being transferred to CCUs. All were involuntarily admitted to mental health institutions. From the accounts of those residents that described their involuntary commitment, it appears that it was a traumatic experience for them. The degree of communication with their family varied, with some having close contact mainly with their parents, but with many having little or no contact with their family. Sources of income mainly included pension or pocket money given by their family during their hospitalisation. Most residents described a rather monotonous everyday life during their stay at hospital. What is very interesting however is that most of them did not mention the hospital's everyday life schedule in a negative way, but rather as a daily routine to

which they had become accustomed. A very interesting point is that most residents actually *enjoyed* and *liked* this relaxing everyday life, with not so many stimuli, constituting a stress-free daily routine that did not put any pressure on to them. As a result, a novel dimension for the term “asylum” is that of segregation from the pressures of the outside world in a peaceful environment – not necessarily modern or new - which managed to offer the opportunity to the residents to follow their own schedule, without being bothered or pressured to work or to participate in any activities they did not wish to. The notion of Thirdspace appears to be very different from the notion of Firstspace, as for the residents the old and neglected buildings of the mental health institutions were not of major importance. What was important for them was that the mental health institution offered a “temporary asylum” from life’s pressuring circumstances.

## **Chapter 6: Relationship with staff members and issues of treatment while in mental health institutions**

Chapter 6 explores issues concerning the relationship that residents developed with staff members in mental health institutions along with issues concerning their treatment. All these areas were important to be explored in order to discover which parameters of residents' everyday life in institutions contributed or not to the notion of asylum.

### **6.1. The good, neutral or poor relationships residents had with the staff in mental health institutions**

As far as the relationships established between the participants and the staff in the psychiatric clinics is concerned, residents expressed mixed feelings. Several residents and especially those who have been recently institutionalised usually mention that they had very good relationships with the psychiatric clinic's staff without much elaboration. Mr. Papadopoulos (49), a resident of the psychogeriatric boarding house stated: "We had fun, I had no problem, we had a good time, the relationships were fine".

Mrs. Bebekou (36), a resident of the hostel, stated that in the psychiatric hospital all the staff members were "...talkative, nice, they would treat us well, they loved us". Another participant too, Mr. Dorakos (52), a resident of the boarding house "Afaia", also mentioned specific members of the staff that he thought had helped him a lot in order to overcome his aggressive behavior:

**R:** I was a bit aggressive towards the other patients. And towards the staff I must admit, in 2004. I wanted to leave and Mrs. Vasakou would tell me: "You will go through a treatment and then after a while you will gradually see an improvement". What Mrs. Vasakou said actually happened.

Therefore, in some cases, the residents reported that they perceived the relationship with staff as good and this had helped them to realise the

need to stay in the psychiatric hospital and the need for treatment. These kinds of relationships were not rare, but at the same time they were not easy to develop within the asylum environment of the psychiatric hospital. When and if these can develop, however, it is a factor that can help patients. Mrs. Koubaraki, a psychologist in Dromokaition stated on this matter:

**R:** When – and not always because this is not the norm – the therapeutic relationship between the patient and the staff is established, and the relationship becomes one of mutual trust, this is something that supports the patient greatly even for these issues that are very difficult to be dealt... so, one can find courage and strength. Availability of the therapists and staff is also helpful since they can listen to someone's problem and help them accept it...without labeling it as a “disease” or attaching a fatalistic dimension to it.

In some cases residents were rather reluctant to speak about hospital staff because they felt that they [the staff] were not very willing to help them. As Mrs. Amygdalou comments “they must not have had fond memories so they don't want to remember”. Mr. Louloudis (39), a resident of the boarding house “Afaia” stated:

**R:** ...The second time I went to Tarsi Clinic the staff was not that good, it was a little problematic, so I did not have a good time at the psychiatric hospital... the nurses' behavior was very strange, weird. They were half-hearted in helping the patients.

Mr Louloudis however, mentioned that during his other hospitalisations, the relationship that was developed between him and the staff was rather good.

In certain cases the staff members of Klimaka commented very negatively on the hospital staff's indifference, which they actually faced when they went there to prepare the residents for their transition to their community care units. Mrs. Aristaki, for example, head nurse of the

psychogeriatric unit, upon her arrival at the hospital discovered that the nursing staff did not look into matters of food, the residents' daily needs, and medication. As mentioned by two more nurses in my sample, in some cases the more functional patients [in mental health institutions] would replace the staff and take over their role in helping other patients receive their medication. Mrs Aristaki stated:

**R:** My personal experience was that there was practically no one to take care of the patients. Neither the food nor their medication was taken care of. They would sit all day on their own, and when there was bedtime they would just go to bed. No involvement...Another patient who was in better shape would give the patients their medication. Some of them would take [the pills], some pills would slip under the bed in the sheets, or under the pillows...The staff members did not take on the task of giving them their medication, or ensuring their cleanliness. Patients who were more functional than others took care of these issues.

According to several staff members of Klimaka, some residents while in hospital were so neglected and so deprived of any human contact that they were completely withdrawn and silent. What is very important however to mention at this point is that these comments were only made by Klimaka's staff members and not by residents themselves. It could be that staff members of CCUs felt that it would be to their advantage to criticise the hospital nurses in order to emphasise the difference between the quality of services being offered in CCUs versus mental health institutions. It could further be that staff members of CCUs greatly emphasised the brutality of the institutions in order to portray themselves as compassionate and caring and the residents as vulnerable people in need of their care and support. One should also consider the fact that residents in this sample spoke in retrospect about their experiences in mental health institutions. This can sometimes lead to a selective memory, in order to avoid talking about painful incidents. It could also be that the residents gave accounts in such a way as to portray themselves as "good patients" through avoiding criticism of the mental health institutions

services and staff. Still however, there is a great difference between residents' accounts and the comments that were made by staff of CCUs. This once again shows the great difference between the notion of Firstspace – the physical dimension of a place, Secondspace, i.e. the relationships developed in a space, with the notion of Thirdspace, which is the lived experience of residents.

All this of course does not mean that things were always smooth and easy between residents and staff members of institutions. In a few cases, residents mentioned that they were restrained in certain occasions, because of their aggressive behaviour. Two residents mentioned that they were tied up for days during a period of time that they did not feel well. Mrs. Iraklidou (70), resident of the psychogeriatric boarding house, said that: "I was locked up, then tied hand and foot, then tied up in bed. They would tie me up in bed". Mr. Dorakos (52), a resident of Afaia, similarly said that tying up was a typical procedure in Dromokaition for patients who were either aggressive or attempted to run away from the psychiatric hospital. He stated:

**R:** I tried to run away from Dromokaition once and fell down and I screamed: "help", I was scared, out of fear. After that they had to tie me up for 3-4 days. Those who were not quiet, they would tie them up too, that was a common practice in Dromokaition just like in all big mental health institutions.

In fact tying patients up was a common and usual way to resolve issues with patients who were aggressive or attempted to run away from the psychiatric hospital. Mrs. Ioannou (62), a resident of the boarding house Afaia, had such an experience when she tried to run away from Dafni:

**R:** At some point, someone had to return the food trays and the dishes back to the kitchen. So someone said: "Who wants to do it?" And I told them: "Me". Then I thought: "That is a chance for me to run away now". So, I took them back to the kitchen and the moment I saw the door open I



said to myself: “Oh my God, this is my chance to run away now”. Then a lady shouted: “Michael, Michael, run, a girl is running away”. He grabbed me and as he was a Cretan, he grabbed me with his hands and he brought me back in. He squeezed me here in my throat. “Let me go” I screamed. “I won’t” he said. He brought me back in and I never got out again. Then I spent some time there I don’t remember how much...

At this point however one must consider that restraining and tying up was used by hospital’s staff members in order to avoid incidents such as patients running away from mental health institutions or in order to control patients’ aggressive behaviour. So some of the hospital staff’s behaviour could be due to the expectations of society, which are that they keep patients safe and perhaps more importantly keep them from getting out. One should not neglect however the possibility that these “safety concerns” simply masked abusive behaviour. As it became clear in Chapter 2, relationships of power and control, which in certain cases resulted to patients being abused by staff members in mental health institutions, had been known to exist in the Greek context (Kouklaki, 2004; Megaloeconomou, 2008).

What is again striking though is that CCUs’ staff members go a step further and talk about the use of physical violence by hospital’s staff, whereas the great majority of residents never mentioned such incidents. According to Klimaka’s staff, the use of physical violence from the hospital’s nursing staff could take extreme forms and there were cases of patients sustaining fractures due to the beatings – especially in previous decades. Mr. Lyrizis, a psychologist of the psychogeriatric boarding house, commented on the experiences that some of the residents had, especially the older ones who had been hospitalised in public psychiatric hospitals for a long time:

**R:** The residents tell me about the times they were beaten up, how much the nurse beat them up and how and to which hospital they were sent because of this...They talk about certain people who gave them a really hard time,

employees at the psychiatric hospital who – it is no exaggeration to say – beat them to death. They would break their bones literally, both nurses and other staff members. They were hospitalised with fractures.

In general, it appears - particularly from the comments of staff members from Klimaka and Dromokaition Mental Health Institution - that within the psychiatric hospital the relationships between staff and residents were rather paternalistic. The form of this paternalistic relationship changes however according to the severity of the incidents and the department in which a patient resides. For example, in a department where long-term patients reside, this controlling relationship is usually manifested in an overbearing and overprotective manner where patients are not allowed to cultivate their abilities and skills and therefore not treated as equals. At the other end of the spectrum, there are the controlling relationships that are developed in the departments of the acute cases. There, because of the severity of the cases, the staff resorts to physical violence and restrictions in order to manage these difficult cases. In reality, however, this kind of violence has become part of the therapeutic practice. Dr Starlis, psychiatrist in Dromokaition referred to this:

**R:** In a department where there are acute cases with severe psychopathology there was tying up of patients. I could easily say that the situation could be characterised as sadomasochistic. Because there is violence from both sides. Of course from the staff's point of view it is justifiable as a measure of restraining patients, or answering back. Now this violence could be either verbal or it could take the form of tying up, restriction of freedom of the other person etc. And I would say that this has been incorporated into the so called therapeutic management of the patient. This to my mind is wrong but it happens.

Relationships developed in mental health institutions between clinical staff and patients have known to be unequal in terms of power and control autocratic and paternalistic in nature (Chow and Priebe, 2013).

What are however the reasons for the development of these authoritative relationships in the psychiatric hospital? First it is the particularity of the SMI which does not allow the psychiatric patient to be treated as any other pathological patient – wrong as it may seem. According to Dr Starlis, in the eyes of some of the staff, the psychiatric patient is in a particular “weak” position and they [the hospital staff] feel superior over him/her:

**R:** I would say that at first the relationships are not equal, they are controlling over the one who owns nothing, because the patient is someone who has nothing. He does not have his/her health, has no money too, has no ownership of him/herself. He/She is very different from a patient who is in a general hospital and suffers from a pathological disease. He/She has his/her family, his/her job, and in the hospital he/she just has a break from his/her daily life. Here a patient is at the mercy of the staff’s mood... So, in the mental health hospital controlling relationships develop.

This brings us to the second serious reason why controlling relationships are created. This is the structure of the asylum itself. The asylum is a power structure with a strict hierarchy, and at the bottom of this hierarchy one can find the patients. According to Mrs. Amygdalou, psychologist, the structure of the asylum itself favours the creation of controlling relationships. She stated:

**R:** ...upon entering the asylum the therapists [in the psychiatric hospital] are crushed by the asylum itself... The function of the asylum determines, actually over-determines the relationships so much that these are completely distorted in many cases.

Before any unfavourable conclusions about the staff are reached, it is necessary to seek further reasons for this type of behavior. To start with, one reason, especially when one talks about the previous decades, was the incompetence of the staff in terms of qualifications. According to Mrs Vlichá, nurse of the psychogeriatric boarding house [with working experience in mental health institutions] anyone could become a nurse in the psychiatric hospital; quite often those seeking a job in the psychiatric

hospital could not find a job elsewhere. This reveals the lack of organisation that existed in the psychiatric sector along with the lack of legislation as regards the specialisation of the psychiatric nurses and their education. Even when this specialisation was introduced for the nurses, the internship was very inadequate. Mr Lyritzis, a psychologist in the psychogeriatric boarding house refers to this situation:

**R:** You know, Greece is the only country in the world where for example a psychiatric nurse sees a patient the first day he/she goes to work. This nurse would not receive any kind of special training, ever.

According to the claims of many staff members of Klimaka, there is a huge need for educational programmes for staff in psychiatric hospitals. This responsibility falls into the hands of the Ministry of Health and Ministry of Education. According to Dr. Kastrinakis, psychiatrist and head of Klimaka, there should also be continuous assessment and evaluation of the people working in psychiatric hospitals.

An additional problem which makes the staff's job difficult is the very low staff-patient ratio. Consequently this makes the working conditions both exhausting and inhumane. According to the staff members of Klimaka, who had previously worked in public psychiatric hospitals, the large number of duties along with the extremely low salaries makes the situation even more problematic. Mr Makedonas stated:

**R:** In particular when 2 nurses have to take care of 50 patients, then one wonders how can you work there? There have been nurses who work in the public sector and have seriously been thinking of giving up. They earn 750 euros and they have 16 to 17 night shifts per month... I was on that point too... I was one of the lucky ones and I got away with it... I consider myself lucky that I didn't have to work for a public psychiatric hospital. I remember being a zombie from all that work.

On occasions, staff works under very dangerous conditions. Mr Sakorafas, a nurse in the psychiatric boarding house, reported an incident

in the public psychiatric hospital: “I remember the following scene in the psychiatric hospital: a patient having a seizure started beating up a nurse with a belt, forcing the rest of the nurses to immobilise him and restrain him”. So there is also the fear that an aggressive patient might not only harm him/herself but also the nursing staff. This creates a sense of insecurity among the staff members.

In conclusion, the residents who are in Klimaka now, while in the public psychiatric hospitals developed relationships with the staff that were either good, neutral and in few occasions bad. According to the accounts of staff members of Klimaka’s CCUs this is due to the hospital’s staff’s indifference as well as to the difficult working conditions. Based on comments made by both staff members of Klimaka and of Dromokaition Mental Health Hospital, these are exacerbated by the lack of staff, training, institutionalisation of staff, burn out, controlling relationships that are developed within the asylum, along with the increasing dangers in some cases.

## **6.2. Pharmacological treatment while in mental health institutions: limited awareness concerning medication, but with trust in treatment**

Medication as a psychiatric intervention has been known to be the first and frequently the major line of intervention for patients with SMI hospitalised in mental health institutions (Torrey, 1988; Isaac and Armat, 1990; Torrey, 1995). Under the biomedical model of practicing psychiatry, medication is the major form of intervention, with psychosocial therapies supplementing the scheme, but always with an emphasis on drugs (Torrey, 1995). The emphasis on medication has been revealed in my previous research as being dominant in institutions in the Greek context (Lentis, 2008), and through this research the same finding appeared strong from residents’ experiences. This section explores issues of

pharmacological treatment that residents received while in mental health institutions.

**a) Residents who did not know what kind of treatment they were receiving while in mental health institutions**

About two thirds of the thirty residents, who participated in this study, did not know what kind of pharmaceutical treatment they were receiving while in mental health institutions, although in most cases they believed that the pharmaceutical treatment was helpful for them. The comments of Mr. Kerkyraios (42) were representative for this group:

**R:** ...I don't know what kind of drugs they were exactly. They were drugs for tachycardia – for the heart and for the nerves, I believe for my nerves. I was also taking some drugs for my neurological coolness. I don't know the drugs' names though, because they were in a foreign language... The pharmaceutical treatment helped me very much.... I got liveliness, and with the drugs I was able to take some bad thoughts out of my mind in a short period of time.

Similar was the perception of Mr. Leonidopoulos (64), a resident of the psychogeriatric boarding house, who also did not know what kind of medication he was receiving while in the hospital. However, he thought that the medication really helped him to take unpleasant memories from the time he was homeless out of his mind:

**R:** It helped me tremendously. It helped me to get away from the thought of the period I was homeless and suffered very much. When I was not getting the drugs I used to turn in the past, turn in the past remembering all the suffering I have experienced as homeless.

Also similar was the perception of Mr. Dimoulas (53), a resident of the boarding house Afaia, who was getting the medication that the doctor ordered, showing complete confidence in the prescription process. He believed that the pharmaceutical treatment really helped him to overcome the traumatic experience of his divorce:

**R:** My divorce was a really painful experience for me... With the pharmaceutical treatment I started feeling calm and thinking positively on how to live my life, and that was very helpful for me.

In this group of residents, some of them, although they did not know the names of the drugs they were receiving while in hospital or the active substance they contained, they *recognised* the drugs of their everyday treatment from their number, their shape and their colour, in other words from the *morphology* of the pills they were getting. Mrs. Maragakis' comments (58), a resident of the boarding house Afaia, were typical:

**R:** At the beginning I was getting a few drugs, after a while a bit more... I don't know [what kind of drugs they were]. If I see them, yes, I would recognise them, but I don't know their names. From the shape and the colour I recognise them, I recognise them this way.

Although this morphological recognition of drugs has helped residents while in mental health institutions to identify drugs, nowadays, with the great financial crisis that Greece is experiencing, it is very difficult for this to continue, because there is a major replacement of prototype drugs by their generics. The Ministry of Health in Greece has taken several serious measures in order to increase the use of generics, and this is happening because Greece has one of the lowest rates of generic penetration in Europe (Gabionline.net, 2011). The goal of the Ministry of Health is for generics to account for 50% of all medicines used in hospitals by the end of 2015 (Protothema.gr, 2015). The replacement of neuroleptic drugs by their generics has brought though serious confusion to patients experiencing SMI, because they cannot recognise morphologically the drugs they have been receiving for years in mental health institutions. Up until now, patients in mental health institutions have been more acquainted with the morphology of pills than psychiatrists themselves. Dr. Stalris' comments from Dromokaition Mental Health Hospital are very characteristic:

**R:** Patients recognise them [the pills] mainly from the colour. In many cases patients recognise the pills and I don't, because I know the name, what it contains, the active substance, but not the morphology of the pill, because nowadays they change all the time, now with the generics there is great confusion. For example a patient comes to me and says: "I want the yellow pill".

In conclusion, residents in this group did not know which drugs they were receiving while in the institution, however they had faith in the prescribing process by the hospital's psychiatrist. It seems though from residents' comments that although they had faith in the prescription of the doctor, at the same time they themselves did not have any particular say in the configuration and shaping of the pharmaceutical treatment that was ordered for them. This was supported by the comments of Klimaka's staff members who had previous working experience in mental health institutions. Mrs. Alikaki, nurse at the psychogeriatric boarding house, stated:

**R:** Patients knew the quantity of drugs they were getting, and they knew the colours [that pills had]... Now, the names [of the drugs]?... Some of them were asking, but I don't think they were getting any answers: "Just drink the drugs and don't ask too much" was the usual reply. But patients would firstly look at the pills and *then* they would swallow them, and if there was something unusual or something that they didn't like, they would just say it. Or, the ones that were not very talkative, they would show them [the pills]. They were showing them.

It is obvious that the way the shaping and administration of pharmaceutical treatment works, lies within the boundaries of paternalism, leaning closer to a strong paternalism approach. Much of the traditional psychiatric practice has been based on an unequal power relation: the doctor being in the superior position (sometimes even supreme), and the patient in the helpless role (Lim, 2002). However, in more recent years, with information more readily available through the Internet, patients are becoming more knowledgeable (Christmann, 2013), and consequently involved in their own health care management, prompting doctors to



recognise the prudence of not imposing their views, unless they want to become the subject of a lawsuit (Lim, 2002). The real question behind this argument should be how one human being should treat another if both are to maintain integrity and humanity in their intercourse.

As it became clear in chapters 3 and 4 there has been internationally a paradigm shift from a doctor-directed to a more patient-centered approach, with the aim to correct the traditional imbalance of power between doctor and patient (Staniszewska and West, 2004). It appears that *achieving* a purely patient-centered approach in the Greek context and in particular shared decision making is still a long way from becoming the norm, particularly in mental health institutions, that have a long history of functioning in an authoritarian way, practicing psychiatry under a paternalistic model (Lentis, 2008). However, achieving a middle ground could be a good starting point *towards* that direction. So a good start for practicing psychiatry could be the “guided paternalism model that moves from strong to weak paternalism on the doctor’s end, and towards a more “enhanced autonomy” at the patient’s end” (Lim, 2002). This model recognises that the doctor is professionally equipped to give informed advice, while at the same time respecting the patient and the wishes he/she has (Lim, 2002). It appears that in order to achieve this middle ground approach, much work is still needed in the context of Greek mental health institutions.

#### **b) Residents who knew which drugs they were receiving while in mental health institutions**

About one third of the residents who participated in this study knew which drugs they were getting while in mental health institution. Very typical is the case of Mr. Papadopoulos (49), a resident of the psychogeriatric boarding house, who knew in detail the drugs he was receiving in the hospital. He felt though that besides the help that the pharmaceutical treatment offered him in order to feel better, what mostly

helped him was the support of his parents, who used to visit him every day in the institution. He stated:

**R:** I was getting Largactil [Chlorpromazine] and Depakine [Valproic acid]. Now I am talking to you about a time period of eight years – from 22 to 30 years old. After that period, I went to Saint Olga and to Dafni, and there they gave me Zyprexa [Olanzapine] and Lamictal [Lamotrigine], and a vitamin for the neurological problems... And one injection of Interferon every week [for the multiple sclerosis he is suffering from]... It helped me [the drug treatment], but that was not the only help I had; the most important thing was that I had my parents and they were supporting me. It was the support from the environment. That was what saved me, because at that time my mind was over my head. If I didn't have my parents, I was finished.

Equally aware about the pharmaceutical treatment he was receiving while in the institution was Mr. Barbarigos (43), a resident of the psychogeriatric boarding house, who felt that the drug treatment was helpful:

**R:** At the beginning in Dromokaition they were administering to me Aloperidin [Haloperidol] in injections, when I first went there... after a while they started administering me pills... I think they were also giving me Akineton [Biperiden]... for the quiver of my hands, for the quiver.

As a result, residents in this group seem to be fully aware of the drugs they were receiving while in hospital. What is impressive though is that again – as it happened with residents in the previous group – most did not know *why* they were receiving those drugs as far as SMI is concerned, and they could not influence the changes that were happening to their treatment or the prescription process in any way. The comments of Mr. Kalos (54), a resident of the psychogeriatric boarding house, were very characteristic; he mentioned not having any say to the changes that were happening to his drug treatment, although in general he found those changes beneficial for the course of his treatment:

- I: Did you request to have your drug therapy changed?  
R: No, they changed my drugs by themselves. After a while they changed Largactil [Chlorpromazine] and they gave me Aloperidin [Haloperidol]... Aloperidin helped me to feel I have more strength. I found myself. It was a good change.

Similar was the case of Mrs. Zachou (63), a resident of the protected apartment in Aigina: although no one explained to her *why* she was receiving the particular pharmaceutical treatment, or *why* certain changes had to take place in her drug therapy, she however felt that the treatment helped her to overcome the serious anorexia nervosa she was suffering from.

In conclusion, these residents seem to know which drugs they were receiving while in institution. This however is not due to a different therapeutic approach by the part of hospital's staff, because as it became clear no one ever devoted the necessary time to explain to them the reasons behind why they were getting administered the particular drug therapy. Most probably, the residents' knowing the drugs they were receiving was simply due to a better level of awareness.

However, the opinion of residents themselves seems to be entirely absent from decisions about drug therapy. What staff members of mental health institutions seem to neglect – or don't fully recognise yet – is that in the clinical encounter there are two experts present: the clinicians having technical knowledge, and the people with SMI, having expertise by experience. There is a great and equal value of both professional and personal knowledge, and the more *both* sides are taken into serious consideration the closer psychiatric practice will come to a more balanced and evidence-based approach to treatment (South London and Maudsley NHS Foundation Trust and South West London and St George's Mental Health NHS Trust, 2010). What is encouraging though is that more and more patients are seeking information and education concerning their treatment, along with greater involvement in the decision making process. That, in conjunction with patients' organisations and family members' organisations, can push practice towards the direction of a more patient-

centred approach. Mrs. Koubaraki, one of the Dromokaition Hospital's psychologists, stated on the matter:

**R:** There are some [patients] who know names of the drugs and who are much more active as far as their drug treatment is concerned, and they talk about it, and they *require* to have the necessary information – most of them – but most of the time they do not get that information, and it is not their fault... Most of them have *huge* experience concerning what particular effect each drug has on their body, and I think that someone should listen very carefully on what they have to say on the matter...

### **c) Side effects residents experienced because of the drug treatment while in mental health institutions**

Residents in both groups – those who knew and those who did not know the drugs they were receiving – felt rather disempowered from the prescription process, which did not address their own opinions or concerns. Because of the lack of monitoring, along with the authoritative approach of practicing psychiatry, certain residents experienced serious side effects from the drugs they were receiving, but it seems that no one ever took their complains into serious consideration. Mrs Ioannou (62), a resident of Afaia, stated about the side effects of the drugs she was receiving while in the institution:

**R:** They were giving me heavy drugs... My head was feeling like lead. I was like lead. I did not know where I was stepping and where I was going.

In many cases, drugs given for SMI may treat disease symptoms, but at the same time produce side-effects that can impact upon physical health (Bebbington et al, 2009). Confusion and drowsiness due to sedation in the central nervous system by most neuroleptic drugs are very common side effects among patients with schizophrenia, who are under drug treatment (Mycek et al., 2003). In cases like this, patients – on an international scale – complain that doctors in charge do not take their complaints seriously (Barham and Hayward, 1991; Lentis, 2008). This

mainly stems from poor relationships between psychiatric staff and patients, which are often referred to as a poor therapeutic alliance (Lacro et al, 2002). The only way to resolve this and make things easier for patients is by taking the time to listen to patients, treating them with respect, explaining things to them and involving them in treatment decisions insofar as this is feasible (Day et al, 2005).

One should also not neglect the fact that it is often an unfortunate but common practice for patients in long-stay institutions to be given high doses of medication (Snowden et al., 2000), which aim not only to decrease the psychotic symptoms, but also to make it easier for staff to cope [rather than the individual].

According to Dr. Starlis – psychiatrist at Dromokaition – the most common side effects that patients complain about in the institution are: drowsiness, reduction of vigor and of feeling energetic, along with extrapyramidal symptoms – basically trembling. Patients also complain about xerostomia (dry mouth), excess salivation, and akathisia. One resident in this group also mentioned that he was adversely affected by the polypharmacy, and this resulted in him deteriorating while in the hospital and under drug treatment, instead of showing improvement. Mr. Poulakis (47), a resident of the hostel stated:

**R:** [In the mental health hospital] they changed my drugs many times, and in fact during the period I was receiving too many drugs I was deteriorating, because I was experiencing the complete opposite comparing to the period I was getting few drugs... in fact, I reached a point in the mental health institution where I lost 25 pounds because of the drugs, that's how badly they affected me. When I got out [from the hospital] I had the impression that I might not have been able to continue my job as an EKAB [ambulance] driver and that I would lose my job, that's why I had to take for one month Seroquel [Quetiapine] of 75 mg, and for one month Ladose [Fluoxetine].

In cases like this though, an individual suffering from SMI may experience feelings such as being involved in a futile situation: on the one hand, he/she takes the drugs to reduce the emergence of psychotic

episodes, and on the other hand, the side effects of these drugs lead the individual to a reduced ability to function efficiently on a daily basis, something that acts as a constant reminder of the fact that the individual is suffering from schizophrenia (Barham and Hayward, 1991). This issue however makes it even more urgent for the voice of patients with SMI to be taken seriously into consideration, until the most effective treatment is found for each particular patient. Clearly, there is no single pharmaceutical scheme that “fits” all patients. Apparently, there is a great need for more personalised treatment plans that would best serve the particular needs of each individual. In order to achieve this, there needs to be greater collaboration between doctors and patients, placing emphasis on each individual patient’s best interests (Day et al, 2005).

### **6.3 Residents who had experienced electroconvulsive therapy while in mental health institution**

Three residents in this research study had undergone electroconvulsive therapy while in the mental health hospital, and two of them mentioned it as an extremely traumatic experience. Mrs. Chatzichristou (84), a resident of the psychogeriatric boarding house, stated: “In the hospital they gave me shock, shock, shock [electroconvulsive therapy]. Thanasis the doctor gave me shock”. Staff members in the community care units of Klimaka have noticed that those residents who have had the negative experience of going through electroconvulsive treatment in the hospital, when they first got transferred to the CCU were even afraid to blow-dry their hair, because they had associated in their minds electricity with electroconvulsive therapy. Mrs. Aristaki, head nurse of the psychogeriatric boarding house mentions on the matter:

- R:** In here we have older people, and when we first brought them here we started helping them to take their bath, wash their hair, and then to blow-dry their hair with the blow-dryer... We have an older lady who as soon as they tried to help her blow-dry her hair with the blow-drier she started shouting and screaming that

they were trying to harm her. She has memories from electroshock treatments.

Another resident in the hostel also mentions electroshock in a very negative way to staff members. The nurses at the hostel stated that every time he remembers having electroshock in the hospital he gets very upset. Mrs. Boukala, a nurse at the hostel, stated: “when he [the resident] mentions it, he starts losing himself and becomes a totally different person”. This clearly shows that although these residents had undergone ECT years ago, the effects of this type of treatment are lasting.

It is true that electroconvulsive therapy – particularly in older years, when it was performed without first giving anesthesia to patients, was an extremely traumatic experience for people with SMI (Isaac and Armat, 1990). Of course there are several psychiatrists and neuroscientists who believe that electroconvulsive therapy – without a known mechanism – in some cases helps the brain to restore the balance between the levels of neurotransmitters, and as a result some patients may see an improvement with electroshock treatments along with the drug therapy (Schizophrenia.com, 2012). In fact, ECT has been shown to be an effective form of treatment for severe depression, and for schizophrenia accompanied by catatonia, extreme depression, mania or other effective components (Schizophrenia.com, 2012). What has progressed with ECT in recent years – to make it a less traumatic experience – is that patients are given first anesthesia: they are put to sleep with a very short-acting barbiturate, and then the drug succinylcholine is administered to temporarily paralyse the muscles so that they do not contract during the treatment, because that is something that can cause fractures (Schizophrenia.com, 2012; MayoClinic.org, 2012). When waking up patients, usually they do not remember anything from the treatment (MayoClinic.org, 2012), although they may experience some side effects such as a brief period of confusion, headache, muscle stiffness, short memory loss, and some heart rhythm disturbances (Schizophrenia.com, 2012).

What is impressive in this research study is that one participant, Mr. Poulakis (47), resident at the hostel, believes that the electroconvulsive treatment he had while in the mental health institution was much more beneficial to him than the pharmaceutical treatment, because while he experiences serious side effects from the drugs, he experienced no side effects after each ECT, and he has no lasting negative experiences from the sessions. In fact, he believes that the 11 electroshock treatments he had within a period of 20 days, helped him so much, so that he was quickly able to return to work (he has working as an EKAB [ambulance] driver).

In fact, Mr. Poulakis, has already told his psychiatrist (that treats him in the CCU) that if he ever relapses again, he would definitely prefer to be sent to a mental health hospital in order to have electroshock treatments. He stated:

**R:** Even now I say to my doctor that in case I relapse... because I have a very bad experience from drugs, they bring me many side effects.... So, I've told him: "now that I am sane, in full consciousness and able to talk, in case I have a relapse and start hearing voices again – because I was hearing voices during the whole period back then – then It would be better to give me electroshock instead of "crushing" me with so many drugs".

**I:** So you prefer electroshock treatment than drugs?

**R:** Yes. It depends on what suits each particular person. I was helped more by electroconvulsive therapy, because it caused less side effects. They put you to sleep first, and then they perform the ECT, so you don't feel anything while it lasts.

Although Mr Poulakis' case is unique in this study, however the case of patients feeling that ECT is beneficial as a form of treatment has been reported before (Isaac and Armat, 1990). In the Greek context though, cases like Mr. Poulakis, - who think ECT is very beneficial – are rare (Lentis, 2008).



#### **6.4. Limited to non-existent participation of residents in psychotherapy while in mental health institutions**

A fact which is exceptionally impressive within this sample of thirty residents is that more than three fourths of the participants while in the psychiatric hospital did not receive any kind of psychotherapy whatsoever. Mr Kerkyraios (42), a resident of the psychogeriatric boarding house was a typical example of this group:

**R:** No, I didn't receive any kind of therapy from a psychologist...I only took my medicine.

Therefore, the majority of participants in this research appear not to have taken part in any organised psychotherapy while in the psychiatric hospital. This shows how the biomedical model of treatment prevails, based mainly on pharmaceutical treatment, instead of an implementation of the bio-psycho-social model, which is based not only on drug treatment, but also on psychotherapy and social skills learning. The main reason behind this is the lack of trained staff. According to Dr. Kastrinakis, psychiatrist and head of Klimaka, the maximum number of psychologists in every psychiatric hospital is 4 to 5 who cannot cope with the workload. Further, few of the psychologists working in mental health institutions have received the necessary training in order to practice psychotherapy. In Greece unfortunately, training in psychotherapy is in deficit and most of the professionals – psychiatrists and psychologists - never receive a proper and systematic training on the specific subject. Dr. Starlis, psychiatrist at Dromokaition Mental Health Hospital commented on that:

**R:** No psychotherapy takes place. There are no trained psychiatrists in psychotherapy and if any they are few. Because during their training, psychotherapy is not included and if it is, it is in a form of theoretical lessons. To practice psychotherapy is to go through psychotherapy yourself and this must be done in private sectors and/or institutions. It is a long-term process and an experiential one.... In the psychiatric hospital, let's say here in our place there might only be two or three that really know the subject... And there

are many psychiatrists who do not believe in it [in psychotherapy], they don't.

Clearly, therefore, many psychiatrists [in Greek mental health institutions] enforce the practice of the biomedical model at the expense of the bio-psycho-social model and this is done in an authoritative manner. This reinforces the model of strong paternalism. One of the great advantages of the psychotherapeutic process is that it creates a dialogue between the doctor and the patient and establishes certain conditions for a more patient-centered approach. However, it seems that this is far from reaching reality in Greek mental health institutions.

Finally another serious reason – according to hospital's staff members - why most residents did not participate in psychotherapy programmes while in the psychiatric hospital is because of the pathogenic environment of the psychiatric hospital itself: through the procedure of incarceration, hope for the future is removed from the patient's life. This automatically removes any kind of mood for psychotherapy from the patient's part. Consequently, no objectives can be set out let alone be materialised through a psychotherapeutic process. Mrs Koubaraki, psychologist of Dromokaition referred to this:

**R:** If perspective is taken away from people, then any psychotherapy or any type of intervention is automatically rendered as useless. And this is only natural. If someone said to us "You are sentenced to 100 years imprisonment", then what? Psychotherapy? Well...it's over... You associate certain things with your life. If you do not have any kind of perspective, or goals? The sense of perspective is something that one cannot find alone unless the mental health system provides it somehow.

Therefore, for all these reasons, the majority of the residents of this sample had never participated in psychotherapy sessions while in the psychiatric hospital. A small minority, however, the one fourth of it – appeared to have participated in psychotherapy programs while in the

psychiatric hospital. They even claimed that this had particularly helped them.

Mr Dimoulas (53), a resident of Afaia, mentioned that while in the psychiatric hospital he participated in a psychotherapy group once a month and felt that he was helped:

**R:** [It helped] a lot. Because the things I had, hidden in my soul, would give them to someone like you, and this pleased me.

Mrs Maragkaki (58), a resident of Afaia, felt that she was helped too by the psychotherapy sessions:

**I:** While in the psychiatric hospital, did you participate in psychotherapy with a psychologist?

**R:** Yes.

**I:** Did that help you, talking with a psychologist?

**R:** Yes, we talked, chatted....it helped me.

There is not enough evidence in order to draw conclusions about why these particular residents participated in psychotherapy whereas the majority did not. Those residents however who underwent psychotherapy were greatly helped through the sessions.

What should also be considered in the Greek context however is to follow other approaches as well, such as the Cognitive Behavioral Therapy (CBT). CBT has emerged as one of the most effective evidence-based adjunctive treatment for psychiatric disorders (Pinninti et al, 2006). Evidence for the efficacy of CBT for schizophrenia is increasing: Studies (Malik et al, 2009) suggest that there are beneficial effects on relapse and rehospitalisation following brief CBT delivered by mental health nurses in patients with schizophrenia, which are maintained at 24-month follow-up. In the UK nowadays, CBT is taught in short courses to all kinds of medical professionals, particularly nurses. This is an approach that should also be considered by the Greek Ministry of Health as well.

## **6.5. Notion of temporary “asylum” while in mental health institution**

As it has already been stated in Chapter 1, the notion of “asylum” entails one’s sense of feeling safe and protected. Judging by the problems the residents described as having faced within the mental health hospital it only stands to reason that some residents responded that they felt neither safe nor protected inside the hospital. That which is impressive is that when the question was raised with the participants themselves, there were only six residents who responded that they did not feel safe and protected during the course of their therapy. Those who responded in this manner were mostly afraid of other patients in the same ward and were overwhelmed with anxiety that they may be attacked.

Mrs Marouli (62), a former hostel resident, living on her own at the time of the interview, stated characteristically:

- I:** Did you feel safe and protected inside the hospital?  
**R:** No, on the contrary. Because...what I didn’t like was that there were a lot of paranoid women who could hurt me, pretend they were angry, and that show of anger I didn’t like at all. I thought of it as an opposite, something negative, very negative. [I felt] anything but safe.

The impression that Mrs Aggelopoulou (30), a resident of the hostel, had gathered was a similar one:

- I:** During the time you spent at the mental health hospital did you feel safe and protected?  
**R:** Not always.  
**I:** Why?  
**R:** I was afraid of the Ethiopian guy.

The fear overwhelming residents had to do with the fact they felt their physical wellbeing was being threatened. It also had to do with the possibility that someone in the ward would steal their personal belongings. As stated by Mrs Vlichá, General Duties staff member of the psychogeriatric boarding house [from her experience in working in public

mental health institutions the same period that some of the residents were in the institutions]: “No, safe they didn’t feel, they didn’t feel it because they had to guard themselves from all sides: They didn’t know whether somebody would come at them while they were asleep and hurt them or steal from them inside the ward”. Thus, it was only natural that those residents, feeling insecure within the mental hospital, could never see its premises as home – a process which, of course, necessitates the presence of an additional sense of “belonging” (Twerski, 2000). The statement made by Mrs Vasilikou (53), a resident at the Protected Apartment in Aigina is characteristic of that group:

- I:** Did you feel safe and protected during the time you spent at the mental health hospital?  
**R:** No.  
**I:** Why? What was the reason? Were you afraid of something?  
**R:** Other patients.  
**I:** Were there a lot of other patients in the room you lived in?  
**R:** Yes.  
**I:** And where did you feel your home was during that period?  
**R:** At Spata, at my parents’ home.

What is very impressive though is that the images that staff members of Klimaka describe, concerning issues of safety in mental health institutions, are much stronger and intense than those that residents themselves described. This shows once again the great difference between the notion of Firstspace, Secondspace and Thirdspace – the lived experience of residents. Mrs Dimitraki, hostel nurse, [with an extensive work experience in public psychiatric hospitals the same period that some of the residents were in the institutions], described a typical image from Dafni Mental Health Hospital:

- R:** I have experience from Wing 17 at Dafni Hospital, which had the worst cases of patients: all patients during night time used to be naked and were masturbating, all the boys, so if you wanted to pass through their beds, you had to walk very lightly... as if you were ballet dancing, in order not to interrupt them, and I remember myself thinking: “if another inmate interrupted them, they would beat him to death”. You never

knew what could happen...

According to Klimaka's staff members, it is only natural that the residents who never felt protected and safe in the mental health hospital, stand in fear and trepidation of even the notion of a possible return to the hospital, even if it means that they would spend just a few hours there so that they can have a test or have their medications prescribed by the doctor. However, what is again interesting to note is that none of the residents mentioned this as a fear they experience when thinking about the mental health institution.

Be that as it may, surprisingly, several of the residents mentioned that they did feel safe and protected within the mental health hospital. Safety and protection – according to their responses – had to do mostly with having their basic needs fulfilled: a roof over their heads, heating, and food. Still, however safe and protected they felt, they never felt that the mental health hospital was their actual home. The statement by Mr. Barbarigos (43), a resident of the psychogeriatric boarding house, is characteristic of that group:

- R:** Safe I was, yes...What I mean is, I had my food, a bed, and my medications...I also had some money to buy cigarettes with...I was, safe, yes. I felt that my basic needs were being met.
- I:** At that time, where did you feel your home was?
- R:** Look, I had anxiety swelling, I still got it, and that didn't help me to adjust, meaning, feel very comfortable, let's say, in my space, get used, that is, to sitting around with nothing bothering me...My home, I felt my home was still at Aghios Dimitrios.

As expected, fulfillment of those basic needs was an extremely important consideration to the residents who had experienced the sense of homelessness before being admitted to the mental health hospital. For instance, Mr Leonidopoulos (64), a resident of the psychogeriatric boarding house who had experienced homelessness for long periods of time before being admitted to the mental health hospital, felt good about the fact that he was put in a new ward, where his basic needs were being

met. Mr. Dimoulas (53), another resident of the Afaia boarding house, did feel safe and protected in hospital “because I had the caretakers who administered my treatment, my medications, and that was it”. Still he was unable to feel the mental health hospital as home. For him, “home” was his parent’s home:

**R:** No, no [I never felt the mental health hospital as my home]. There were far too many people in there and you lost yourself in there, you didn’t know what you were doing. But I have found peace and quiet and things are now straightened out.

Out of all the group’s residents who participated in the present study, only one female resident reports that she felt the mental health hospital as her home but that was out of *need* and not by *choice*. Mrs Chrysalis (67), a resident of the psychogeriatric boarding house, who had been evicted from her house by the owner and, all of a sudden, found herself out in the street, was relieved to find a roof over her head and food at the mental health hospital. Without a parental home to fall back on and without any contact with her siblings, she was forced by necessity to feel the mental health hospital as home. This is how she described the experience:

**R:** ...I wasn’t happy I was in hospital. I should say though that I wasn’t displeased either: Why should I blame them? They wanted to do right by me: food and sleep. They offered me shelter and food.

**I:** Did you feel safe and protected while in hospital?

**R:** Yes.

**I:** If somebody asked you where home was during the time you spent in hospital, what would you say?

**R:** That I’m staying in hospital. And that’s because I had left the other house in a hurry.

Thus there was only one female resident out of the entire group, who felt the hospital had become her home. As reported by Dr. Starlis from the Dromakaition Mental Health Hospital, that does happen in some cases, especially to patients who do not have a parental home any longer and/or have become institutionalised after years of treatment (Lentis, 2008). Dr. Starlis reported characteristically:

**R:** When they [patients] become institutionalised then it [the mental health hospital] becomes their home. What if they have no house out there? Well, even I, if I lose my home out there, lose my money, and so on, anyone who provides me with food and shelter, well, that's where my home would be.

Last, with regard to the recollection residents have of the mental health hospital, the staff of the units of Klimaka reported that life within the mental health hospital may well have been to the residents' liking since it went on without too many stimuli and without exerting any particular pressure on them. In fact, according to Dr. Kastrinakis, head of Klimaka, this particular stress-free routine may have well acted as a relief on residents or even satisfied them.

In conclusion, in the sample of this research, six residents were not feeling safe and secure while in mental health hospital, while the rest felt somewhat protected in hospital, mainly because their basic needs for food and shelter were covered. It appears that mental health hospitals provided an "asylum" that was temporary in nature, with an element of segregation from the pressures of the outside world. *None* of the residents however - with the exception of only one - felt that the mental health hospital ever became "a home" to them.

This chapter explored several aspects of residents' lives in institutions. In conclusion, the residents who are in Klimaka now, while in the public psychiatric hospitals developed relationships with the staff that were usually good or neutral, and in few occasions bad. This was mainly due to difficult working conditions for staff members. About two thirds of the thirty residents who participated in this study did not know what kind of treatment they were receiving in hospital, although in many cases they recognised the drugs morphologically. Most believed that the treatment was helpful and had faith in the prescribing process. Only one third of the residents knew which drugs they were getting while in institution, however most did not know *why* they were receiving those drugs and had no say in the changes that were happening to their drug treatment. It also appears that the majority of residents did not receive any psychotherapy while in



institutions, but those who underwent psychotherapy felt that they were greatly helped through the sessions.

Interestingly, only six residents felt neither safe or protected while in institution, while the majority felt that they did find an “asylum” in the institution. There appears to be a great difference between residents’ accounts and staff members’ comments and this could be due to the following reasons: 1) selective memory from residents’ part due to the retrospective nature of their description of the period they were in institutions, which tends to neutralise negative experiences (Baddeley et al, 2009); 2) residents giving accounts in such a way as to portray themselves as “good patients” through avoiding criticism of the mental health institutions services and staff; 3) overemphasising of negative features of mental health institutions by CCUs’ staff, in order to stress the difference between the two settings; 4) overemphasising by CCUs’ staff members of the brutality of the institutions in order to portray themselves as compassionate and caring and the residents as vulnerable people in need of their care and support. One should also not neglect the fact that in few cases participants had been institutionalised in institutions different from Dromokaition and Dafni, however these cases were few, and cannot justify the great extent of divergence.

Lastly, the notion of “asylum” appears to be that of a place offering shelter and protection, covering all basic needs of residents like food, housing and treatment, while at the same time providing an element of segregation from the pressures of the outside world. It appears that mental health hospitals provided a temporary “asylum” to residents.

All residents in this sample, after their stay in mental health institutions, got deinstitutionalised and transferred to four community care units run by Klimaka, a private, non-profit organisation in Athens, Greece. The following chapters explore residents’ life in the community and the changes this transition brought to their lives.

## **Chapter 7: Contact with family members and financial issues of residents while in the CCUs**

Chapter 7 explores the varied degrees of contact residents had with their family members, the financial exploitation of a few residents by their relatives after their deinstitutionalisation, along with sources of income, managing of monthly income with the aid of staff and financial concerns residents had while in community care units.

### **7.1. Varied degrees of contact residents had with their family members**

Approximately 50% of the residents of Klimaka's CCUs who took part in this research, had some kind of contact with their family members. About half of them had a meaningful and close contact while the rest had more superficial contact, often over the phone. Mr. Kerkyraios (42), a resident of the psychiatric boarding house is one of those who kept contact with their family members:

**R:** I keep contact with my family: I visit my mother in Lefkada once a month. I also see my sisters in Athens. In the past, I would see one of my sisters every day and would help her with her shop [which sells traditional food products]. Now with the strikes I cannot go there because there is no train or bus and the store is far away...

Similarly, Mr. Papadopoulos (49), a resident of the psychiatric boarding house, used to go out to visit his brother and his family in Elefsina:

**R:** [I keep contact] with my brother. I go to Elefsina –my brother is married - and I see my nieces and nephews. This is what I do.

Two female residents, whose both parents and siblings had died, received visits from the other family relatives such as nieces, nephews, and cousins. Mrs. Aggelopoulou (30), a resident of the hostel, received visits from her brother - though not so often due to his professional and family duties - more often she was visited by her godmother and her uncle. Similarly, Mr. Barbarigos (43), a resident of the psychogeriatric boarding house, received frequent visits from his sister, and her husband who would also bring him money.

Two of the residents were allowed to take a leave during the weekends and spend two days with their relatives. Mr. Louloudis (39), a resident of the boarding house Afaia, enjoyed the weekends he spent in his brother's house. This was the only contact he had with any of his relatives since his mother who lived in the countryside, suffered from serious psychological problems too:

**R:** My brother comes, picks me up and takes me home...to enjoy ourselves, to play a game, to watch TV along with his girlfriend. This is my sole contact. My mother is in Kefalonia and I am not aware of her condition. She also has psychological problems and she cannot travel.

Similarly, Mrs. Marouli (62), a former hostel resident, who lived independently at the time of the interview, used to visit her cousin's house at the weekends and on holidays [during the period she was in the CCU]. One of her sons would visit her quite often in the CCU. While living independently in her own flat, she was hosting her son when he visited her from Cyprus. She had no contact with her other son, however:

**R:** [I keep] very good contact [with one of my sons]. My son lives in Cyprus while my other son is in Germany so I do not get to see him so often. I have no contact with him, unfortunately. I had left him there when he was 3 years old...I was in Germany with him when this incident happened: he was in a nursery school and I left him there and when I went back they would not let me see him. Another family had adopted him. I keep contact with my first son, he is in Cyprus. He was here the other day, in

November. He stayed with me with his girlfriend. He works in Cyprus and he is happy. I also have a good contact with my cousins.

The kind of contact Mr. Poulakis (47), a resident of the hostel had with his family was frequent, on a weekly basis. However, they did not visit him in the hostel but in the restaurant run by Klimaka. It was easier for them to visit him there since they could eat something or have a coffee with him.

Finally, two residents had grown-up children, who would visit them on a weekly basis. Mrs. Karamouza (52), a resident of the boarding house Afaia, received visits from both her husband and daughter twice a week. Similarly, Mrs. Vasilikou (53), a resident of the protected flat in Aigina, received visits from her daughter every Sunday. This was very important for Mrs. Vasilikou because prior to her arrival at Klimaka she was homeless and had lost all contact with her family. After her transfer to the community care unit the contact and relationship with her daughter was restored.

Klimaka's staff members stressed the importance of the restoration of contact between the residents and their family members. They had searched for all residents' relatives and they had tried hard to restore the contact. Mrs. Aristaki, head nurse of the psychogeriatric boarding house reported:

**R:** The deinstitutionalisation programme dictates that a contact with the family members of the patients [the residents] should be established. We have achieved that to a certain extent...We have also managed to persuade even those [relatives] who did not wish to come. For example, we have tried for half a year to convince a daughter to come and see her mother. We wish [residents] to have that kind of contact.

In some cases, on their transfer to the community care units residents developed the need to re-establish their contact with their families. Mrs. Amygdalou, psychologist of the hostel, stated about this:

**R:** Patients [residents] themselves ask to re-establish the contact with their families...They suddenly feel like that - it happens. I have seen patients [residents] who during their stay in the hostel had initially no contact with their families but later on that wanted to develop one. I believe that this is too a first step and progress for the [goals] of the multidynamic therapeutic group which works with these people...

The restoration of contact with the family however was not easy, according to staff members of both CCUs and mental health hospital. When it was achieved however, it was a big step for the residents. Mrs. Koubaraki, psychologist of Dromokaition who had extensive experience with patients who re-established their contact with their families after their deinstitutionalisation from Leros' mental health institution, stated:

**R:** ... although [after all those years] any kind of contact with the relatives was a painful procedure, it was worth it, it was a step forward for those people... it is a help towards their improvement within the structure and an acceptance of the new reality.

According to Klimaka's staff members, the residents in Klimaka's CCUs were very happy during their relatives' visits. Mrs. Fotinopoulou, nurse of the psychogeriatric boarding house, stated that these residents: "feel nicer, you can tell they are happy, they would say: 'here comes my sister'...they are very glad I think". For that reason Klimaka's staff members tried really hard to establish as much contact as possible between the residents and their relatives.

Another 25% of the total number of residents who participated in this research, only had rare contact with their families; they called their relatives from time to time and they received visits in the community care unit from them once a month; in other cases this was less frequent. This usually happened when the parents of the residents were dead or their

relatives had tight family and working schedules. A typical case was that of Mr. Kalos (54), a resident of the psychogeriatric boarding house:

**R:** I do not have many relatives... my dad is dead my mum is too old...one of my brothers is dead the other comes and sees me...I call him. We talk on the phone and he tells me when he is coming to see me. He comes and visits me approximately once a month.

An additional reason why the residents of this group could not maintain a close contact with their relatives was the geographical distance. For example, Mr. Dorakos (52), a resident of the boarding house Afaia, rarely received visits from his brother, who lived with his family and worked in Crete [an island that is five hours away from Athens by boat], so he could not visit him often. However, Mr. Dorakos described that his brother cared about him a lot and called him many times. He stated:

**R:** My brother rarely comes, usually during holidays. He calls me on the phone, he visits me and he takes good care of me.

For two residents of the protected flat in Aigina the contact with their relatives was not very frequent because it was not easy for their relatives to travel so often to visit them [it is a one-hour boat trip from Athens to the island of Aigina]. Mr. Monachos (53) said that his relatives visited him every 20 or 30 days in Aigina and took him out for a coffee.

To those residents who saw their relatives very rarely, the meetings could be very emotional. According to Mrs. Galena, general duties staff member of the psychogeriatric boarding house:

**R:** It has a positive impact on them [when they see their relatives]. Although I believe that on that day and for the next couple of them they are more sensitive, it still has a positive effect on them.

Mrs. Kafetzi, psychologist of the psychogeriatric boarding house echoed this by saying that the contact of the residents with their relatives gave them both pleasure and frustration:

**R:** This helps the patients [the residents] a lot [the contact with the relatives]...Now the first day, if they haven't seen them for quite some time...it depends on the person: some ask for their relatives a lot and they are very happy to see them... For some others it is not so easy to visit a relative they have not seen for a long time or they only see them once a year. This upsets them a bit, it takes them out of the schedule and frustrates them.

About half of the participants in this study had little contact with their relatives. Mr. Vlachos (77), a resident of the psychogeriatric boarding house, was married and divorced twice, and had four children, but he was only visited by one son who came and saw him every two months. The rest of the family kept no contact. His second wife wanted to have no contact with him. She would only send him part of his pension money so that some of his expenses could be covered. Similarly, Mrs. Iraklidou, a resident of the psychogeriatric boarding house, had no contact with her siblings, saying:

**R:** They have abandoned me in here to die. They do not want me to go back to Crete again. Nobody wants me. They want me to die.

Three residents of the boarding house Afaia, also stated that they had "no contact" with their relatives. Things became a little more complicated in two cases where the residents were parents but had no contact with their children and naturally, they missed them a lot. Mrs. Bebekou (36), for example, a resident of the hostel, seemed to greatly miss her contact with her little girl. She had even lost phone contact with her husband and her parents:

**R:** My family is in a village in Lakonia, they have not seen me for a long time. When I was at home in Papadiamadopoulou Street, they would come, but then...now I haven't seen them for 7 years.

**I:** Do you keep contact with the other members of the family? With your husband or your mother-in-law?

**R:** Ok, yes I do. My in-laws have come and seen me once and then they would call me on the phone but now they do not.

- I:** Do you have contact with your little girl?  
**R:** Now I don't. She would call me on the phone with her father and we would talk but it has been a while now since we last talked.

In few cases when residents had not seen their relatives for a very long time, they believed that these had died. Mrs. Aristaki, head nurse of the psychogeriatric boarding house gave the following example:

- R:** Here is a characteristic story: we have a lady here whose siblings are very old and haven't paid a visit for quite some time, so at some point she asked me to buy her a black robe. I asked her: "What do you want the black robe for?" She says: "My brother has died". And I tell her: "Why are you saying this? Who has told you this?" And she says: "Since he hasn't come to see me, then he must be dead". She thought he had died because she hadn't seen him for quite some time. They want to see their relatives, otherwise they start worrying.

In the above cases, according to staff members, there was usually some kind of explanation about the lack of contact: relatives either did not want to maintain this contact or they could not handle it. Dr. Kastrinakis, head of Klimaka, gave two possible reasons:

- R:** The biggest percentage - if I can say an accurate number around 60-70% - do not have good relationships with their families. These relationships bear the burden of stigma and up to a certain point that of financial exploitation. So there are no good relationships. Stigma continues to play an important role. The rest...yes, I could say they have good relationships. You know what? If a patient is functional and has good relationships with his family he/she does not have to be in a hostel or in a boarding house. He/she would go home. And then with some psychiatric monitoring he/she could live alone. So what I describe here is rather ambivalent.

Therefore, the issue of friction between the residents and their relatives for financial and heritage issues seemed to create once again serious problems in their relationships, even after their transfer to the community care unit.



## **7.2. Financial exploitation of the residents by their relatives after their deinstitutionalisation and their transfer into the community care unit**

The issue of the residents' financial exploitation by their relatives even after their transfer to the community care unit was a rather isolated phenomenon among the residents in this specific sample; however I considered it worth analysing, since it was mentioned not only by two residents, but by staff members as well. The motives behind this behavior were either for the relatives to benefit from the inheritance rights of the resident or to be able to manage and eventually take advantage of the resident's monthly income, which came from their pensions.

In the cases of two residents in this sample, there were serious frictions with the relatives because of inheritance disputes. The staff of the psychogeriatric boarding house for example, reported that Mrs. Hatzichristou (84) would receive visits only twice a year. During her few first years, no relatives would visit due to the fact that they claimed part of her fortune. Mrs. Ioannou faced similar problems, and had no contact with her relatives: one of her sisters tried to exploit her financially and take Mrs. Ioannou's share of the family house. She tried to do this during the first period of time when Mrs. Ioannou had been transferred to the boarding house Afaia, which was at that time located in the island of Aigina. Mrs. Ioannou reported on the matter:

**R:** Once my sister came to Aigina...and she tells me: "I have brought some papers for you to sign, since you have no money to pay your taxes. Sign the papers so I can pay it for you". I agreed. When I tell the staff about this, they tell me: "Do not sign anything"; she has taken some land from me and she has also taken my father's house. She wanted all my inheritance. A relative of my father used to tell him: "Costas, give the house to her so as to remember you". "First I will die and then I will do it" he used to say. He finally died without doing it".

The financial exploitation could also take the form of abuse from the relatives who were in charge of the resident's pension money. Some of

them obtained the entire pension, while sending part of it to their relative for his/her needs in the community care unit, money which was usually not enough for residents to cover their personal needs. Mr. Vlastos (77), a resident of the psychogeriatric boarding house, stated:

**R:** I have never received my pension. My wife receives it and sends me a small part of it. She has been taking it for years now...it is not enough [this part].

Staff members also reported that there were cases where the relatives had convinced the resident not to spend a lot of money, so as more money to be left to them [the relatives]. Although the resident understood that this was some kind of exploitation, he still accepted this as a way of keeping contact with his relatives. Mrs. Virgouli, nurse of the psychogeriatric boarding house, talked about a resident:

**R:** In some cases there is financial exploitation from the patients' [residents'] relatives. In one specific case the relatives were in charge of the patient's [the resident's] pension money and they would only give him a small allowance. What is more, they have persuaded him not to spend a lot of money. So, when the patient [the resident] had to buy an expensive pair of glasses because he had sight problems, he himself did not want to buy them so as not to burden his relatives financially. He did it, himself, in order to economise. Even when he needed some clothes we had to call them [the relatives] so as to send him the money. They give him a very small amount from his pension.

At this point it is important to note that in some cases, the relatives asked residents for financial help. This has been especially evident in recent years, with the severe economic crisis in Greece. In several cases the residents understood and accepted this, and wanted to help their relatives. Dr. Kastrinakis, head of Klimaka stated:

**R:** There are some [residents] who help [their relatives]; ...they themselves help the families with their pension money...We see this as something positive in this whole process. They

use the money, most of them they do.

However, the limits between the real financial need of the relatives and the exploitation of their sick relative [who is a resident of a CCU] are not always clear. In some cases, relatives have found ways to manage their ill relative's money as judicial supporters. [In the Greek context, courts in some cases can appoint judicial supporters and give authority to an individual – usually a relative of a resident – to take care of their ill relative's finances]. According to Mr Alogskoufis, legal counselor of Klimaka, in cases like these the role of the controlling authorities should have been enhanced, so that it could be determined whether the resident *is* in need of a judicial supporter, who would act in favour of the resident. In cases of severe exploitation, a solution could be for the lasting powers of attorney to be withdrawn from the relatives and be appointed to the community care unit. Recently, there have been legal decisions that appointed community care units as judicial supporters of a resident of a CCU, instead of his/her relatives. Mr. Alogskoufis pointed out:

**R:** Klimaka has taken initiative for a case in Patra where relatives withdrew 22,000 euros from a resident's bank account. The joint account holder was a relative who was not a judicial supporter and left only 500 euros in the resident's account. Then the Social Welfare along with Klimaka got mobilised since this situation could no longer go on...There was a trial and the court appointed Klimaka as the resident's judicial supporter and not his/her relatives. This was a big step for us because in this way we can cover all patients: those with no relatives, those with indifferent ones and those whose relatives that are only interested in taking advantage and exploiting the residents' situation so that they can get financial benefits... This is a new chapter not only for Klimaka but also for Mental Health in general and we are planning to continue this.

According to Mr. Nikolaou, from the Department of Mental Health of the Ministry of Health, if such a need appears, usually it is a relative of a resident that is appointed as a judicial supporter, in most countries. When this relative does not perform his/her duties lawfully then he/she can be

substituted by the community care unit, which is then appointed as the judicial supporter of the resident. But this should be done individually and it is a time-consuming procedure. Mr. Nikolaou explained:

**R:** There are hundreds of patients [residents] with hundreds of cases that need to be examined and tried, but these in turn cost a lot of money. You cannot skip procedures or bypass them. One needs to go to the court for this. This is extremely time-consuming since there are so many bodies, institutions, structures and patients [residents] involved.

In summary, the issue of residents' financial exploitation concerned only two residents in this sample; however it is an issue that was stressed by staff members. Once again, there appears to be a great difference between the lived experience of residents - Thirdspace - and the perception that staff members of CCUs had. One possible explanation for this could be that this was a very sensitive issue that many residents did not want to discuss, or that in some cases residents did understand the financial exploitation but did not perceive it as such, since they wanted to help their families in the midst of the serious financial crisis that Greece has been experiencing.

### **7.3. Financial issues concerning the residents while in the community care units**

#### **7.3.1. Sources of income**

A very pleasant fact which shows that there has been considerable improvement during the period of time when residents were transferred to the community care units was that they were able to receive their pension from the Greek Social Security Organisations or other benefits from the Social Welfare. Only two residents in the sample did not receive anything - neither a pension nor a benefit. Mrs. Colliou, a resident of the psychogeriatric boarding house, received neither a pension nor any help from the State. Her niece used to bring her some money but she stated

that it was insufficient to cover her needs. Mrs. Pappas, in her 70s, also resident of the psychogeriatric boarding house, was in an even more difficult situation, since she had no relatives to help her.

One resident, Mrs. Karamouza (52) was in the process of starting to receive her pension and her family was helping her in the meantime:

**R:** My pension is going to be issued soon. Meanwhile my husband and my daughter bring me everything that I need.

Fortunately, the rest of the residents received some sort of help from the State, either in the form of a pension or of a benefit. Since all the basic needs were covered by Klimaka, this money went for their personal basic expenses such as buying cigarettes, going out, buying coffee and some personal hygiene things and clothes. Few residents though felt it was just enough to cover these needs. For most residents however, this money was enough. For example, Mr. Dorakos (52), a resident of the psychogeriatric boarding house, received his pension from IKA and according to him it was enough to cover his personal expenses and be able to play the lottery:

**R:** Every Wednesday or Thursday Klimaka gives us an amount of money which is enough for a week or 10 days. I economise a lot but I still play the lottery because I like it but not like a gambler - I am not a gambler.

Mr. Louloudis (39), a resident of the boarding house Afaia, receives a pension which was "...626 euros every two months, in other words 313 euros per month". At first, he had difficulties because he had to pay a debt to his insurance company from the period he used to work as a cartoonist. When that was over, he realised that this money was enough since his basic expenses were covered by Klimaka:

**R:** Now that this is over, I save it for a rainy day, let's say. It is enough for my personal expenses. To tell you the truth I spend it all...on a lot of food, when we go out, on coffee and on packet of cigarettes per week...Still, the money is enough because our basic expenses are covered.

Three more residents reported that the money was more than enough. Mr. Monachos (53), resident of the protected flat in Aigina, said that his pension money: “is more than enough” and he spent it on “coffee, sugar, cigarettes, fruit, clothes, shoes, toiletries and other personal items”. Mrs. Aggelopoulou, a resident of the boarding house was pleased too:

**R:** The benefit is more than enough. I buy other people stuff when we go out too. I pay for the taxi, pay half of it, every Saturday when we go to Klimaka’s restaurant. We all pay our share for the taxi that takes us there and brings us back.

Three residents from the sample however, reported that their pension money was not enough to cover their personal needs. Mrs. Iraklidou, resident of the psychogeriatric boarding house, along with Mrs. Ioannou (62), a resident of the boarding house of Afaia, received a very small pension which was not enough for them. Mr. Vlastos (77), a resident of the psychogeriatric boarding house, stated that the amount of money his ex-wife sent him from his pension was not enough for him:

**R:** I have never received my pension. My wife receives it and sends me a small part of it....it is not enough [this part].

Two residents had an extra income apart from their money they received from the State. This came from some form of a job. Mr. Kerkyraios (42), a resident of the psychogeriatric unit, had had paid work in a garage and at the time of the interview he had moved on to working in his sister’s mini-market. Two female residents, Mrs. Bebekou (36), a resident of the hostel and Mrs. Olympiou (38), resident of the hostel too, worked in Klimaka’s restaurant. For Mrs. Bebekou this was her sole income but it was enough: “...for my daily expenses: coffee, juice, stuff like that”. Mrs. Olympiou, too, received a small payment for her work in the restaurant and along with the benefit she received from the Welfare, she

got by: “I get little money from the restaurant, I get paid a certain amount of money... together with the benefit I get by”.

Therefore, the majority of the residents appeared to receive some sort of pension or a benefit and for most of the residents this money seemed to cover their basic needs. To achieve this level of management, however, required intense preparation by Klimaka’s staff members.

### **7.3.2. Receiving the money and managing of the monthly income with the aid of staff members**

From those residents who received either a benefit or a pension from the State – which was practically all residents except two - four of them had their relatives receive this money and send it to them in the community care unit. Apart from Mr. Vlastos (77), a resident of the psychiatric boarding house, whose wife sent him only a small part of his pension, in the other 3 cases things ran smoothly between the residents and the relatives. Mr. Barbarigos (43), for example, resident of the psychogeriatric boarding house, had his sister’s husband receive the money, which he then brought to him every month at the CCU.

In most cases, the pension or the benefit of the residents arrived at the community care unit and a managerial committee helped the residents with money management. Some residents could go to the bank alone and receive their benefit or pension, but the majority, regardless of the way the money was received, gave their money to the administrator who was in charge of allocating the money to the residents gradually. Mr. Leonidopoulos (64), a resident of the psychogeriatric boarding house reported:

**R:** I do not keep the money I receive, I give it to Mr. Lyritzis who is a psychologist and is in charge of our finances. He gives me some pocket money.

Mrs. Aristaki, head nurse of the psychogeriatric boarding house, explained how the financial system works:

**R:** Look: Very old people have no special personal expenses so the money is more than enough. They do not receive their money of course, the boarding house does, and in turn deposits it in their bank account. Every expense is registered and a receipt is left in a financial planner. So if someone wants to check, everything is ok. All the money goes into the bank... Those people who can manage their money go and receive the Welfare benefit alone: they can move and they are functional, so they leave the boarding house, go to the bank, receive the money and then give it to the administrative clerk, who in turn gives them little each time to ensure that not all money is spent at once. Every week the administrator gives them some money so they can do things.

At this point one could wonder about whether or not this attitude is really promoting autonomy. According to staff members however, most residents needed serious help in learning how to manage their monthly income. This need for help comes from the fact that residents who had spent a lot of time in institutions had not had much experience or practice in money management. Besides, one should not forget that most of them never had the chance before their deinstitutionalisation to actually *have* any money, since their pension or benefit were issued *after* they were transferred to the community care units. At the same time, this perceived inability to manage their money can be associated with the nature of mental illness itself. Mrs. Dimitraki, a nurse of the hostel, stated:

**R:** They [the residents] constantly complain. This is a daily issue. On the other hand, they consume a lot. They want to buy this dress while they have many clothes in their wardrobe. They are crazy with clothes, they want to shop all the time. This consumption mania is part of the illness, but still they are very great spenders.

A similar belief about the managing weaknesses of the residents was held by Mr. Makedonas, nurse of the hostel. He explained that there were certain residents who, as soon as they received their money, preferred to buy 40 packets of cigarettes instead of something to eat. According to Mr.



Makedonas, some residents knew how to manage their money, while others did not and they ran the risk of being exploited within the community:

**R:** Most of them know how to manage their money. There are residents who do not, however. If you leave those people alone to go shopping for example, they will be deceived. They would pay more money than is needed because they do not know. So the staff must help them.

This need for training is very important and was done intensively by the staff members of Klimaka. So the staff, along with the residents, organised a weekly expense planner and staff members tried to explain to the residents that the money they received every week was enough to cover their expenses. The financial planning created with the help of the staff was very thorough and assessed each resident's needs individually. One should mention though that it appears that staff did not consider residents' wishes very much, as they seemed to assume that residents would spend their money unwisely. The financial planning took into consideration the potential expenses of the resident on a weekly and monthly basis. Mrs. Vlichá, a general duties staff member of the psychogeriatric boarding house, stated:

**R:** They take their money and they need to manage it. We help them in this management. How they should go and buy coffee, cigarettes, do this and that, visit one's mother - there is someone who visits his mother - or go to church, tickets etc. The social worker, the psychologist and the residents have worked together and created an expense planning. There has been a special training concerning their money management.

Of course, there were various cases among the residents: for some of them the money they received each month was not enough and they needed more guidance; there were some others though, that could manage money well and they in turn helped their fellow residents. Mrs. Amygdalou, psychologist of the hostel stated:

**R:** You can see this by listening to the residents' discussions. For example, they discuss: 'Why do you want to spend this money? You will have run out by the end of the month'.

What happens here therefore is important: those residents who managed their money well helped the other ones, therefore encouraging them to manage their own money better. This is a very interesting finding which shows that: 1) money was of vital importance among the residents (as in all of us) and 2) there was a sense of solidarity among the residents which facilitated their peaceful co-existence.

The objective of this training effort was for the residents to eventually have their own accounts and manage their money independently. According to Mr. Kastrinakis:

**R:** Yes, I think there are a lot of residents now that they have their own accounts and manage their money alone. Of course, there are a lot.

In conclusion, residents of Klimaka's CCUs were helped by staff members through educational sessions to learn how to better manage their monthly income, which usually came in the form of a pension or benefit. The staff, along with the residents, organised a weekly expense planner, which assessed each resident's needs individually. What was impressive was that some residents could not only manage their money well, but they could also help their fellow residents to manage their own money better.

#### **7.4. Financial concerns of residents on a microeconomic and macroeconomic scale**

Despite the fact that in the previous section it appears that the money seemed enough for the majority of residents, there were some residents who still felt that they hardly made ends meet and at the same time worried that they might not receive money on a steady basis. A typical

case was that of Mrs. Chrysalis (67), a resident of the psychogeriatric boarding house, who received her pension from the Agricultural Insurance Organisation (OGA) and a Welfare benefit. However, she did not receive it on a steady basis. This made her feel insecure for her future since it prevented her from making long term plans – such as renting a small flat for herself:

**R:** I have economised greatly, I have savings. I receive a benefit and I have been receiving my pension from OGA since the age of 65. This is enough to rent a flat [...] However, after a while I stopped receiving the benefit. Then the social worker, Mrs. Efi, talked and gave it back to me. But this is not on a steady basis. That is why I cannot rent the flat right now because they do not give me the benefit.

It appears that Mrs. Chrysalis was extremely careful with her money and even tried to save. In several cases, however, residents who received only the Welfare benefit could not cover the cost of their basic personal expenses. According to Mr. Starlis, psychiatrist at Dromokaition Mental Health Hospital, even this little money from the Welfare has therapeutic value and allows a resident do certain things within the community:

**R:** In other words, this amount of 350 euros allows him/her to go out, to have a coffee. It has a therapeutic value.

The biggest overturn, however, happened with the Memorandum in 31/07/2011 [a day before the beginning of the summer vacation in the Parliament], when it was announced that pensions and benefits of residents of CCUs or of psychiatric hospitals' patients which exceed a certain amount of money, would be cut by 40% in order to cover part of their living costs in the units. At the same time, however, there were budget cuts in the units too. So patients in psychiatric hospitals and residents of CCUs have been practically asked since 2011 to cover part of the structures' expenses. Mr. Nikolaou, from the Ministry of Health explained:

- R:** This has already been passed, yes. It literally says that the patient who is hospitalised whether in the psychiatric hospitals, public institutions, or socio-psychological rehabilitation centres has his/her pension withheld if this is more than 200 or 300 euros.
- I:** What you mean is that if a pension is more than 200 or 300 euros, the state withholds this extra amount? Does this go to the psychiatric hospital or the community care unit?
- R:** Yes, yes...I do not know what is the expected outcome of this... I think that what would be ideal is for the [a] patient [in mental health institution] [or a resident of a CCU] to spend as much money as he/she wishes and if there is a surplus then this can be used accordingly.

Amid this economic crisis, this ideal solution has been very difficult to be implemented, that is why the State announced this extreme withholding of the residents' money and benefits. This, in combination with the broader framework of cuts in pensions and benefits that the State has done under the Memorandum guidelines, created a lot of stress among the residents and worry about their monthly incomes. At this point it is important to note that these concerns were mentioned mainly by staff members and not so much by residents themselves. This once again shows the great difference between the perception of reality that staff have, compared to the *lived experience* of residents – the Thirdspace. However, I decided it was important at this point to include staff's views, reporting on the worries that residents shared with them, since this is an era of probably the most serious economic crisis that Greece has ever experienced. Mrs. Amygdalou, psychologist of the hostel, stated:

- R:** Of course they worry a lot, of course they understand and are under stress about how all these are going to affect them: "Will our incomes be affected or not? What will happen?" They surely get affected...not directly, but they surely will do. When for example, the postman might not bring their pension or benefits on time and there is a delay for a couple of days, there is fuss over it: "Will they cut it? Will we receive it? Is there a chance I might never receive my benefit again? What will happen to me?"

According to Mrs.Koubaraki, psychologist of Dromokaition, with such severe austerity measures such as pension cuts, there is always the risk of creating financial insecurity among patients of mental health institutions and residents of CCUs, which can even take the form of aggression which derives from despair. She stated:

**R:** If we have to deal with people who have no money, this can lead to aggression...When you deprive someone of something then he/she can become really violent because of this.

This overall financial climate that the Greek society has been experiencing is very stressful for residents. According to staff members of Klimaka, the residents of the community care units worried not only about the cuts in their pensions and benefits but also about the sustainability of these units which are so important to their future. Several residents openly expressed their worries to the staff. Mr. Dimitraki, a nurse of the hostel, stated:

**R:** The residents ask: "What will happen? There is no food to eat?"... Or they see people looking for food in the garbage and this makes an impression, it makes them wonder. Even though many of them were homeless once...they are still impressed and do not seem to understand it... They ask: "Will we end up like that?" And I say: "No, you will not end up like that. You are here and you are protected". We try to boost their sense of security. But they are insecure. Mass media also augments this feeling of insecurity... because they exaggerate the situation...

At the same time, Dr. Kastrinakis, head of Klimaka, expressed a more positive opinion. He stated that the residents' worries showed that they were informed about current events and the tough reality of the Greek society. According to Dr. Kastrinakis this healthy concern from all people involved can become a springboard for solutions and measures that can be taken towards to the right direction:

**R:** I see this as something healthy at every level. They are synchronised with the reality the nurses, their carers and even their doctors live in. Do not forget that this crisis affects us all. I consider it healthy that they are in a process of thinking and worrying about it. This can lead to some kind of solution.

It is clear therefore that this crisis has deeply affected not only the residents of the units but also the staff and administrators of the community care units. The regulations dictated by the Memorandum have led to cuts, not only on a microeconomic but also on a macroeconomic level, and this can in turn lead to even more serious concerns and considerations.

In conclusion, Chapter 7 explored the contact the residents had with their family members, along with financial issues, while in the CCUs. Approximately 50% of the residents of Klimaka's CCUs who took part in this research, appeared not to have any kind of contact with their family members while the rest of it had. From this 50% of those who kept contact half of them (25% of the total) appeared to have a meaningful and close contact, while the rest had more superficial contact, which often took place over the phone. In a few cases financial exploitation of residents appeared to be taking place after their deinstitutionalisation and transfer to CCUs. The main source of residents' income was either a pension from the Greek Social Security Organisations or a benefit from the Greek government. Most residents needed during their first months after being transferred, serious help and training in order to learn how to manage their monthly income. Few residents reported financial concerns for the serious economic crisis that Greece is experiencing, which has resulted in cuts in pensions. This however was an issue mainly reported by staff members of the CCUs, who described the concerns that residents express to them, both at a microeconomic and a macroeconomic level. This once again shows the difference between the lived experience of residents – the

*Thirdspace* – expressed through the residents' reports, and the issues that are of greater concern to staff.

## **Chapter 8: Daily schedule and routine of residents while in CCUs**

Chapter 8 explores the daily schedule and routine of residents, along with issues of work and occupational therapy while in the community care units. These issues were critical in order to explore how the everyday life of residents has been constructed in the community care units.

### **8.1. Daily personal hygiene activities and taking vital signs**

The first thing that residents of all four community care units did when they woke up was to take a shower and attend to their personal hygiene. The elderly residents who faced serious mobility problems were helped by the staff, while the rest took care of themselves. This situation was significantly different and greatly improved in relation to what happened in the psychiatric hospital. As it became clear in Chapter 5, in the hospital, the residents would have a shower once a week. This has changed dramatically, making the ritual of taking a shower a daily routine. Mrs. Kostaki (72), a resident of the psychogeriatric boarding house, stated: "Here, we take a shower in the morning - every day, and then we go down to have our breakfast, to have our coffee...". At first, they would take showers with the help of a nurse, and then they would do it alone. Mrs. Aggelopoulou (30), a resident of the hostel, stated: "Errr...we wake up at 7:00 – 7:15 am, and go to the bathroom. I go first to take a shower either with the help of a nurse - if he/she is around- or alone and then get ready, get dressed...". As Mrs. Boukala, a nurse at the hostel, explained: "it is very important for the residents to be clean and take care of themselves and have a neat appearance".

For someone to get used to such a great change and to the routine of the community care unit concerning personal hygiene was not easy for all residents. Several of them found it difficult to adjust and reacted against having to take a shower every day. Mrs. Dimitraki, a nurse at the hostel, described:



**R:** They say [the residents]: “A shower, every day? Who are we? Lepers? Filthy?”. They think that they disgust us. We explain to them that it is a matter of personal hygiene, that: “There are germs since you are so many in here”. We still have a problem with many of the residents who are still unwilling to take a shower.

Some residents however did enjoy this everyday showering routine. To go a step further, along with the recreational groups which residents attended every day, special groups concerning manicure and beauty were formed, in order to enhance this sense of personal hygiene. After systematic encouragement the residents got used to the fact that they had to wash themselves daily, even those who at first reacted. As time passed by, everybody got used to it and considered it part of their daily routine.

The sense of personal care was further enhanced by the staff emphasising overall grooming. In the community care units the residents could go shopping [accompanied by staff members] and they could buy clothes they had picked themselves. According to Mr. Makedonas, a nurse at the hostel, this was something that happened quite frequently. As a result, the external appearance of the residents was considerably improved in relation to the neglected one they had had in the psychiatric hospital. At the same time they acquired an individuality which contrasted with the uniform appearance of the residents in the psychiatric institutions, where self was “...systematically, if often unintentionally mortified” (Goffman, 1961, pg. 24). The enhancement of the residents’ individuality was one of the initial goals for Klimaka’s staff. Dr. Kastrinakis, psychiatrist and head of Klimaka, stated:

**R:** We wanted them to have their individual existence. We wanted them to have a mirror, to look at themselves, we wanted the women to wear make-up, to groom themselves in every possible way, to have mirrors in their rooms, photographs - we wanted them to have a sense of their personal history - so they can have a sense of continuation: “I am here, I move on...” For us this was important and we still want this to happen.

The improvement of this image had to do with the strong encouragement by the staff members. The high staff/resident ratio played an important role, because it allowed the staff members to be closely involved with the care and improvement of the residents' appearance.

Along with the care of the personal hygiene of the residents, staff members took the residents' blood pressure and temperature every day, along with regular blood tests – usually once a month. This is considered necessary in the Greek medical culture, since residents, and particularly the older ones, receive many drugs, not only for SMI, but for other medical conditions as well. Because of this, it is considered best to monitor residents on a regular basis. Once the process of personal hygiene and measurement of the residents' vital signs was over, then the residents were ready to face their daily activities.

## **8.2. Breakfast and “Community”**

Residents had breakfast in the communal dining room. In the psychogeriatric boarding house, breakfast was already prepared by the unit's staff. According to Mr. Kalos (54), a resident of the psychogeriatric boarding house: “In the morning we take our breakfast, usually corn flakes with milk, or sometimes bread with milk”. In the other units - like in the hostel, the protected apartment and the boarding house Afaia - the residents prepared their breakfast, lunch and dinner themselves, according to Mrs. Amygdalou, a psychologist at the hostel. This was a first step that the units tried to promote towards the independence of the residents and their transition towards a more independent type of living.

After the residents had taken their medication, everybody in all units took part in the “community”. The “community” was essentially a group discussion under a psychologist's or a nurse's guidance. The first thing that happened was that one of the residents would stand up and write the date in the white board with a marker. After that, a discussion began on the current news - what was the weather like, political news or general current issues, as for example the Eurovision song contest. Mrs. Chrysalis

(67), a resident of the psychogeriatric boarding house stated:

**R:** In the 'community' we discuss. We talk with the general duties staff members, the psychologist, or one of the nurses about our problems and about current issues. We talk about politics and the general political situation.

According to Mrs. Lalou, a general duties staff member at the psychogeriatric boarding house: "Those who participate [in the community] are those who can answer questions, but even those who cannot do that, they participate in order to learn. Most of them take part in this group and it is something that they enjoy". According to Mr. Lyritzis, a psychologist at the psychogeriatric boarding house, this discussion was a communication channel between the staff and the residents.

At the same time, the "community" gave the chance to the residents to express any complaints or propose things that had to do with their daily life. After the completion of the "community", came the occupational therapy and/or the creative activities, or for a few residents the time to work.

### **8.3. Occupational therapy and work mostly for the younger residents**

Participation in the occupational therapy offered by the CCUs was directly linked to the age and mobility of the residents: the younger and more mobile residents were, the greater the participation was in the occupational therapy programmes. Only three of the residents of the psychogeriatric boarding house of Klimaka, could go to the occupational therapy centre of Klimaka, which was in Kipseli, where a paper recycling centre operated. Two of the residents were going there regularly, while the third one only occasionally. Mr. Leonidopoulos (64), went there on a regular basis:

**R:** According to the daily programme, we wake up in the morning, take our bath, go down, have our breakfast, take

our medication and then I go to the paper recycling centre of Mrs. Dimitras Lianou-Terzakis. The hostel [Klimaka's unit] also takes part in this programme, which is in Kipseli. We recycle.

Mr. Barbarigos (43), a resident of the psychogeriatric boarding house, who resided there not because of his age, but due to geographical proximity to his sister, was also visiting the occupational therapy centre daily. This involvement helped him because of the change of scenery. Despite the fact that he was not getting paid, not even a small benefit, this did not seem to bother him; on the contrary, he enjoyed this daily involvement: "I go to the paper recycling centre...every day. Now it is closed for the holidays...It is nice [the activity], I like it. I escape a little, I go to a different environment, I am involved in something". Mr. Papadopoulos (49), on the other hand, explained that he did not go regularly due to the mobility problems he faced, as he suffered from multiple sclerosis.

Of the four residents of the protected flat in Agina, who came to Athens for a few weeks to have their medical check-ups and visit Klimaka's psychiatrists, two of them participated in the paper recycling programme. Mr. Monachos (52), a resident of the protected flat seemed pleased with this activity: "We go to the occupational therapy [daily]...in the paper recycling centre...It is nice, I like it. Time passes by in a pleasant and creative way".

Of the residents of the boarding house Afaia, four of seven were taking part in the occupational therapy and this appeared to be beneficial for the majority of them. Mr. Dorakos (52), a resident of the boarding house Afaia, stated: "We go to the occupational therapy which is essential to us because we do an occupational therapy with cards, we recycle paper. I attend this programme systematically, I have never been absent". Finally, of the four residents of the hostel that participated in this research, one of the residents participated in the occupational therapy on a regular basis and three people would work – one voluntarily and two on a paid basis. Mrs. Aggelopoulou (30), a resident of the hostel, found her participation in the occupational therapy very interesting:

**R:** I go to the occupational therapy where I paint and do collages; I also go to the paper recycling centre. We made Christmas and Easter cards last year.

In the units that had younger residents and a more independent living system, the number of residents who took part in the occupational therapy and even worked, increased. What were the problems, however, that kept preventing other residents from taking part in the occupational therapy programmes?

The first reason which has already been mentioned was the old age and mobility problems. For older residents (over 70), with serious mobility problems there can be limited expectations about participating in occupational therapy programmes. According to Mrs. Gyrla, a staff member at the psychogeriatric boarding house:

**R:** The older residents... have no stamina to take part because of old age. They like to be involved in some games here in this space.

A second reason was that because of the nature of severe mental illness, some residents preferred the leisure activities and did not feel like participating in occupational therapy. Mr. Kalos (54), a resident of the psychogeriatric boarding house, stated:

**R:** I don't go [to occupational therapy]. I am bored with these. I prefer going out with my friends for a coffee.

A third reason was that the specific activity that a centre offers – like that of the paper recycling centre – might not appeal to everybody. Mrs Vasilikou (53), resident of the protected apartment in Aigina, stated that she was not very pleased with the activity and she would prefer something different. Dr. Starlis, a psychiatrist at Dromokaition Mental Health Hospital - who has great experience with the organising of the community care units that operate under the aegis of Dromolaition - explained: "These are activities not chosen by the resident, we have done that for him, so there

lies a problem". Since different people have different needs and abilities, new programmes should be created; however, this is particularly hard with the limited funds that the Ministry of Health allocates for such purposes.

A fourth reason was the difficult access of the residents to the occupational therapy centre due to the numerous strikes in public transport. Unfortunately, due to the economic crisis, these strikes are more frequent, since the employees protest against their salary cuts. Because of these strikes, however, the whole city is paralysed and travelling becomes almost impossible. Mrs. Ioannou (62), a resident of the hostel Afaia, who used to take part in the occupational therapy programmes, but stopped because of the transportation problems, explained:

**R:** I used to go the paper recycling centre. Then...one day, there was a protest and they got us off at 'Wild Attiki' (Attiki square). I walked and walked... 'Hey Vangelis [the nurse]' I said, 'I cannot do it, my feet are trembling, I can't make it'... With the strikes I had a problem getting there.

A fifth and important reason preventing some residents from participating in occupational therapy, was the economic crisis that deprived the residents of the small benefit they used to receive from the state for their involvement in it. While this did not seem to bother some of them, one resident made it clear that it did bother him. Thus, the motive of involvement in occupational therapy for some residents was at least partly financial, and when this was taken away they stopped attending. Mr. Kerkyraios (42), a resident of the psychogeriatric boarding house talked about his former involvement in the workshop where he used to make chairs:

**R:** When PASOK [Socialists' Party] came to power, an occupational programme with different specialisations was created. I picked the one with the chairs, others something else. We received some money for this occupational programme which was deposited in Peiraios Bank...The programme lasted for a specific time. It lasted four months,

approximately. Then I stopped going because I was not getting paid. I sometimes go there for 10 minutes, I see them and talk. Due to the economic crisis, some of the occupational therapy workshops which operated under the auspices of the municipality were closed down.

Despite the adverse conditions that some residents faced, their involvement in the occupational therapy programmes was greater than in the psychiatric hospital, and that is a considerable improvement. As shown before, the majority of the residents who took part in the programme seemed pleased and embraced it. The majority of those who took part and went regularly, understood and identified that the occupational therapy was beneficial to them, because of the change of scenery it brought to them and the involvement in a creative activity. Mrs. Nitsou, a nurse at the hostel, stated:

**R:** It helps, yes, it helps [participation in the occupational therapy]. They spend their time, they are creatively involved in an activity. They do not sit in front of the TV all day.

Therefore, this parameter in the life of the residents appears to be improved in relation to the psychiatric hospital. What is even more encouraging is that some residents had a regular job. One resident from the psychogeriatric boarding house, Mr Kerkyraios (42), used to work from time to time in a garage next to the unit, while at the time of the interview he worked from time to time – because of the strikes in public transport – in his sister’s mini market where he got paid.

The case of Mrs. Marouli (62) was also interesting, because she lived independently under the hostel’s monitoring and worked as a secretary in Klimaka. This job made her feel better and helped her organise her time and life better:

**R:** I work every day, I come to Klimaka... I like the fact that I work, since my day passes by more easily, I have something to be engaged with, I go out, I get organised.

Three residents of the hostel worked in Klimaka's restaurant, one voluntarily – he was a pensioner of the public sector, so he was just helping – and two ladies who worked on a steady basis and were paid. Both ladies appeared very pleased with the multiple – not only financial – benefits that they received from their job. Mrs. Bebekou (36), stated:

**R:** Maria and I go to the restaurant and work together...We go to the restaurant at 9:00 o'clock and we return at around 6:00 to 7:00... I like it [this activity], it is nice...Going to the restaurant makes my life easier, I see people and I get away a bit...I also receive a benefit from the restaurant. [This money] is enough for my daily expenses.

The second lady, Mrs. Olympiou (38), a resident of the hostel was pleased too. She described her job in Klimaka's restaurant:

**R:** I have been working in Klimaka's restaurant for two years, I and Katerina. We are in charge of the chores outside the restaurant. I am in charge in the restaurant too, but more in the outside chores: I go shopping, I deliver food...I am happy, I have not had a problem and the people in charge are happy [with my work]...they don't have a problem....I like it [the job], I like it and I want to do it, I like keeping myself busy...We receive some money, I get paid a small amount of money.

Both residents, therefore, who worked at Klimaka's restaurant, seemed to enjoy multiple benefits of their job: Firstly, they got paid and this covered them some of their basic personal needs. Additionally, they liked finding themselves in a different environment and they came into contact with many people. This seemed to improve their mood considerably. Furthermore, their participation in this programme of organised work at the restaurant kept their mind occupied and their time was spent in a creative way. These findings agree with the previous literature: a study by Boyce et al (2008) on the experiences of 20 mental health service users' on returning to paid employment showed that although there were varying degrees of job satisfaction, none of the



participants described any negative effects, and even those who were less satisfied with their jobs identified benefits.

According to the staff of Klimaka, the participation of the residents in this programme of organised work had exceptional results. Mrs. Amygdalou, a psychologist at Klimaka's hostel, stated: "[This job participation has] a great effect; a very positive effect. Exceptionally positive...I think that they are greatly motivated and we see results". A similar opinion was held by Mrs. Nitsou, a nurse at the hostel, who agreed that although sometimes the residents reported that they got tired, it was obvious that working had a beneficial effect on them:

**R:** My opinion is that it helps them a lot, to spend their time in a creative way, and to earn some money; this pleases them a lot. They claim that they get a little tired but on the other hand it is good.

Mrs. Dimitraki, a nurse at the hostel, made an additional observation, when she described how having a job made these two individuals feel superior over the other residents due to the fact that they were working and getting paid. This was sometimes expressed with comments like: "...see? I work at the restaurant and I get paid". Therefore, the job was boosting their sense of self-worth, making them feel particularly useful and productive.

Klimaka's aim is to involve more residents from the community care units in the restaurant's working programme. One could argue that there may be problems or ethical issues with residents of CCUs working in an organisation purposing to look after them. At this point however, it should be explained that Klimaka's restaurant operates under the auspice of KOISPE (Social Cooperative of Limited Liability). The social cooperatives in Greece have been legislated as Mental Health Units since 1999, and operate under the supervision of the Ministry of Health. Today there are 22 KOISPE (Social Cooperative of Limited Liability) operating throughout Greece (Mpraoudakis et al, 2015). Their main target is the employment and social inclusion of people with mental illnesses. Members can be: a)

people with psycho-social disorders, at a percentage of 35%, b) employees in the Mental Health Sector, at a percentage up to 45%, and c) organisations or natural persons, at a percentage of up to 20% ([www.koispe.gr](http://www.koispe.gr), 2015). Involving more residents from the CCUs to the restaurant's working programme however, according to Dr. Kastrinakis, head of Klimaka, presupposes a certain degree of flexibility coming from the state which funds the KOIPSE programme, in order to overcome several bureaucratic procedures. Adding to bureaucracy the financial restraints that the IMF has imposed on the Greek Ministries, makes the expansion of such programmes rather difficult.

Although the Greek economy faces exceptional challenges, one needs to take the international experience on the matter into consideration as well. A study by Secker and Gelling in Great Britain (2006) revealed that although there are high numbers of mental health service users who are interested in pursuing training goals, education and/or employment, at the same time they lack the support they need in order to achieve this. For service users that do get into supported employment, a study by Johnson et al (2009) demonstrated that there were several key factors that service users found particularly helpful: 1) emotional support, which includes motivation, encouragement, building self-confidence, and availability of support should the service user needed it, 2) practical assistance with job preparation, job searching and application and recruitment process, and 3) a client-centred approach, with tailored support and appropriate job matching between particular jobs and the service users' needs and talents.

As far as job retention for people with SMI is concerned, Secker and Membrey (2003) revealed that four organisational themes are very important in order to promote mentally healthy workplaces: 1) a formal period of induction of sufficient length, in order for the employee to familiarise him/herself with the work environment, 2) attention to the employee's ongoing development through supervision and appraisal procedures, 3) team building in order to create a welcoming workplace with acceptance of difference, and 4) staff management that explores the

boundaries between a friendly supportive approach and ensuring that work is completed. These crucial elements from international experience need to be taken into consideration by the Greek Ministry of Health, particularly in the midst of an extended period of financial crisis, in order to create more job opportunities for residents of CCUs.

#### **8.4. Creative activities in groups**

For the residents of Klimaka's community care units who would not go to the occupational therapy and stayed in the unit, there was a special programme of groups with creative activities. These groups aimed to motivate the residents to cultivate new interests and skills. In the psychogeriatric boarding house the activities were various and covered a wide range. Mrs. Kafetzi, a psychologist at the psychogeriatric boarding house, described:

**R:** After [breakfast], there is the group of creative activities where we try to involve those residents who stay behind in the unit. This happens either individually or as a group with some games...And later, once a week, there is a dance group, before their dinner, where those who take part are those residents who are more functional and mobile...In the afternoon, once a week, there is a beauty group for grooming, where mostly women take part and a man from time to time. There are also reading groups where a book or a fairy tale is read and then there is discussion.

The residents who took part in the morning groups were those who would not go to the occupational therapy, while in the afternoon groups everybody participated. From time to time, some artists offered their services voluntarily and taught the residents certain skills, such as painting for example. The residents' programme was also enriched with several board games, which were mostly enjoyed by the younger ones, with a particular preference for backgammon.

Therefore, the residents' programme appeared to be full, with many activities. The majority of the residents seemed to accept the participation in these groups pleasantly by choosing the group according to their

interest: Mrs. Georgitzi (87) liked crafts and puzzles, while Mrs. Iraklidou (70) enjoyed the beauty group where she polished her nails red. Mr. Papadopoulos (49) liked the reading group: "In the afternoon we do a puzzle and then we read. I read newspapers, a book, if I find a nice book I read...I read the VIMA newspaper and the NEA, almost every day". On the other hand, Mrs. Kostaki (72) liked painting and board games.

All the residents of the psychogeriatric boarding house seemed to enjoy their participation in the groups, apart from two: Mr. Voskopoulos (71) mentioned that he did not particularly enjoy participation and Mrs. Pappas (70) preferred to make embroideries. This means that a very high percentage of the residents were involved in a group of creative activities on a daily basis - depending on their interests. This is a major change in relation to the rather dull routine residents had, with not so many stimuli, in the psychiatric hospital.

A factor that played a very important role in the participation of older residents in group activities was the intensified involvement of the staff with the residents, in the psychogeriatric boarding house. Usually, one staff member was in charge of one resident only and tried to guide him/her so as to develop certain skills within a group. This brought about big changes in the residents. Mrs. Vlichia, a general duties staff member at the psychogeriatric boarding house stated:

**R:** Those who can take part in the occupational therapy programmes and those who are not, are all encouraged to take part in activities. A staff member sits next to that person [resident] and tries to teach him/her something to do, as far as she/he can. We have many activities: we do the best we can to alert them and to motivate them, we do that... During this period [that they have been in the CCU] they have changed a lot. A person [resident] who was bed-ridden, while in Crystal [one of the hotels where patients from the public mental health institutions got transferred after the 1999 earthquake], began to walk when she was moved here, just fine...we tried a lot and we insisted.

In the other three units - the protected flat, the hostel and the boarding house Afaia - the percentage of residents who took part in

groups was also high. For those few residents who would not go to the occupational therapy programmes in the morning, there were creative activities within the units, while in the afternoon activities all residents would take part. Group activities covered a greater range of activities than those in the psychogeriatric boarding house; this is expected, since most residents of these units were younger and with no mobility problems. Mrs. Maragaki (58), resident of the boarding house Afaia, described:

**R:** [Staff members] create groups, where we talk about certain subjects such as history, geography, mythology. We also have our maps and we show them the places in geography.

Mrs. Karamouza (52), a resident of the boarding house Afaia, particularly liked these groups, which she would always attend, both in the morning and in the afternoon. She especially liked the money management lesson:

**R:** We have groups too...In the afternoon we have the History of Art lesson with Ioanna. We also learn about geography, writing, spelling and reading. We also learn about money. We learn what we can buy with it and this is very helpful.

These groups, therefore, covered a wide range of activities, and there was effort to include new ones. One of the new activities at the time of the interviews was the publication of a newspaper, which some residents were really looking forward to. Mr. Dorakos (52), a resident of the boarding house Afaia, explained:

**R:** The psychologist has already taken out some of the programmes and we will replace them with the publication of a six-page newspaper. I will write the sports section and the outdoors activities and entertainment: theatre and cinema, because I like theatre very much. I have taken a degree in Shipping, I also have a high school diploma, I know typing and word processing in the computer, I know how to surf on the internet, so I can really help with that.

Mrs. Aggelopoulou (30), a resident of the hostel felt equally excited:

“We are about to publish a newspaper and I take part in it too”.

According to the staff, there was a range of participation, which depended on the mood residents had that particular day. Generally speaking, however, the level of participation was high. One resident stated that he wanted these activities to be more enriched. Mr. Louloudis (39), a resident of the boarding house Afaia, would like more activities and would like a choir to be formed again. The first time, it was voluntarily organised by a musician, who managed to get the chorus to participate in a European contest in Crete:

**R:** When we went to Crete, to Europesing, we sang very beautifully; I also sang an English song beautifully and most of the people were surprised and would ask: ‘How did you manage to learn an English song?’ It was Pink Floyd’s ‘I wish you were here’. The memory of that moment is very intense. We need to organise the chorus again but we do not have someone to coordinate us well, and this is a bit hard.

Therefore, the majority of the residents liked the group activities and welcomed the creation of new ones, like the publishing of a newspaper, or the formation of a choir. This is exceptional progress in relation to their previous monotonous programme in the psychiatric hospital. Dr. Kastrinakis stated:

**R:** Most of them ask for activities, so it is up to us what kind of activities we will choose to offer them. They want activities and not flat time. They want to do something. So any intervention we have done, they have embraced it and accepted it really well. The painting/art groups, the puppet groups, the fairy tales groups, at all levels. There have always been some of the users of these services [the residents] who have played a very important role and still do. Ok, there will always be some people, around 3%-5% who do not want to participate, because they feel that they belong somewhere else... because of their disease, though.

In conclusion, it appears that participation in creative groups

appealed to residents and really helped them. This agrees with the experience of other countries, such as Great Britain, where the impact of participatory art projects for people with mental health needs has been evaluated as having a positive impact. A study by Hacking et al (2008) on 44 female and 18 male new art project participants attending 22 art projects in England, revealed that arts participation increased levels of empowerment, while at the same time had potential to improve not only social inclusion, but mental health as well. The most profound and significant outcomes of participation in art projects have been found to be: 1) creating a sense of meaning and purpose, 2) fostering of hope, 3) developing new coping mechanisms, and 4) rebuilding identities (Spandler et al, 2007). According to Spandler et al (2007), in the context of growing emphasis on recovery-oriented mental health services, while not necessarily appeal to all service users, arts and mental health initiatives could make an essential contribution to social care provision.

One last interesting point concerning these activities, which were offered in the Klimaka's CCUs in groups, was that through them some residents found not only an outlet for their interests, but also developed and furthered their skills on a personal level by taking some steps that went beyond these groups. Mrs. Aggelopoulou (30) for example, having developed her talent in painting, moved on to writing, something she felt very proud of:

**R:** I have written six fairy tales. Eleni [the person in charge] has them and Georgia, Dimitra, all the nurses and my relatives have seen them. If you want, Eleni or Georgia can give these to you and you can read them, to see what kind of a person I am.

It is clear that the residents' involvement in the groups of creative activities helped them a lot to develop their interests and skills, an opportunity that they would not normally have in the psychiatric hospital. The high ratio of staff/resident helped towards that direction, along with the fact that the residents had responded to the staff's interest. What also

played a major role in this was the plethora of groups on offer by the Klimaka's staff, which gave the chance to residents to choose the activity they preferred.

This does not mean that all community care units function like this in Greece, since there are units which just reproduce the institutional model of the psychiatric hospital. Dr. Starlis, psychiatrist of Dromokation Mental Health Hospital, who has great experience with the organising of the CCUs that operate under the aegis of Dromokaition, stated:

**R:** Look, it always depends on how they are organised [the CCUs]. There are units within the community, like boarding houses, hostels, etc. who have reproduced the practices of the psychiatric hospital, those of an institution. There are hostels which really function as a house within the community, as a therapeutic community. It is...it depends...it is like a mosaic of different experiences, within the community you can see everything: you can see a reproduction of a department of a psychiatric hospital, or you can see a true rehabilitation unit.

Even for those units which really function as a therapeutic community, there is still room for receiving help from the state to offer more. Mrs. Amygdalou, a psychologist at the hostel, reported:

**R:** Surely, there are a lot more things that can be improved and developed...More programmes, for example, a lot of patients [residents] took part in Leonardo, a programme by the European Union, and went to England through that. More of these programmes [are needed] so more people can go out and experience new things. I believe this is what we can call psychosocial rehabilitation.

### **8.5. Chores and structured daily programme while in the community care units: difficulties in adjusting to rules**

Another activity that the unit residents participated in was the daily chores – apart from those really elderly residents whose serious mobility problems prevented them from doing these activities. Mr. Kalos (54), a resident of the psychogeriatric boarding house stated: “I wake up in the



morning, I make my bed, I get dressed, we go down, I lay the table with the placemats, in order for the tablecloths not to get dirty. Then, if it is noon, I fill the glasses with water, and in the evening I do the same". Mrs. Chrysalis, (67), a resident of the psychogeriatric boarding house, also stated that she helped "every afternoon in the kitchen with the dishes".

Due to the old age of the residents of the psychogeriatric boarding house, most of them did not want to take part in the chores. Mrs. Krinou, a general duties staff member of the unit stated:

**R:** We always try to encourage them to do various things, to take part in the painting groups...even to help with the cleaning. They do not do, much. Most of them are very old and they cannot. But even those who can, we need to tell and remind them all the time.

This encouragement from the staff was continuous, because the difficulties the residents were facing were not only with the chores but with the more structured programme the community care units had. In these units, the daily programme has rules, unlike the relaxed programme of the psychiatric hospital. Mrs. Virgouli, a nurse at the psychogeriatric boarding house, stated:

**R:** What they find difficult at the beginning is that while they used to live a life with no rules, suddenly they need to follow a programme. This difficulty is expressed both verbally and behaviourally; they do not want to follow a programme. Even in our houses – I have happened to explain to them – we have a programme and live accordingly. Each one of us has his/her own jobs, chores and obligations... They do not like the transition to a life with a programme. If we had let them be as in the psychiatric hospital, they would not even have a bath, they wouldn't even seek to be clean, or take care of their personal hygiene - just like in the psychiatric hospital - they wouldn't even take their pills. Let alone cooking and cleaning their own space.

Of course, this difficulty to follow a programme is not only related to old age but also to the nature of SMI: many times the mood and

willingness to participate in a structured programme differs within periods in the same resident, depending on the progress of the disease. Mrs. Makrypoulia, a nurse at the psychogeriatric boarding house stated:

**R:** They find it hard [the structured programme]. And not only in the beginning. I see people [residents] who have always lived in boarding houses...for the last 7-8 years – not necessarily here, but in other boarding houses as well – and they still cannot follow certain rules, cannot adapt not only to the programme but also, let's say, to how many cigarettes they can smoke due to their health problems. They find it difficult to follow a routine, but that also depends on the specific day: if they are ok on a specific day they accept it, if not they react.

In the other units, due to the younger age of the residents along with the more independent nature of the units - especially in the protected flat - the participation of the residents in the chores was high. In fact, the more independent a unit was the bigger the initiative the residents took in relation to the chores. Mrs. Zachou (63), a resident of the protected flat in Aigina, described a typical day in the unit:

**R:** We get up in the morning, and prepare breakfast ourselves. In the beginning, they would bring us a psychologist who asked us: 'What medicine do you take?' and we would take our pills ourselves. Then we would do the chores: sweeping our room, cooking, washing the dishes, ironing, washing...We would do all the chores alone.

All these chores, however, were hard but this was balanced with the fact that there were only three residents in the protected flat of Aigina, so there was peace and quiet: "[I have found it a bit difficult], there are a lot of chores...But I like the fact that we are a few people, it is quiet".

Mrs. Karamouza (52), a resident of the boarding house Afaia, participated on a regular basis in the chores: "I do chores. Here we ... we dust... we mop....We wash the dishes". In the boarding house Afaia and in the hostel, those residents who did not take part in the occupational

therapy were involved in creative activities within the unit and chores, taking care of their living quarters. Mrs. Aggelopoulou (30), a resident of the hostel, described:

**R:** Every Tuesday, we clean our room. I tidy my drawers, so my clothes are kept clean, the wardrobe... I mop, and I make my own bed. We also do a lot of laundry.

As we move from the boarding house to the hostel and from there to the protected flat, the way of living becomes more autonomous, with greater initiative and participation to more chores. This does not presuppose that the residents accepted these willingly. In the beginning, residents reacted, but later on, they got used to it. Mrs. Boukala, a nurse at the hostel, stated:

**R:** Of course there is a lot of reaction. It is an issue for friction with the staff, because you try to involve and coordinate the resident with a programme and especially in some cases you find yourself in front of a wall: 'No! I can't!' he/she says. Just like that...At first they do it as a drag but after a certain point it becomes a routine and this is what we wish to accomplish, right?

What the staff tried to stress to residents is that they should consider the unit as their home; consequently, they should take it as such. Mrs. Dimitraki, nurse at the hostel, stated:

**R:** We call it 'their home', because they are bored with its cleaning, we tell them that this their home and they need to clean it. We identify the unit as their home and say: 'your home' very often, because they are bored to wash the dishes for example. We also tell them: 'would you do that in your own house?... this is your home. You must wash the dishes. There are cockroaches...!'

It becomes clear, that even in more independent units, there were residents who found it difficult to adjust to the rules. Mrs. Marouli's (62) case is exceptional. She first went to a hostel in Singrou, then to a protected flat in Agisilaou and at the time of the interview she was living

alone under the surveillance of the hostel in Tenedou. Her transition from the hostel to the protected flat was difficult, according to her, because of the larger number of chores she had to do, along with the fact that she did not like her roommate:

**R:** We had to cook, we got tired, we had to clean the whole protected flat just the two of us - too many chores. More than those in the hostel. That tired me a bit, I did not like it...In the protected flat my roommate gave me a hard time, and the fact that I had to do a lot of chores and to cook.

These comments however, contrasted with her present situation. She lives alone in a flat, she is in charge of all the chores in her place and she works as secretary in Klimaka on a daily basis:

**R:** [I manage] really well. I have organised myself and my time, so as to clean the whole house once a week. On Tuesday I do the hoovering, I dust all the furniture and decorations...On Wednesday, I mop the marbled floors... and I enjoy it. The rest of the week and at the weekend I do not have any chores, I take care of myself, I do my hair...I am very organised so as not to have extra stress. I also cook 2-3 times per week, that is enough for me and I eat the same food for 2-3 days...I work every day, I come to Klimaka...The day passes by more pleasantly, I am involved in something, I go out, I get organised. I keep the house very neat and tidy, I cook, and everything is ok.

Mrs. Marouli's comments are revealing: What has become obvious is that it was not the number of chores per se that she had to do at the protected apartment, but the fact that she was obliged to do them in an environment she did not like because of her roommate. This shows that the notion of Thirdspace – i.e. the lived experience of residents in community care units – is not so heavily relied on the physical dimension of space – the Firstspace - but it is rather intrinsically connected with the Secondspace, in other words with the human relationships that are developed within this space.

The element of obligation, too, is also a difficult issue, since it is not always easy for the residents with SMI to accept it. This derives from the

fact that they have to adapt to a programme they have not chosen themselves. Dr. Starlis, psychiatrist of Dromokation Mental Health Hospital, who has great experience with the organising of the CCUs that operate under the aegis of Dromokaition, stated:

**R:** Look, the main difficulty is the following: after all those years of institutionalisation, anyone finds it difficult to organise themselves and find out themselves - and consequently the rest of us - what their real needs are. But even if we do find out, we still cannot materialise them. So, in the same institutionalised way, we offer certain, standardised rules...they are rules which, or activities if you prefer the term, which have not been chosen by the residents themselves, we have chosen them for their 'sake'; therefore, even if someone else had dictated our life programme, we would have a problem with that, this is where the problem lies.

Once the residents got over the first period in the CCUs, most of them got used to their new programme, which is structured with certain rules. Mr. Sakorafas, a nurse at the hostel, stated:

**R:** There is some difficulty at the beginning, so that the initial stage is essentially a period of adjustment till they get used to the new programme.

These rules eventually help the residents not only to adjust but to start taking care of themselves with the aim of becoming as autonomous and self-sufficient as possible. This can potentially help them, especially the younger residents to eventually move on to totally autonomous living conditions.

### **8.6. Enjoying leisure activities**

As it was discussed in the previous section, residents derived great pleasure from the leisure activities and especially going out for a coffee. Once a week the residents also went for dinner at Klimaka's restaurant and they really liked it.

The programme in all units was enriched with some cinema, theatre

outings and on a rarer basis with an outing to a nightclub. Mrs. Aggelopoulou (30), resident of the hostel, stated: "I have been to the cinema too, they take us to the theatre...we went last year. But I fall asleep at the theatre". Mr. Dorakos (52), a resident of the boarding house Afaia, added: "Two years ago we went to a night club too, nearby, in Agiou Meletiou. I also danced there too..."

Part of the daily routine of all residents in all units was watching TV. According to Mrs. Lalou, a general duties staff member of the psychogeriatric boarding house, men preferred watching sports, while women preferred the TV series: "They like watching TV. Because they will watch - men more - sports, football, basketball. Women like the TV series a lot, mainly Greek series".

The programme also included some organised excursions for all the residents. Mrs. Aristaki, head nurse of the psychogeriatric boarding house, stated:

**R:** We have outings and organised excursions: in the summer, we go swimming, to Vravra, with Klimaka's coach. Those who can swim, sit at the beach or just wet their feet in the sea, they do it.

On certain occasions, a resident visited the place he/she is from. Mrs. Vlichia, a general duties staff member of the psychogeriatric boarding house, described:

**R:** Let me tell you about this resident whose desire was – once she told me while in the bathroom: "I want to go to Edessa". I found out that she had a kin from Edessa, she came from there. So I took her in my car and we went to Edessa for 5 days and we found her old home, her father's shop, the school she used to go and still operated – she is very old now, 81-82 years old. We just walked around. I found a cousin of hers, we visited him, we met his family, we chatted and we toured around Northern Greece with the car. We went to Florina, Kozani, Grevena, Meteora, everywhere. Nobody could tell that this person was sick...She was so sociable there, with all the stimuli she had...

On certain occasions, special outings were organised for some

residents so that they could have a nice and memorable picture towards the end of their lives. Mrs. Aristaki, head nurse of the psychogeriatric boarding house, stated:

**R:** We have been with our patients [residents], towards the end of their lives - to Hilton and Intercontinental Hotel to eat, to enjoy a nice meal, and to get a better image of life.

Despite these organised outings, some residents were seeking greater number of outings or/and more leisure activities. Mrs. Zachou (63), a resident of the protected flat, stated:

**R:** I would like more leisure activities. To watch more TV, to listen to some songs...[I want] the leisure activities to be more...in the afternoon. That would please me. Oh, and to go out every Sunday.

Mr. Kouroupis (50), a resident of the boarding house Afaia, felt the same:

**R:** They do not take us out many times....I would like to go out more often.

Mr. Kerkyraios (42), a resident of the psychogeriatric boarding house, would also like more excursions to nearby places in Athens, to change environment:

**R:** In the past we did some excursions with the coach. They have stopped this now [in the winter]. This, however, helps us to get away from the daily routine, from the status quo. To change environment, to have new stimuli, not to go to the same places nearby. We used to go to Faliro, to Piraeus, everywhere, in many places outside Athens. Because this has stopped, we feel a bit pressed. We know this area very well; the coach on the other hand would take us to other more distant places, so we got to know more places.

The above organised outings, although even some of the executives of the units wished, require a lot of organisation since the issue of safety

always arises. As Dr. Kastrinakis, head of Klimaka, explained, these outings need to be organised very carefully so as to ensure the residents' safety.

In conclusion, the parameters of daily occupation, participation in occupational therapy and in creative group activities demonstrate significant improvement in relation to the psychiatric hospital. Some residents even went a step further, and developed skills and interests they never had the chance to develop in the psychiatric hospital. What is even more encouraging is that a small number – three residents – had a regular job and seemed to enjoy the benefits of this, i.e. the fact that they got paid, came into contact with many people and spent their time in a creative way. What many residents of Klimaka's CCUs found difficult at first however, was to adjust to an organised daily programme which had certain rules, and this relates not only to taking care of their personal hygiene, but also helping with the daily chores. After an initial period of adjustment, however, residents got used to their new daily programme and activated themselves. This helped the residents to start taking care of themselves with the aim of becoming as autonomous and self-sufficient as possible. This could potentially help them, especially the younger residents to eventually move on to totally autonomous living conditions. Last, but not least, all residents seemed to enjoy the leisure activities offered by Klimaka's CCUs, although some wished for more organised outings and excursions and on a more frequent basis.



## **Chapter 9: Friendships, social networks, degree of freedom and contact with the neighbourhood while in the community care units**

Chapter 9 explores issues of friendships, social networks, degree of freedom, contact with the neighbourhood and stigma that residents experienced while in the community care units. These issues were very important in order to explore the everyday life of residents in the CCUs and compare and contrast them with those that participants had experienced while in hospital.

### **9.1. The increased number of friendships and broader social networks residents developed while in the community care units**

The number of friendships and social networks that residents developed while in the community care units seemed considerably increased in relation to what existed while these residents were in the psychiatric hospitals. What is different among the residents of the community care units is the actual percentage of those who created a friendship and those who just kept company to each other. The distinction between the two is that friendship represents a stronger form of interpersonal bond than keeping company, which is an association.

The pivotal factors that determined the development of a friendship or just company was the age of the residents, their mobility and consequently their ability to share certain activities together or not. In the psychogeriatric boarding house, 50% of the residents had a friendship with some of the other residents, while the other 50% of the residents just kept company with each other.

Mr. Kerkyraios (42), one of the younger residents of the psychogeriatric boarding house, belonged to that group of residents who had formed close friendships with each other: "I have friends. I got a bit sad when we lost a resident, an old lady; she died a few days ago. All of

the residents are very good friends of mine, both men and women, I have no problem". Mr. Leonidopoulos (64), a resident of the psychogeriatric boarding house, stated he developed close friendships too, especially with his roommate: "...I am very close with Mr. T. Papadopoulos, my roommate with whom I communicate wonderfully and has never bothered me for the last 8 years we have been together. We have been living together with no problems. He is my first and best friend". Mr. Leonidopoulos was also a member of another group of 4-5 male residents, who shared many activities together and had a close friendship:

**R:** [I am also friend] with Mr. G. Kalos too. We visit his mother every month. When he goes to the bank to receive his benefit I go with him just to keep him company. I am also friends with Mr. X. Kerkyraios who is now in Lefkada. He left, went to visit his family... These are my very good friends.

As a result, it appears that in the psychogeriatric boarding house there was a group of 3-4 male residents who developed friendships with each other, were younger than the rest of the residents and did not face any particular mobility problems. Therefore, the development of a friendship appears to be age and mobility related. One should also note that a few of these residents were in the psychogeriatric boarding house not because of their actual age, which is younger than the rest, but due to geographic proximity to their closest relatives.

The other 50% of the residents in the psychogeriatric boarding house developed social networks in the form of companionship within the community care unit, and this again depended on the residents' mobility. Mrs. Chrysalis (67), a resident of the community care unit, reported characteristically:

**R:** I hang out with men mostly, I get along with them... Poor [women] are in no mood to talk..., but we go for a coffee with the men and sometimes a lady comes along. Only one. The rest of them cannot come - they have problems with their feet.

A similar opinion was that of Mr. Barbarigos (43), a resident of the psychogeriatric boarding house, who spent time with those residents with whom he could share some activities but without forming any close friendships:

**R:** They are good [the relationships]...I know all of them – no doubt about it - If I want to go out for a coffee, I can join them...I treat them all the same, I mean those who I communicate more ...because the other residents are old ladies and I don't have much contact with them.

The relationships that Mr. Barbarigos created with some of the residents helped him forget any unpleasant feelings he experienced:

**R:** We talk, that helps. Thank God. When we are in the mood we talk about politics or other staff, social issues... Stress is tough... it is something that does not go away but with the discussion sometimes it helps.

Similar was the case of Mr. Vlastos (77), a resident of the psychogeriatric boarding house: “We sit next to the other and drink our coffee. All is good and quiet with no close friendships. We just hang out with each other, we are not friends. We are all selfish”.

Sometimes small frictions were created among the residents. According to Mrs. Vlichá, general duties staff member of the psychogeriatric boarding house, some residents were difficult and did not want to be bothered or develop close relationships: “There are of course some people who are loners and they would want to be left alone; even if they were ok, they would not want to form relationships”. In conclusion, it seems that the elderly residents of the unit did not form close relationships, but mainly kept company to each other.

Moving on to the three other units, the protected flat, the hostel and the boarding house of Afaia, where the age of the residents was much younger than that of the psychogeriatric boarding house, along with a greater degree of functionality, the percentage of those residents who

formed closer relationships within the unit was increased. There is only one resident from the protected flat of Aigina and two female residents from the boarding house Afaia who reported that they did not form very close friendships but they spent time with everybody. The rest of the residents reported that they formed close friendships.

The residents of these units made positive comments on the friendships they created. Mrs. Zachou (63), a resident of the protected flat in Aigina, reported that she had befriended two other residents of the protected flat: "At first we were four of us and then three. I get along really well with the others. We have developed a friendly relationship". The residents of the protected flat were able to co-exist harmoniously and they could go out for a coffee in Aigina's town every week with the psychologist. Mr. Dimoulas (53), a resident of Afaia, also developed good relationships with the residents of the boarding house of Afaia with whom he shared several daily creative activities:

**R:** We are all friends with each other. There is no problem...We go out for a coffee and every day to the occupational therapy. At the paper recycling center.

Mrs. Maragaki (58), a resident of the boarding house of Afaia, stated that: "We are like a family". Mrs. Aggelopoulou (30), a resident of the hostel, felt the same way, as she believed that the friendships that were developed were so close that some of them could be considered as family ties: "We are all good friends. We are like relatives".

Two female residents of the hostel worked in Klimaka's restaurant in the Votanikos area. This shared job brought them even closer and so a close friendship was formed. Mrs. Bebekou (36), stated: "I have created friendships: I have Maria who works with me at the restaurant. I have friendly relationships with the rest of the girls and the other people".

Mrs. Marouli (62), who lived independently at the time of the interview, also developed a very close friendship. Mrs. Marouli had been transferred along with her friend from Dromokaition to a hostel in Singrou

Street first, where she had a good time thanks to her friend. After that, she was transferred to a protected flat in Agisilaou Street, where she started facing problems with the other residents:

**R:** I spent two to three years [in the hostel in Singrou Avenue]. Then I went to the protected flat in Agisilaou. There, instead of being with all the others, I was only with two [co-residents]. I did not like this. My friend was in Singrou, while I had no friends in the protected flat...I did not like the other girl we lived together [in the protected flat]...We did not match. She pretended she enjoyed my company but she was always upset and disgruntled; I did not like this. I preferred the hostel because I had my friend there and we shared the same room. While in the protected flat I was with only two [co-residents], and with the one I did not get along. I cried all the time.

For Mrs Marouli, the concept of “space” was inextricably linked with the individuals who lived in that space. Here, we have a clear distinction between the concept of Firstspace and Thirdspace, i.e. between the physical dimension of space and the way a human being, who is the recipient of the services provided, perceives the space. For Mrs Marouli, the notion of Secondspace – i.e. the relationships developed in a space, along with the notion of Thirdspace – i.e. the lived experience, were far more important than the notion of Firstspace, i.e. the physical dimension of a space. To Mrs. Marouli, the friendship that she made in the hospital and continued in the first hostel to which she got transferred was an important parameter of her life, and she did not want to part with her friend. Losing their friendship network is a major concern for individuals like her. One solution to this is for hospitals and community care units to cooperate - as it happened the first time for Mrs. Marouli – in forming a plan for the individuals’ transfer that would enable them to co-reside with their close friends. Planning of this nature would assist in reducing the stress individuals experience during transfer and would help them adjust to their community care units more easily (Lentis, 2008).

During the time that Mrs. Marouli was in the protected flat, she could see her friend only once a week: “...She would come every Saturday,

when they were invited for dinner”. At the time of the interview Mrs. Marouli lived independently - but under the hostel’s monitoring - however she kept seeing her friend and taking her out for lunch:

**R:** Every time I go to the hostel, I see my friend. I have made arrangements for this Tuesday to take her out, the poor woman. My friend K. is still there in the hostel which has been relocated in Tenedou Street, in Amerikis Square.

What is interesting to point out is that among the residents of the hostel and the boarding house Afaia, there were 3 males who not only developed close friendships with the other residents but maintained their relationships with friends they had prior to their admission to the psychiatric hospital. Two out of the three residents found it difficult to meet their old friends frequently because Klimaka monitored the residents’ contacts so as to avoid problems. Mr. Dorakos (52), a resident of the boarding house of Afaia, stated:

**R:** I have friends: my friend Kostas [in the community care unit]. And I have more friends and other ones from when I used to live in Petroupoli...I call them [those friends]. Of course, I need to be careful because Klimaka needs to know [who] our friends [are], if they are nice people so as not to develop bad habits. This is what Klimaka wants. A friend of mine from Petroupoli has visited me along with another friend. One is a storekeeper in the Army and the other one is a University Professor in the Engineering Department.

At this point one could argue that monitoring residents’ contacts with their old friends, could be counter-therapeutic. However, there was no indication that staff of Klimaka was stopping residents from seeing their old friends. What was actually happening was a monitoring in order to check that the contact would not create possible dangers relating to residents’ security. Still though, the fact that the three residents could not see as often as they wished their old friends could be considered as not promoting independence.

Among the residents of these units only three people appeared not to have developed close friendships but they just got on well with the rest of the residents and enjoyed the common group outings that the units organised. One such case was that of Mrs. Karamouza (52), a resident of the boarding house Afaia, who, although she had no close friendships in Afaia, still spent time with everybody and enjoyed the time they went for a coffee [twice per week] and for lunch every Saturday: "We go for a coffee every Wednesday, or Thursday and on Sunday. We all go for a coffee. This is very pleasant...On Saturday we go to the Cooperative's tavern in Votanikos. I like this a lot, it is very nice when we go there". Similarly, Mrs. Ioannou (62), a resident of the boarding house Afaia, stated that she did not have close friendships but she kept company with her fellow residents. She obviously cared for her fellow residents since she had knitted a blanket for each one of them:

**R:** I knit. Now I am knitting this big blanket...This is my job, to make embroideries. So, at some point I say to myself: "Why don't I start knitting?" ...The first blanket was for Vangelitsa. Then I made one for myself. But then I thought: "Why don't you give it to Despina for her niece to sleep on it?" After Despina's, I made one for Giorgos. I made one for all the residents".

To conclude, the friendly relationships and the social networks formed by the residents in the community care units were clearly more developed than those in the psychiatric hospitals. According to Mrs. Koubaraki, psychologist of Dromokaition [who had extensive experience with patients who got deinstitutionalised from Leros' mental health institution], in general the relationships that have been developed among residents in community care units are: "...very different from those in the psychiatric hospitals. They become...emotionally deeper than they were before". Most participants in this study developed friendly relationships and those who did not, could still enjoy the company of the rest of the residents and the shared activities. The residents had learned to function

as members of a team and they seemed to care for one other. Dr. Kastrinakis, head of Klimaka, explained:

**R:** Most times, relationships are good...The friendships that are forged are closer than those in the psychiatric hospital. In other words, there is a differentiation in their feelings. They share a lot of things...For example they will play the lottery, they will share the agony of winning or not, they will go on an excursion, they get ready together. They can dream. And when you are able to dream and the other person participates in this, that is the most important thing of all.

### **9.2. Greater degree of freedom while in the community care unit**

The degree of freedom that the residents experienced within the community care unit was greater than in the psychiatric hospital. As was previously highlighted, there was no possibility within the psychiatric hospital to go out, so the contact with the neighborhood was nonexistent. In the community care units residents could go out for a coffee in the neighbourhood, for example. However, there were certain conditions.

When it came to the residents of the psychogeriatric boarding house, these fell under two categories: the first one consisted of the elderly residents who due to mobility problems could not leave the community care unit independently. The second one consisted of the rest - between 42 and 72- who did not face mobility problems, and could go out for a coffee every day as long as they were part of a group of 3-4 residents together. Mr. Kalos, for example, said that he went for a coffee "with the guys" to the café every day, while Mrs. Chrysalis mentioned that she - and sometimes another lady - went for a coffee every day with a group of 4-5 male residents.

One resident, Mr. Vlastos (77), had to be accompanied by the staff because in the past he had created problems in a café due to his heavy drinking: "I used to go out [for a coffee] but now I must be accompanied in case I drink alcohol. I will not drink, but there is no trust".

Therefore, the majority of residents of the psychogeriatric boarding house who could go out were only allowed as a group. The older



residents, according to Mrs. Vlichá, staff member, went to the café next door while the younger ones preferred the more distant ones in the neighbourhood, while during the weekend they would go even further. For example, they would take the metro and go to Syntagma to have their coffee and do their shopping. They could go alone without being accompanied by the staff. This increased sense of freedom - for the functional residents - was very helpful in the sense that they got a lot of stimuli. Mrs. Galena, a general duties staff member of the psychogeriatric boarding house stated:

**R:** I believe that this kind of 'freedom' is helping them: they can go out, come into contact with the rest of the world. They are no longer isolated in a building ...I believe this has helped - the functional people [residents] of course who can still have a kind of contact with the community.

The desire expressed by the residents to go out was so intense that sometimes – according to the staff - they preferred not to do the creative activities but go out instead. A major factor that contributed to this possibility of the residents having a contact with the neighbourhood was also the fact that the boarding house was established in the area in 2004, so both the residents of the area and the residents of the boarding house were acquainted with each other. Another important factor was the creation of a metro station in the specific area which created a commercial centre. This upgraded the area and rendered it relatively safe.

Going for a coffee - as aforementioned - was enjoyed by the residents when they were in the psychiatric hospital too, even though this was restricted within the premises of the asylum. In the community care units where there was the possibility of having a contact with the wider community, this same need appeared to be more imperative. According to Mrs. Kafetzi, psychologist at the psychogeriatric boarding house, the only objection to this going out for coffee was that, in her opinion, this should be combined with a more constructive activity:

**R:** I think that the whole issue with the boarding houses, the hostels, and CCUs is for the residents to understand that they can do other things as well, even have their coffee in a more constructive way, in another place, or they might even combine it with a visit to a museum, for example. The goal is to do something different, in other words, to combine activities together that could broaden their horizons.

In the other three units - the protected flat in Aigina, the hostel and the boarding house of Afaia, this outing for coffee was not a daily routine but twice a week for the majority of residents. There were only two residents who had a higher degree of functionality and they could go out every day. Mr. Poulakis (47), a resident of the hostel who helped voluntarily in the restaurant, could go out every day and in that way he felt that he had a sense of freedom. However, he would still go out with the rest of the group 2-3 times per week and he did understand why some residents could not have this kind of freedom: "It depends on the resident. Some of them feel like running away, some others are suicidal - not many though - hence they do not have the freedom I have". A similar kind of freedom was enjoyed by Mrs. Olympiou (38), a resident of the hostel, who worked in Klimaka's restaurant in Votanikos, daily: "I can do whatever I want alone, I can buy my own things, go shopping alone".

For the rest of the residents in the three community care units, going out for a coffee was a group activity and they were always accompanied by the staff. Mrs. Zachou (63), a resident of the protected flat of Aigina, stated that in Aigina they went out for a coffee twice a week, on Thursday and Sunday, all together with the psychologist. The same thing was mentioned by Mrs. Bebekou (36), a resident of the hostel, who worked in Klimaka's restaurant in Votanikos every day: "We go out for a coffee with the other people [residents] here every Sunday or on a weekday or on a holiday".

From all of the above it appears that although the residents of the units might go to the occupational therapy centres daily [which were close to the units] and went out for a coffee twice a week, they still did the

majority of these with the presence of the staff. Beyond what is apparent, in this case the residents' functionality, an important factor that contributed to this phenomenon was the fact that the hostel and the boarding house Afaia were relocated in the areas around Amerikis square and Kipseli, both in central Athens, where the crime rate was very high. Mrs. Marouli (62), an ex-resident of the units, who lived independently at the time of the interview under the hostel's monitoring, described the experience she had had while living in the protected flat which was located in the Omonia area [in the centre of Athens]:

**R:** I did not feel protected because... the area in Agisilaou street where the protected flat was located, was so bad...I would return from my cousin at 8 o'clock in the evening and I was trembling on my way back, even when I got into the building. Once there was an accident: someone was stabbed just across us, in the opposite building. There was always trouble at night...among the immigrants...the homeless, all of those people who were there in the same area. I felt anything but protected. It was awful because of the area of Omonia. I told you that in Singrou [where the hostel was first located] I was much happier than in the protected flat because of the area that the protected flat was located. The fact that there were so many foreigners, so many immigrants in the area bothered me. They would be drunk and would ring the bells of the flat...I was panicked along with another lady. We were panicked because of the area. Very ugly area, very ugly.

In this particular case the notion of Firstspace and Thirdspace seem to coincide: The degrading area of Omonia Square was perceived by the resident as dangerous and her living there made her feel very insecure, without being able to find "asylum". What is also apparent is that great responsibility lies in the unit staff's shoulders when it comes to the protection and safety of the residents, when CCUs are located in such areas. So, even though some residents asked for more outings, the staff needs to organise this in order to ensure the residents' safety.

The issue of safety however, is not only related to extrinsic conditions like the dangerous neighbourhood but also to the SMI's very nature: due

to the symptoms of the illness, some residents can potentially have a tendency to run away and put themselves in danger. Dr. Kastrinakis, head of Klimaka, explained:

**R:** You know that all these carry a lot of responsibilities, right? However, we still see it as something positive. We would also like them to go out more often. The other day someone ran away, after being here for eight months. He used to come here [at Klimaka's headquarters] every Thursday [from the CCU he was residing] in order for me to see him and examine him. It happened last Thursday. He ran away in the afternoon and he was found in Korinthos [a city which is an hour and a half away from Athens]. Things worked out well, he came back, but these things happen. Schizophrenia is a disease, a strange one, unfortunately... We need to anticipate things we are not ready for and the staff needs to show the best possible monitoring.

Hence, it appears that the residents of the community care units had more freedom than in the psychiatric hospital, but this was restricted to a certain degree, based on certain conditions: the functionality of the resident, his or her mobility, and the seriousness of the SMI symptoms, along with the safety of the area around the community care unit.

### **9.3. Increased contact with the neighbourhood and notion of stigma in the community**

What became apparent in the previous section is the fact that the contact the residents had with the neighbourhood was greater than that in the psychiatric hospital. This contact with the neighbourhood, however, had not always been easy, mainly due to the stigma that SMI bears in Greece. Mr. Kerkyraios (42), a resident of the psychogeriatric boarding house, explained:

**R:** We go to a café in a Metro station. We go to HIVE or SOHO. They don't let us get in, in the other cafés, because we take up too much of their space - we go there as a group. We get together, 5-6 people [residents], and we take over their space so there is no space for other people. That is why they have thrown us away. They don't accept

us. George and Uncle Thomas would go there and they told them: “Don’t you ever come back”. But the rest of the people must be trained on these issues. There used to be trees where the cafés now stand and now we are not welcome anymore. But we have been here longer than these cafés.

Mr. Kerkyraios’ description highlights the social stigma that the residents of the psychogeriatric boarding house faced when the neighbourhood’s character started to change. At first, [2003-2004], the neighbourhood of Keramikos was a very quiet area, [fifteen minutes by car from the centre of Athens], and all residents there had already been informed about the establishment of the psychogeriatric boarding house. According to Mrs. Vlichia, a general duties staff member of the unit:

**R:** When the boarding house was established, the neighbourhood was informed - there were few residents back then. There was the appropriate preparation, everything was planned out. We did not just show up, out of the blue. We have planned everything.

A few years later, however, a big Metro station opened in Keramikos and as a result the place experienced a commercial development with the opening of many cafés, restaurants and bars. Big investments occurred in that area. Initially, this brought about big changes according to Mrs. Aristaki, head nurse of the psychogeriatric boarding house:

**R:** When the boarding house opened, the neighbourhood was empty. There was only one shady café, where we used to go since it was not crowded; so we did not have a problem. The surrounding neighbourhood had no problem with us, nobody ever complained. The moment the Metro station opened and with all these cafés, the atmosphere of the place changed completely. Those who used to welcome us when we were the only customers, at some point they told us: “Don’t you ever come back because this is not good for the image of our place”. Of course, a complaint was filed and when this hit the headlines of the newspapers they took back what they said by telling us: “No, we want you here”. However, the residents never returned. There are so

many cafés around the boarding house so we do not have a problem.

To a certain extent this reaction from the owners of the cafés derived from the lack of knowledge around the symptoms of SMI and the side effects of drugs. When the residents described the incident to the staff, they specifically mentioned that the owners did not want them because they saw them “move around all the time”. Mrs. Vlichá, a general duties staff member of the psychogeriatric boarding house stated:

**R:** The residents were put in an awkward position because they were reprimanded. They told us: ‘They reprimanded us because they did not want the clients to sit next to someone who fidgets all the time’.

It is a fact that people with SMI often experience symptoms as a side effect of the drugs. Some of the neuroleptic drugs cause trembling and fidgeting that resembles Parkinson’s like symptoms (Mycek et al, 2003). According to the staff, the residents got really upset with this particular incident. This incident hit the news (Klimaka, 2010) and when that happened, the owners of the specific cafés tried to take it back. The residents though did not want to go back to these coffee shops anymore, as they perceived the whole incident as a serious offence.

This negative experience made the residents prefer two specific coffee shops where they felt comfortable, so as to avoid any possible incidents of social discrimination. It also led residents to the establishment of a notion of solidarity among them: Regardless of whether some residents were friends with each other or just kept company to each other, they still felt that they should be united against the prejudice of the wider society. According to Mrs. Makrypoulia, a nurse at the psychogeriatric boarding house: “...They care for each other. There is solidarity, in other words ‘we are together and when we go out to the society we protect one another’”. Mr. Kastrinakis, chief psychiatrist and head of Klimaka, stated on the matter: “It is true. They do not express it verbally [this solidarity], but

they show it. It has not taken the form of an organised movement, but they show it very expressively”.

As years have passed by, this social stigma seems to have receded in the neighbourhood of Keramikos. According to Dr. Kastrinakis, with Klimaka’s intervention and greater public awareness, things have gradually started to change:

**R:** When the incident happened, we went to all the places and we talked to the people. We explained what this is, how things work, we talked on the radio, the newspapers reported it and I think their attitude changed almost immediately and very easily. Perhaps a part [of this incident might be explained as this]: when a businessman opens a shop and expects to make money out of it, and the first people he sees coming to his/her shop are some people who do not talk, they are isolated in a corner of the café and stay there for two hours, this is something they might perceive it differently. And you know what? One does not have to be mentally ill. You could have little money and go and sit at the corner of a fancy pastry shop and be disliked by the owner...we intervened immediately and there was a resolution.

Generally speaking, the neighbourhood of Keramikos seems to have grown accustomed to the presence of the psychogeriatric boarding house, in recent years. Mrs. Vlichá, a staff member of the unit, stated: “I believe that as time has passed by we have all got used to this. Now if for some reason the residents do not go out for a coffee, we are asked: ‘Why didn’t they come?’ Now all the shops’ doors are open to the residents”. What helped towards this direction was the financial crisis too, since the residents were regular customers to these places, so the money they spent was valuable to each business.

The residents themselves seemed to experience this acceptance from the neighborhood; that is why they did not mention any recent negative incident, which would suggest social stigma. On the contrary, they were welcome to the coffee shops they went, despite being cautious with their choices. Some residents also experienced a “blessed

anonymity”, which basically referred to the fact that no one really knew in the neighbourhood details relating to their previous hospitalisations, because of their SMI. Mr. Kalos (54), a resident of the psychogeriatric boarding house, stated:

- I:** When you go out for a coffee, what do you think of the neighborhood, in general?  
**R:** Well. They do not know us.  
**I:** Do you like that?  
**R:** It is better. There is anonymity.

The situation, however, was not so good for the residents of the other units - that of the hostel and the boarding house Afaia, which were relocated in 2 neighbourhoods in the centre of Athens, in Amerikis square and Kipseli, respectively. Both areas are deprived and the stigma associated with mental illness is still prevalent. In some cases, of course, the residents neither noticed nor paid attention to this. For example, Mr. Dimoulas (53), a resident of the boarding house Afaia, talked about the contact he had with the neighbourhood and the reaction of the neighbours: “I personally, do not care at all, I am not upset by this. Everybody minds his own business. It does not bother me”. Similarly, Mrs. Karamouza (52), saw the reaction of the neighbourhood as a “blessed anonymity”, where no one placed any of the residents in an embarrassing position, since nobody seemed to care and they did not ask: “It is ok. Everyone here is quiet, they do not bother us. They do not even talk to us. Nothing”. The two female residents, who worked at Klimaka’s restaurant, said that they saw no problem with the neighbourhood there. Mrs. Olympiou (38), a resident of the hostel, for example, stated that: “There is no problem with the neighbourhood”, either that of the hostel or the restaurant.

However, despite the nature of these urban neighbourhoods, with a high percentage of immigrants who were mostly indifferent to the community care unit, there were incidents coming from Greek people, especially owners or assistants of small businesses closely located to the units. They would ask residents indiscreet and tactless questions which



made some of them really upset. Mr. Dorakos (52), a resident of the boarding house Afaia explained:

**R:** This neighbourhood here, Kipseli, is strange. I do not know if you know. It is a neighbourhood of black people, of immigrants...I got a little upset about how they found out that we are here. They say we are an institution. We are not an institution here. Someone has informed the owner of a newsagent where we go and buy our soft drinks, that we are an institution. I told that to Georgia [the psychologist] and she told me: "Do not talk to them. You had better avoid them. This is not an institution. The hostel is not an institution"... The neighbours talk to each other about us being an institution. They see that we go out every Sunday, for our coffee. On Saturday we go and eat at Klimaka's restaurant in Keramikos... I got upset at the reaction of the neighbours, but I forgot it, it is ok.

Mr. Louloudis (39), a resident of the boarding house Afaia, felt embarrassed on several occasions as well. He did not like the behaviour of some "fascists"- he meant right wing proponents, who treated immigrants badly. Despite the reports in the newspapers about crimes committed by immigrants, Mr. Louloudis did not mention violent incidents of such kind, but rather suspicious behaviour from the Greek neighbours:

**R:** Kipseli is a rather difficult neighbourhood. People here gossip and are a bit mean. There are also fascists, there are some lowlifes here in Kipseli, it is strange place because...I am not bothered by the immigrants but what bothers me is that they are treated really badly. Everybody says: "What? Is he black? He must be scum". But I know that black people don't bother anyone and they are very quiet people who do not want to create any problems anywhere. That's all.

Mr. Louloudis felt that he himself - along with all the residents of the community care unit - and the immigrants of the area, were in a very difficult position since they seemed to occupy the margins of the society. The feeling Mr. Louloudis had for the Thirdspace – the lived experience of the margin - he found himself, made him feel sympathy and empathy for

the immigrants who many times experienced the neighbourhood's prejudice. The tactless questions of the neighbourhood about the residents and the biased comments about the immigrants created a problem for Mr. Louloudis, who consciously decided that he did not want anything to do with the neighbourhood:

**R:** I have no contact with the people [of the neighbourhood], I don't know [anyone]. The other guys [residents] know them all... opposite in the mini-market, the kiosk, but I don't know anyone, I have not created any kind of relationship, just with my friend [from the community care unit] that we talk when we go out.

Therefore, despite the fact that there was a high percentage of immigrants who resided in this neighbourhood, it was the Greek people who became quite indiscreet when it came to the community care unit. The questions came – according to the staff - mainly from the Greek owners of the small businesses, closely located to the community care unit. Mrs. Amygdalou, the psychologist of the hostel and the boarding house Afaia, stated:

**R:** Recently, we have moved to Drosopoulou street here, so I can tell you a few things about how the neighbourhood has seen us. They started asking: "Where are you from? Are you from the hospital? From the clinic?" Some still refer to the hostel as a clinic. And they keep asking: "What is wrong with you? And why are you living over there?" They try to find more things. There is great skepticism and suspicion. Mostly from the Greeks, those who own businesses nearby.

To those people's minds, the community care unit was synonymous with the mental health hospital, although there are great differences between the two, not only due to the smaller scale of population in the CCUs, but also due to the higher degree of freedom, contact with the neighbourhood, larger social networks and increased number and diversity of daily activities, as it will become clear in the next chapter. This shows how much prejudice still exists in relation to SMI within the Greek society,

along with the lack of information about deinstitutionalisation. These indiscreet questions coming from the neighbourhood, however, irritated and stressed the residents greatly, rendering some residents' contact with the neighbourhood and making their acclimatisation to the community difficult. Sometimes the indiscreet questions became so intense not only from the neighbourhood but also from passengers on public transport. Mrs. Nitsou, a nurse at the hostel, stated:

**R:** Some people ask. Especially when we take the residents to activities with the bus, they ask us: "Where are you from?" They also ask the patients [the residents]. They ask: "What is this place that you live?" Or people from the neighbourhood ask: "What is here?" Because they see so many people in here and they ask: "What is this? What is here?"

For the residents to cope with all these questions, the staff prepared answers and had a handling strategy. So, the members of the staff by reenacting hypothetical dialogues, tried to prepare the residents to feel less stress while contacting the wider community. Mrs. Amygdalou, the psychologist at the hostel, and the boarding house Afaia, stated:

**R:** A great deal of stress [the residents experience]: when they were transferred in I. Drosopoulou, they would say: "What will we say the first time? And if they ask us, what will we say?" "And what?" "But we here..." But I say: "When they asked you if this was a clinic, what did you tell them?" "We said that this is a house, not a clinic" they said. That is, they try to draw some lines regarding these questions. And I think it is important to teach them how to draw these lines and learn how to respond appropriately to avoid misunderstandings.

As far as the indiscretion of the neighbours was concerned, according to Dr. Kastrinakis, head of Klimaka, these problems usually arise within micro-societies. According to Dr. Kastrinakis, there has been a great effort from the staff to make the residents understand that the community care unit is not an institution to start with, but "...a house of 10-

12 people who can live freely and do what they like". Despite the premeditated answers of the residents towards the neighbours, the indiscreet questions did not recede. According to Mrs. Dimitraki, a nurse at the hostel, there should have been a more intensified briefing of the neighbourhood during the community care unit's establishment, to inform all small businesses. She believed that this would have made matters easier:

**R:** The businesses, we need to inform them too...so as not to be afraid and create problems. So we can be safe too, the staff; that we send the resident to the supermarket and the other [the owner] knows us.

This prejudice, except the indiscreet questions, might take the form of a behaviour towards the residents, which connoted repulsion, as if SMI was a contagious disease. An incident like that happened shortly before the interviews in a café. Mr. Sakorafas, a nurse at the hostel, reported:

**R:** A couple of weeks ago, I and the guys [residents] went for a coffee, and the waitress who was there did not want to come close and serve us the glasses of water. She wanted to serve us from a distance and she would look at the residents in a strange way, we understood it too. And the moment we left, the residents said: "we do want to come here again for our coffee". They understand this.

The handling strategy in these cases was - as it happened in the psychogeriatric boarding house - that the residents together with the staff visited specific coffee shops where they were already known. This weekly contact that was eventually established, according to Mrs. Dimitraki, a nurse at the hostel, made the coffee shops recover from the reservations which existed at first, while according to Mr. Sakorafas, a nurse at the hostel, once these coffee shops "know the people [the residents], they take care of them, are interested...there is contact".

It should be reported that in the case of one community care unit of Klimaka - the boarding house Afaia - which was transferred from the island of Aigina to I. Drosopoulou, during the first period of operation in Aigina,

the staff faced severe reactions from the local community. Mr. Alogoskoufis, legal counselor of Klimaka stated:

**R:** The experience there was very intense. In fact, there was fear that the price of land there might be devalued, because of the presence of a boarding house for mentally ill people. The local authorities supported the whole situation, along with the Mayor and other authorities and local business people. They even stationed a refuse collection vehicle in front of the entrance of the boarding house to block access. So if the staff wanted to get in they had to jump over rails in order to do so. They would throw Molotov cocktails in the boarding house's yard. They would gather outside the boarding house all night and they would yell...The police had kept a very low profile along with the Ministry of Health back then. This was very encouraging and it was honorable of him [the Minister]. Then we took interim measures to prevent them [local people] from intervening and distracting. This has helped to defuse the whole situation...

A major reason behind all these intense reactions was the notion of NIMBYism (Not In My Back Yard) (Sibley, 1995). According to Mrs. Koubaraki, the psychologist of Dromokaition, the fear of the property devaluation is prevalent and a serious one in many areas around Greece, especially in the countryside and on the islands. According to her, this requires a great deal of determination from the people who establish of a community care unit in such areas, so as to overcome any resistance. A second reason behind all these intense reactions was the attitude many people share about mentally ill people who are automatically labeled as "bad". Dr. Starlis, a psychiatrist in Dromokation, stated:

**R:** Again it is this picture of a mentally ill person that the community has, unfortunately, which we the experts have created. Talking about dangerous patients, or about dangerous diseases, and by keeping the psychiatric hospitals for so long, we have created the idea that for those patients the only 'normal' way of life is that in the psychiatric hospital. I have numerous violent incidents where the staff had been beaten up when they tried to set up units with a community...there is a great gap between fantasy and reality.

According to Mrs. Koubaraki, the psychologist in Dromokaition - who had extensive experience with patients who got deinstitutionalised from Leros' mental health institution- this fear is beginning to recede when the community comes into contact with the residents and realise that their fears were just imaginary: "They get over these when these people come in contact and see that the imaginary and potential dangers are overturned".

A third reason was purely financial: When the residents became clients to the community's shops and businesses and their revenue was increased, then these initial reservations were overcome. This is very important nowadays with the economic crisis. The resident of a CCU with the imaginary dangerous profile, suddenly gains the dimensions of a real and ordinary person - a consumer. Mrs. Koubaraki explained:

**R:** The patients who go out in the community start to claim their own space and presence. This many times happens on financial terms...by becoming customers to shops in the neighbourhood.

A fourth reason why things finally calmed down was the fact that some locals saw job opportunities in the boarding house for them and their children. This helped the situation a lot according to Mr. Alogoskoufis, legal counselor of Klimaka:

**R:** Later on, the same people who rejected the boarding house in the area, wanted more contact and asked if there were jobs for their children in the boarding house.

Within the course of action, the picture in Aigina changed along with the local community which finally accepted the residents. A few years later, however, the boarding house had to be moved to Athens. The main reason, according to Dr. Kastrinakis, head of Klimaka, was that many staff members had to come and go from Athens daily and that meant "a lot of expenses, human resources and fatigue". It should also be mentioned,

that all three residents of the protected flat still operating in Aigina, mentioned that their contact with the neighbourhood there was “friendly” with no problems. Also when other residents of other units went to Aigina on holidays during the summer, the atmosphere was friendly: “[The community] has moved on...now during our holidays they welcome us”, Dr. Kastinakis stated.

As time passes by, therefore, it is apparent that the communities get accustomed. The first period of a community care unit’s establishment is not always easy and the stigma associated with SMI is still intense. There is a great need for the public to be informed with educational programmes so that obsolete ideas which seem to be rooted deeply within our culture can be overcome.

In conclusion, it appears that the friendly relationships and social networks developed by the residents in the CCUs were more developed than those in the mental health hospitals. Residents also learned to function as members of a team. The degree of freedom was higher than it was in the psychiatric hospital, but was restricted to a degree by the functionality of the resident, his or her motility, and the seriousness of the SMI symptoms, along with the safety of the area around the CCU. The contact with the neighbourhood was greater compared to the hospital, where it was practically non-existent.

Finding asylum in the community though has not been an easy process, especially during the initial phase of operation of certain CCUs. CCUs in smaller areas like Aigina, initially faced serious problems from local communities because of the stigma associated with SMI. The situation has not been easy for residents of CCUs in urban neighbourhoods either: although big cities offer a “blessed anonymity” (Dear and Wolch, 1987; Sibley, 1995), at the same time there have been incidents indicating that the stigma associated with mental illness is still prevalent. As time passes by though, communities seem to get accustomed. There appears to be a contradiction between the notion of

Firstspace and Thirdspace once again: one would expect that because of the smaller scale of units, and the higher degree of freedom and contact with neighbourhood, residents would easily find asylum. The lived experience of residents though indicated that this was hindered in some cases by the lack of safety residents felt in certain dangerous neighbourhoods, along with the stigma from the local communities. Progress though has been made in all cases, indicating that for future residents of CCUs the process of finding asylum in the community could be easier and smoother.



## **Chapter 10: Relationships with the staff, pharmaceutical treatment, religious aspects and notions of “asylum” while in the CCUs**

Chapter 10 explores the relationships of residents with staff, along with issues of pharmaceutical treatment, psychotherapy and religious aspects while in the community care units. These issues were important in order to explore not only how the everyday life of residents has changed in comparison to their previous life in mental health institutions, but also on whether residents managed to find asylum in the CCUs and even came to feel at home while in the units.

### **10.1. Good relationships with the staff while in the CCUs**

The relationships developed between the residents and the staff of Klimaka's units were perceived to be very good by the majority of the residents. Of the entire sample, only one resident claimed that his relationships were not very good; however, it was not due to the way staff members treated him, but because he wanted to go and live on his own. Mr. Voskopoulos (71), a resident of the psychogeriatric boarding house, stated:

**R:** We get along well [with the staff]... However, I want to leave... what I mean is that my relationships with the staff are quite tense. They are hostile, quite hostile. I want to leave and go to Livadia.

The majority of the residents felt that they were helped by the staff's care and interest, and this was helped by the high staff/resident ratio. This facilitated an intensified care to all residents. Mr. Kerkyraios (42), a resident of the psychogeriatric boarding house, stated:

**R:** They are very calm, they are quiet and calm [the relationships with the staff]. In general, I have been helped a lot by the staff.

A similar opinion was held by Mr. Vlastos (77), a resident of the same unit, who felt that the contact with the staff was extremely beneficial to him:

**R:** I feel that I have been helped from... the contact with the doctor, the psychologist, the nurses, [they] bring a sense of serenity and tranquility.

In the other units too, the relationships between the staff and the residents were good and generally speaking this aspect of life was clearly improved in relation to the psychiatric hospital. Mr. Dimoulas (53), a resident of boarding house Afaia, had a positive feeling concerning his relationship with staff. This relationship appeared to be of vital importance for him, since it helped him adjust when he first went to the island of Aigina [this was where the boarding house was first, before transferring to Athens]. He stated:

**R:** It is very nice. I do not have any problems, at all... At first, I was upset with the fact that I had to go to Aigina, at first... [I was worried] about being isolated from the world, who I would meet, who I would hang out with, stuff like that... But once I went there, they embraced me with warmth and benevolence, and I felt like home, that it was my home here... life in the community has helped me a lot, and I have a better time here than in Dromokaition.

The residents of the hostel also seemed satisfied with their relationships with the staff. Mr. Poulakis (47), a resident of the hostel, stated that his relationship with staff was “very good, very good”. What is interesting in Mr. Poulakis’ case is that he had been accustomed to the CCUs’ way of functioning, since his psychiatrist was Dr. Kastrinakis, head of Klimaka. The hostel’s psychologist mentioned that one of the first people who gave her a tour and informed her about Klimaka was Mr. Poulakis and this shows that Klimaka stresses the importance of the residents’ empowerment. Clearly, the psychiatrists of Klimaka felt that Mr

Poulakis could handle the responsibility of showing to new staff members the way Klimaka operates and this shows a shift towards a relationship that values the resident as the “knowledgeable” one.

Finally, all residents of the protected flat in Aigina reported that they were happy with their relationship with the one staff member, either a psychologist or a nurse, who was always with them in the unit. Although their way of living in the protected flat was clearly more independent than the other units, with the residents being in charge of taking care of their space, still the psychologist ensured that they took their medication and organised recreational groups.

All this however, does not mean that every day life was problem-free when it came to both the residents and the staff. An issue which appears in all human relationships is the “chemistry” [as a staff member stated] between people – not everybody gets along with everybody else and some people might like some others more than others. Mr. Leonidopoulos (64), a resident of the psychogeriatric boarding house, stated characteristically:

**R:** I am very careful when it comes to my relationships – I talk about myself – I am very careful with my relationships with the staff. I admit that I am reserved, because each one of us has his/her own personality... and because of that I keep my distances. When I say distances, I do not mean that I do not like it; on the contrary, I have been very satisfied with the services offered here for the last eight years and I respect and love them for that. But I show these in a reserved way. I keep my distances a little, depending on the personality and character of each person that I see and meet.

So in certain cases there was a slight reservation from the residents. According to Mrs Amygdalou, psychologist of the hostel, this reservation from certain residents could be a bit more intense during their first period of adjustment in the CCU, or when a new staff member joined the unit. However, as time passed, residents got used to the staff members, and started communicating more openly.

Clearly, as times passed by, some staff members [in certain cases] had the chance to develop a closer relationship with some of the residents because of the personal element that came into the relationship. Mrs. Makrypoulia, nurse of the psychogeriatric boarding house, stated: "Ok, the relationship with some people is better, with others worse, it is not always the patients to be blamed, there is the issue of [personal] chemistry". Therefore, there are some easy and some difficult relationships with some good and bad moments.

Apart from personal relationships, a second reason that could create certain frictions between residents and staff was the difficulty residents faced in getting used to a way of life with rules in contrast with the relaxed daily routine they had experienced in the psychiatric hospital. Mr. Louloudis (39), a resident of the boarding house Afaia, stated:

- R:** Really good [the contact with the staff]. I like them all. They are very nice people. Apart from one or two, I like all the rest. These two give me trouble and I do not want any kind of relationship with them.
- I:** What kind of problems? What kind of trouble?
- R:** We do not have much freedom. They tell us: Don't do this, don't do that".

The most common source of friction was the number of cigarettes the residents were allowed to smoke. Mrs. Vlichia, general duties staff member of the psychogeriatric boarding house, stated:

- R:** Cigarettes is always the issue, for most of them. If you take the cigarettes away, they react. There is someone who has a serious health problem with his heart and he should not be smoking. But, you say, ok let him smoke a couple.

There was also the daily timetable which gave them trouble too, because they needed to follow a strict and structured programme with certain hours for their bath, their meals, their recreational activities and their coffee. Mrs. Kafetzi, psychologist of the psychogeriatric boarding house, stated:

- R:** The issue with the rules is something that is hard for them in the beginning; even now, sometimes there is a problem because they want to be freer, not that they are not, but for them this sense of freedom is different from what they understand in relation to how they used to have with their regular family and relatives.

Despite these issues that could potentially create some sort of friction, the overall impression one received about the relationship between the residents and the staff members was very good. The residents had the chance to express any of their needs and they knew that their voice would be heard. The 24 hour presence of the staff who worked in shifts, also created a sense of a steady presence since residents knew that even if something happened in the difficult night hours, someone was there for them no matter what. Mrs. Boukala, nurse of the hostel, stated:

- R:** They are never alone. They know that if they wake up at night the nurses are there, for sure, the carers are always by their side, if they wake up from a nightmare, there will be a person to talk, right? I believe that this is a very big thing for them. They feel that their needs are covered, they have been helped to move on and they feel insecure if they are alone.

In conclusion, the relationship of residents with staff members of the CCUs appeared to be good, however residents faced difficulties at first in getting used to a structured daily life with certain rules, in contrast with the relaxed daily life they had experienced in institutions. One cannot exclude the possibility that the residents might have tried to give accounts that would portray themselves as “good residents” through avoiding criticism of the CCUs’ services and staff. Still though, the overall impression indicated improved relationships between residents and staff members, in comparison to those developed in mental health institutions, and most importantly with the absence of abuse incidents.

## **10.2. Pharmaceutical treatment and psychotherapy while in the CCUs: increased awareness and participation to psychotherapy**

The issue of pharmaceutical treatment and psychotherapy appeared to have several differences – but also improvements – in relation to what the residents received in the psychiatric hospital. Almost all residents of the units believed that the pharmaceutical treatment helped them. Moreover, more residents knew the kind of pharmaceutical treatment they received and in fact this number increased as we moved on to more independent living conditions.

In the psychogeriatric boarding house, five residents who had already known what drugs they used to take in the psychiatric hospital, knew in the CCU too. Mr. Papadopoulos (49), a resident of the psychogeriatric boarding house stated about his drug treatment:

**R:** I know what drugs I take. The same I used to take in Dafni. Nothing has changed, because the treatment was good but ...I still take Zyprexa, Lamictal, and B<sub>1</sub>, B<sub>6</sub> and B<sub>12</sub> vitamins. Something like Neurobion. I am also given an Interferon injection once a week, for my nervous system, the multiple sclerosis... It is good [the treatment], it stabilises me. But not only that, the entire supportive system too [is helpful]. That is why I have told you: the doctor gives the treatment but who is going to support you after that? It is the supportive system mainly. And the help from the nurses, the psychologists of course, more or less from everybody.

Two more residents of the psychogeriatric boarding house did not know what drugs they were taking but they recognised their shape. Mrs. Iraklidou (70), for example, knew that she was taking “1 red and 3 in small pieces [pills]”, which she thought helped her. The rest of the residents of the psychogeriatric boarding house who were very old, did not know what they were taking, but they trusted the doctor and were co-operative when it came to treatment. Because of the residents’ old age and their serious health problems there was close monitoring from the staff to ensure that they were indeed taking their drugs. Mrs. Krinou, general duties staff member of the psychogeriatric boarding house, stated:

**R:** I think that [the treatment] helps most of them and they show it. Many times when I give them the drugs I tell them: “Open your mouth to see if you have taken them” and some of them usually say: “Ok, I take them, here you are” and open their mouth. They say: “The drugs help me, that is why the doctor prescribes these to me. That is why we feel well, that is why we feel the way we feel”. They take them and are positive.

In the boarding house Afaia, four out of seven residents did not know what drugs they were taking, but they believed that drugs helped a lot. Mr. Dimoulas (53), a resident of Afaia, stated:

**R:** I don't know them [the drugs] but they help me a lot. I trust the treatment that the doctor has given me and I trust the nurses too.

Out of the seven residents of the boarding house Afaia who took part in the research, three knew what drugs they were taking: two of them knew what drugs they used to take while in the psychiatric hospital, and why they had to take them, while the third one, who knew in the CCU what drugs he was taking, had not known what drugs he was taking while in the psychiatric hospital. The fact that he knew in the CCU the medication he was receiving is a clear improvement in relation to his previous life at the psychiatric hospital. He believed that the treatment helped him a lot. Mr. Louloudis stated:

**R:** Yes, of course [I know the drugs]: Akineton, Largactil, these are the drugs I take... So as to act normally, not to do anything stupid like I used to do: I guess this treatment helps me a lot.

Consequently, three out of the seven residents of the boarding house Afaia knew what pharmaceutical treatment they were receiving.

In the hostel the percentage of residents who knew what drugs they were receiving was even higher. Out of the five residents of the hostel who participated in the research, four residing in the hostel and one living independently under the supervision of the hostel, only one – Mrs.

Bebekou (36) - did not know what drugs she was taking, but believed that the treatment was helping her a lot. The other 4 residents of the hostel knew what drugs they were taking. Two of them - Mrs Aggelopoulou and Mr Poulakis – also had known the treatment they used to receive while in the psychiatric hospital. Interestingly Mr. Poulakis authorised his doctor to give him an electroshock whenever he relapsed, since he believed that this was a better option for him than drugs.

Finally, out of the four residents of the hostel who knew what drugs they were taking, two of them knew unlike the past when they had not in the psychiatric hospital. Mrs. Marouli (62) who lived independently under the hostel's supervision stated:

**R:** Yes, of course [I know what drugs I take] They are called Leponex... 3 pills per day. This is what I take... Only Leponex ... [It helps] I am telling you. I feel a bit sleepy.

Finally, in the protected flat of Aigina, 100% of the residents knew what drugs they were taking every day. Two residents – Mrs. Zachou and Mrs. Vasilikou – had known this since the psychiatric hospital. Mrs. Vasilikou (53), a resident of the protected flat stated:

**R:** I still take one of the drugs I used to take while in the psychiatric hospital and Dr. Kastrinakis has added more... Risperdal, Aloperidin, Milibrat... I do not remember now, but there is another one... Yes [the drugs help me]: I hear voices, and when I take the drugs I feel better, I hear fewer voices.

A third resident of the protected flat, Mr Monachos (53), had not known what drugs he was taking while in the psychiatric hospital but in the CCU he knew in detail:

**R:** [I take] Stilnox 10mgr, Zyprexa 5mgr, 2 pills Ribex, Zantac, and Disipal 50mgr. And Neurobion, the vitamin complex. It helps me [the treatment]. I sleep better, more quietly.



Another thing that was different for the residents of the protected flat was the way they received treatment and its monitoring. Unlike in the psychogeriatric boarding house, where the residents were very old and had many pathological problems and the nurses were the ones who administered the drugs and checked if the residents had swallowed them, in the protected flat the residents were taking their drugs on their own under the psychologist's supervision. Mrs. Zachou, (63) stated about the way the drugs were administered: "The psychologist tells us: 'What drugs do you take?' And we take our drugs on our own".

Overall, in Klimaka's CCUs, four residents (Mr. Louloudis, Mrs. Marouli, Mrs. Olympiou and Mr. Monachos) out of the whole population of the residents with SMI had not known what drugs they were taking while in the psychiatric hospital, but knew in the CCU. Furthermore, three more residents (Mrs. Pappas, Mrs. Iraklidou and Mrs. Ioannou) had not known what kind of treatment they received while in the psychiatric hospital but they knew what kind of drugs they were taking in the CCU, recognising them by their shape. It is apparent, therefore that there was a considerable improvement in understanding about treatment among residents, in relation to the psychiatric hospital. There is still room for improvement so that the percentage could rise. For this to happen, however, certain obstacles must be overcome.

There are two factors that inhibited this percentage of residents with insight about the treatment they received from increasing. The first, according to staff members, was the old age of some residents. Due to this – especially in the psychiatric boarding house – and to the many years they had spent at the psychiatric hospital, communication on this issue was very difficult. According to Mrs Aristaki, head nurse, this justified why the staff strictly controlled the administration of drugs to ensure that the residents took them. However, the younger the residents the easier the communication. That increased the insight in relation to drugs.

The second factor that inhibited the increase of insight of the residents was the denial of some of them that they suffered from SMI. Mrs.

Olympiou (38), a resident of the hostel, is an interesting case because she had spent many years in Theotokos Institution, a place for children with special needs. At some point, she was diagnosed with SMI and had to be transferred to the community care units of Klimaka. At first, she had difficulty accepting the fact that she had to receive treatment for SMI but after a series of extensive discussions with the psychiatrist she came to an understanding:

**R:** Yes, I know what drugs I take, but at first I was upset and cried [and used to say]: ‘why do I take drugs?’ Then I got used to it, I talked with the psychologist, the doctor and they explained the reasons and I finally got over it.

Mrs. Olympiou’s case demonstrates how important it is to educate residents on the issues related to SMI’s nature, the recognition of the symptoms along with treatment of the disease with drugs and psychotherapy (Day et al., 2005). Educating the resident plays a central role in the increase of insight and enables residents to reach a point where they can take their drugs on their own. This principle governs the way Klimaka’s community care units operate. Dr. Kastrinakis, head of Klimaka, stated:

**R:** A very large number of patients [residents] understand the importance of drugs. This understanding has been facilitated due to our own intervention with a number of educational activities, concerning SMI: what is this disease, what is the role of this drug, the role of the external conditions. We offer it [this information] continuously, or we have given it so many times that they understand... The approach was the following: you take this drug so that you will have fewer ideas, fewer audio illusions, so that you can realise all these faster and come and talk to us so that we can modify the treatment... There is great cooperation with the patients [the residents] here.

This comprehension and realisation along with the insight about the pharmaceutical treatment is very important in order for residents to

experience “enhanced autonomy” (Lim, 2002). This in turn can facilitate them to make a successful transition to more independent living conditions either in the protected flat or living alone outside the unit.

Another positive feature of Klimaka’s way of operation, according to staff members, was the significant monitoring of the residents from the staff [both doctors and nurses] and the cooperation between the staff and the residents. The result of this was that the physician could understand better what the resident experiences. Mr. Lyritzis, psychologist, explained:

**R:** Many times when they do not feel well, the residents themselves will come and talk to us about their drugs and this helps us modify the pharmaceutical treatment. Then we can immediately intervene. We are not the type of boarding house that the psychiatrist visits once a week... We have psychiatrists here from 9.00 o’clock in the morning to 12.00 o’clock at night every day. So there is immediate access to a psychiatrist, truly immediate.

This close monitoring of the residents facilitated immediate treatment of possible relapses, which could happen to the residents. This was something that the residents themselves realised, so they would inform the psychiatrist or the psychologist in order for immediate modification in pharmaceutical treatment to take place. Mr. Leonidopoulos (64), a resident of the psychiatric boarding house, is a characteristic example. He relapsed from time to time when he remembered an old incident during which he blamed himself:

**R:** Look: There is a possibility of relapsing... when we relapse, we reach a point where we say enough is enough, I cannot take it anymore, I utter these words to the psychologist. Then the psychologist alerts the psychiatrist and he comes down with the head nurse and changes the medication. This helps, this helps a lot.

Furthermore, each member of Klimaka’s staff functioned as a “reference person” for 1 or 2 residents. He/she was responsible for recording their progress within the CCUs and whether he/she had

achieved the specific goals set by the therapeutic team. Mrs. Vlichá, general duties staff member of the psychogeriatric boarding house explained:

- R:** There are 'reference persons' who are responsible for certain people [residents]. I am responsible for two women [residents]. I am responsible for the programme assigned for them: it is called the upgrading programme. It sets goals and every time we set a new goal which improves their functionality. Every six months a meeting takes place and we talk about these specific people [residents].

Finally, another parameter that helped the residents greatly and was an integral part in their treatment was psychotherapy. As mentioned in chapter 6, for the elderly residents there had been no psychotherapeutic approach while in the psychiatric hospital. On the other hand – according to one of Klimáka's psychologists, with many years of experience in working at public psychiatric institutions - the younger residents, while in hospital, went through a lot of discomfort due to the great number of "psychotherapists" who had neither the knowledge nor the specialisation to use psychotherapy per se. The environment of the hospital also played a negative role in the sense that it deprived the residents of any notion of perspective. In the CCUs, however, the framework was such that the residents knew that they could visit a psychologist at any given moment and discuss anything that bothered them, when they needed it, without feeling that they were obliged to do so. Mr. Lyritzis, psychologist of the psychogeriatric boarding house stated:

- R:** When they [the residents] are in a state of intense stress, you can see that they ask for it. You know, I do not believe that someone who has been a patient for 50 or 30 years does him/her any good to undergo psychotherapy for the 68<sup>th</sup> time, let's say with a different therapist, because he/she has seen so many, right? Ultimately, it cannot be therapeutic; on the contrary, it can prove very traumatic to such a point that it resurfaces traumatic experiences. What I am interested in is for the residents to be able to have an emotional and immediate relationship with us, so we can discuss anything at

any given moment... on a human level, outside the formal role of the therapist and the patient [the resident].

Consequently, psychotherapy in the CCUs was taking place on a more relaxed basis, where residents who were preoccupied with something could talk about it. Mr. Poulakis, a 47-year-old resident of the hostel stated: "I will see the psychologist here when I have a problem. I will ask to see her. The system is more autonomous here. I am more autonomous".

What was also interesting was that the main goal of psychotherapy in the CCUs was to help and educate residents on how to deal with daily issues rather than setting long-term goals. The daily issues were vitally important for the residents who needed to adjust to the new circumstances within the community. Mr. Dimoulas (53), a resident of the boarding house Afaia, stated:

**R:** It helps us [the psychotherapy] to deal with the things the way they are. She tells us [the psychologist] what we need to do, how to be careful in the streets when we walk, stuff like that. How to be careful in general and how to adjust in the community and the society. Psychotherapy helps a lot.

This type of psychotherapeutic approach had a counseling nature and aimed to help the residents with daily issues instead of long-term ones. Mrs. Dimitraki, nurse of the hostel, explained:

**R:** Psychotherapy...they [the residents] do not do psychotherapy the way I or you do...in the sense that we ask for it and we would go to a psychologist or a psychotherapist. It is part of the unit. Mainly it takes the form of a discussion about daily issues. This is the framework... We offer counseling here and supportive psychotherapy. In other words, when they [the residents] do not feel well, or are afraid of something we discuss it [and ask:] 'why do you feel like this?' something like that. It is more of a supportive process.

In conclusion, it is apparent from the results that issues concerning pharmaceutical treatment and psychotherapy were clearly improved in

relation to the psychiatric hospital. The residents' insight and understanding of the systematic administration of pharmaceutical treatment and participation in psychotherapy were increased in most cases.

### **10.3. Religious aspects and therapeutic value of spirituality**

For some residents practicing their religious rights appeared to have a great therapeutic value. Klimaka's general policy on religious issues and practices was that every resident was free to go to any religious place he/she felt good about, depending on his/her religious denomination.

From each unit, 1-2 people per unit wanted to go to church systematically, while the rest were more relaxed. Those residents who did not face mobility problems and could move around alone in the busy streets of Athens, went to church alone and as often as they wanted. This activity helped them a lot and gave them a psychological boost. Mr. Monachos (53), a resident of the protected flat in Aigina, stated: "Yes, I go [to church]. Especially at Easter, we go every day. It boosts me psychologically. I believe in God". A similar experience is that of Mr. Dimoulas (53), a resident of the hostel Afaia who could go to church any time he felt like doing so:

**R:** There is a church close by... anyone can go, he/she can light a candle, worship God... yes, I like it, yes. It is mentally soothing.

Finally, there was a special case of a resident who wanted to exercise his religious duties systematically. Mr. Leonidopoulos, (64) kept going to a church-society of a different Christian denomination - that of Protestantism - where he used to go to before coming to the CCU too. Since Klimaka felt that there should be freedom in exercising one's religious duties regardless of religion or denomination and with complete respect to the religious minorities, he could go to church anytime he felt like. He went twice per week, on Wednesday evening and on Sunday

morning, and believed that this kind of participation and religiosity boosted him a lot:

**R:** I go twice per week, on Wednesday and Sunday. It helps me a lot. I pray and I feel relieved, it soothes the pain, the thoughts are gone and in this way, I avoid relapses. It somehow organises my thoughts. This contact helps me a lot. The doctor can see that too, that is why he lets me go. That is why I go with so much joy every Wednesday and Sunday.

#### **10.4. Community Care Units offering temporary and permanent asylum**

In this section the notion of CCUs offering “asylum” is being explored. Findings suggest that the majority of residents of all four units of Klimaka felt safe and protected, and seemed to have found “asylum” in the CCUs. A parameter that appears to be different in relation to their previous life in institutions is that a fairly big percentage of the residents felt at home in the CCUs. As a result, CCUs appear to offer an “asylum” more permanent in nature than mental health institutions did.

##### **10.4.1. Notion of “asylum”: feeling safe and protected while in the CCU**

The majority of residents of all four units of Klimaka felt safe and protected. Only one resident of the psychogeriatric boarding house, claimed that he did not feel “that safe”, since from time to time some of the residents and the staff members seemed a little “wild”. The rest of the residents felt really safe and protected in the CCU. The answer that Mr. Leonidopoulos (64), a resident of the psychogeriatric boarding house, offered was a typical one: “I feel very safe, a lot”. Mrs. Olympiou (38), a resident of the hostel, felt the same:

**R:** Of course, yes, [I feel safe and protected]. If I were out, I would be in danger.

One reason why residents felt safe and protected is that, unlike in the impersonal institution, they found themselves in a small scale place where all their basic needs – food, water, heating and treatment - were covered. So, the residents felt that their quality of life greatly improved. Mr. Barbarigos (43), a resident of the psychogeriatric boarding house, stated:

**R:** Look, here we have heating, air-condition in our rooms when there is a heat wave in the summer, things I did not have in my place. I have no problem.

The second reason that made residents feel that they found “shelter” in the CCU was that there was a high staff/resident ratio in the CCU. Consequently, there was a lot of care and attention, things that they had not have in the psychiatric hospital and they would definitely not get if they were at home. Mr. Papadopoulos (49), a resident of the psychogeriatric boarding house, explained:

**R:** [I feel] very safe and protected. Otherwise, where would I go, who would take me? My brother has a wife and children; he could not take care of me. His children are small, that is why. Here I feel protection and safety.

Because of this high staff/resident ratio, the residents were never alone, literally speaking. The presence of staff and of the other residents made them feel that they lived within a group of people without feeling lonely. So, they knew that there was always someone in CCU who they could talk to. Mr. Poulakis (47), a resident of the hostel, explained:

**R:** Being with a company here in the hostel makes things better, because I was alone at home. So it feels good to be with other people and not alone in the evening.

Likewise, Mr. Dorakos (52), a resident of the hostel Afaia, felt that it was important to be around people all the time because he did not like loneliness. He explained:

**R:** Mrs. Dorothy, I cannot live alone; if I am alone all day,



thoughts keep coming... [I want to be] with the folks, with a group of people who I can talk with, so I won't be alone, because I cannot.

Lastly, according to staff members, a third reason why residents felt safe and protected was that their transition from the psychiatric hospital to the CCU was done in a smooth way. They found themselves in a quite environment and felt welcome. This made a positive impression on them and helped the whole situation. Mr Lyritzis, psychologist of the psychogeriatric boarding house, explained:

**R:** We did the best we could to achieve a smooth transition. It is important for us to welcome these people, for many reasons: one is our dignity and the fact that if a resident relapses then we would be in trouble.

For all these reasons, almost all residents felt safe and protected and seemed to have found “asylum” in the CCUs.

#### **10.4.2. Where did participants feel at home while in the CCUs**

A very interesting parameter that appears to be different in relation to the residents' previous life is that a fairly big percentage of the residents felt at home in the CCU. Nineteen residents of the total sample of the participants felt at home in the CCU. Two subcategories can be found within this population: 12 residents felt that the CCU was their permanent residence while 7 of them their temporary one, a transitional stage before moving on to a more autonomous living conditions.

Those 12 residents who felt that the CCU was their home, were accustomed to it completely and besides feeling safe and protected, they also experienced a sense of belonging. The majority of those cases were residents who had been away from home for many years so even if their family home still existed they came to recognise the CCU as the place where they belonged to. Mr. Kerkyraios (42), a resident of the psychogeriatric boarding house, stated characteristically:

**R:** My home is right here. I have been away from Lefkada for many years. I don't consider Lefkada my home anymore. I'd rather have Klimaka as my home.

In several cases, the residents' family house no longer existed after their parents' death. Mr. Dimoulas (53), a resident of the boarding house Afaia, stated characteristically:

**R:** My home ... [is] here. My home is in Klimaka. I have no other place to go, my home is here... It's much easier [life in the CCU] because I see it in a nice way. I feel that everything is OK. I would not like any changes. We are fine the way we are. It is fine.

Mr. Stonakis (30), a resident of the boarding house Afaia, who had not seen his parents for more than a decade, felt the same: "I haven't seen my parents for a decade. My family home is in Egaleo. Later on, we moved somewhere else. My home is here now". In the case of Mr. Kouroupis (50), resident of the boarding house Afaia, there was no recollection of "home" since, before his admission to the psychiatric hospital, he had been homeless. He stated:

**R:** [My home is] here, in this boarding house... I didn't have, I didn't have [a family home]... [I lived] nowhere... Everything is nice in the boarding house. I find [life in the CCU] better. Better than life in the hospital, where I was always inside.

In several cases, along with the parents' home the main supportive network of the residents – their parents – had ceased to exist too. Therefore, even if they could visit their siblings' home on a few-day leave, this could, in no way, substitute their parents' home. Mr. Louloudis (39), a resident of Afaia, explained:

**R:** My home is here now. I have no other place... My brother cannot put me up because I have to take drugs, to see my psychologists and stuff like that, and because he works long hours, he cannot. He just comes and sees me and he takes me...once a week. He comes and takes me, I sleep over [to his place] and he brings me back the next morning. He has a

dog and a cat, which are very quiet, that is a very nice past-time.

Some residents could not stand the loneliness of independent living and they wanted to live within a group of people and enjoyed the staff's care and attention along with the company of the other residents. A characteristic case was that of Mr. Dorakos (52), a resident of the boarding house Afaia. He explained:

**R:** I have some thoughts: "If I won a lot of money, would I leave this place, yes, or no? But then again I say to myself: "stay where you are." Dr. Kastrinakis tells me to stay. Because I cannot live alone... I don't have a place now, I am not at home now, I don't have a place because since my mother died I haven't been able to live alone... [the CCU] I feel it like home because it is a place where you live with the nurses, the folks, I communicate, well with the folks, we talk, chat, go out, go to the cinema, the theatre.

This sense of companionship [from the staff and the rest of the residents] was exceptionally relieving for some residents, since they felt that they had a company all the time, and they felt safe within this group. The CCU might not be their chosen home but a home out of necessity, however, it still gave them a sense of belonging.

Another very important factor that contributed to the sense of security and belonging was the all the residents' vital needs – accommodation, food, central heating, clothes – were totally covered, and this made them feel very comfortable and free of any concerns or worries about their life, as it became clear in the previous section.

Within the group of residents who feel CCU as home 7 residents considered it as a temporary home or solution, a kind of transitional stage before moving on to a more autonomous way of living. For some of them, however, especially those who were older, the prospect of moving on to more autonomous living conditions was most probably difficult. Mrs. Chrysalis (67), a resident of the psychogeriatric boarding house, stated: "This is my place here...I want them to give me money, to rent a flat". This

was probably difficult, since her little pension money was not enough for renting a place. Similarly, Mrs. Colliou (74), resident of the psychogeriatric boarding house thought she had two places: the CCU and her old one in Peiraias:

**R:** I live now here, but I have my own place in Evangelistria. My home is there, in Evangelistria.

Since, however, there is no supportive network to take care of her, it is very difficult for her to move on to autonomous living conditions.

According to Mrs. Kafetzi, psychologist of the psychogeriatric boarding house, some residents did not really realise the exact reason why they were in the CCU, and they thought that a transition to a more autonomous way of living was feasible:

**R:** Two people [residents] say so [that they will go to their own place]... they don't understand [however] why they are in the boarding house, so they think that they can save money and go and live somewhere else alone.

Mr. Lyritzis, psychologist of the psychogeriatric boarding house felt the same:

**R:** I believe the specific resident, who feels this way, has complete lack of insightfulness, to tell you the truth: 'I have nothing, I was just evicted, that's it, so when can I leave? I have nothing. I am ok'. She has, however, unfortunately she has.

Within this subpopulation there were some younger residents who kept the hope of a more autonomous way of living. Mr. Louloudis (39), a resident of the boarding house Afaia, would like to move on to a more autonomous way of living, since he felt better in relation to the past:

**R:** I believe that Klimaka loves us all, this unit, and it would be nice at some point for me to be able to stand on my feet and leave this place because I cannot live here for the rest of my

life, in a unit in the community because I cause problems: because there might someone else who wants to come here who is in greater need than me, especially now that I am much better and I am in a nice phase, I sketch more and more even better than in the past....this, in other words, I would like to be able at some point to live alone and lead a more autonomous life.

Finally, in the sample of the residents which took part in the research a population of 9 residents still believed that their former house was their home. Mr. Kalos (54), a resident of the psychogeriatric boarding house, for example, felt that his home was still in Metamorfoosi, where his parents' house was: "In Metamorfoosi I would say [it is my home] but this is not the case because I am hospitalised here... I feel my parents' house as my home." Likewise, Mrs. Kostaki (72), a resident of the psychogeriatric boarding house, felt her parents' house as her home, although she had not visited it for more than a decade.

The reasons why some of the residents felt their old place as "home" were the following: The first reason was that they missed their own people, their relatives, and so "home" was where their own people lived. This element was evident in what residents said and in some cases, it was very intense. Mrs. Karamouza (52), resident of the boarding house Afaia, considered that her home was "in Nireos Street, in Paleo Faliro", since this was where her husband and her 29-year-old daughter lived, who visited her in the CCU very often. Similarly, Mrs. Bebekou (36), a resident of hostel, who, although she had not seen her husband and her 12-year-old daughter for some years, still wanted to leave the hostel and return home where her husband and her child were, which she still considered her home:

**R:** My home is there: Papdiamandopoulou 136, because my home is there where my child with my husband are... I want things to change, I want to change, I don't want to be in the hostel anymore, I want to go home too, some day: to go to my little child, to my man there... I have a small daughter, 12-year-old, she is there.

The second reason why some residents considered their old house as their home was that they missed the sense of freedom of their previous life. Mr. Vlastos (77), a resident of the psychogeriatric boarding house, for example, felt that although his life in the CCU was much easier than in the psychiatric hospital, he still felt restricted in the CCU since he had to go out accompanied by the staff, due to his alcoholic psychosis he suffered from:

**R:** It is easier here [in the CCU], more gently, life is easier from there [the psychiatric hospital], much easier... I feel that my home is in my village, in Kerkyra... [Here it is] like being in prison... Life is easier here [in the CCU], but a person's freedom is the ultimate commodity. I do not have it here completely, one next to the other 24 hours per day, you cannot go anywhere and be alone, alone to listen to a couple of people who have a rational discussion, without talking to them necessarily, without knowing them, but to have a coffee and listen to two people, nice and to a rational discussion.

According to Mr. Lyritzis, psychologist of the psychogeriatric boarding house, while some residents felt that the CCU was their home, there were some who preferred a totally independent and normal life in the community:

**R:** Yes, I believe that this has registered as their home, but at the same time, I believe that they would prefer a better place. They would prefer they were not patients [residents]. They would prefer to have their own family... I am sure that some of them know what they miss.

Being able to move to a more autonomous way of living is not easy, especially for the elderly residents. According to staff members, two major problems are the lack of possibility for continuous pharmaceutical and psychological cover unhindered in independent living conditions, along with the deficit of financial funds. If these two factors were covered, 1-2 of the younger residents would most probably move. Mrs. Vlichas, general duties staff member, explained the essential prerequisites for the

continuation of the pharmaceutical treatment in the community, when a resident is transferred in the community:

**R:** The objective is someday some people [residents] would be able to move to a more independent living unit in the community. You know what, however? The problem is that we are concerned about the drugs, whether they would forget to take them, or continue their treatment. Because there won't be anyone to supervise them and remind them 'take your drugs'. If this issue were solved, and they took their drugs then a couple of residents, the younger ones, would be able to move in the long run. The rest, however, no. They are in need of constant care.

Another serious reason is the financial one, which needs to be taken care of before a resident moves to complete independent living conditions. Amidst the dramatic economic crisis we experience, this issue is far from being resolved. So, one resident who moves on to independent living conditions, unless he/she has a high salary, pension or/and property from his/her family, she/he will find it very difficult to get by. Mr. Makedonas, nurse of the hostel, explained:

**R:** When you have lived in a unit and don't have to pay electricity, water and all of sudden you go out there and you have to pay about everything you need money. They don't have to think about these things here. It is another thing when everything in this building is paid and is another thing when you go out.

What must be mentioned here is that if these two conditions – systematic administration of pharmaceutical treatment and an economic status that can cover the basic living conditions – were fulfilled, then the transition to independent living conditions may be feasible. This happened with Mrs. Marouli (62), who after having lived in 2 Klimaka units, at the time of the interview was living alone in her own flat while working as a secretary in the headquarters of Klimaka. The fact that Mrs. Marouli had her own flat was important, along with the fact that she had a very good

pension and did realise the importance of taking her drugs systematically. She described how she spent her time, while living independently:

**R:** My flat is in Marousi... [It is] great, fantastic. I have no problem. I take my drugs too as my doctor has told me: I cut them in half and I swallow them, 4 in the evening and 1 in the morning and I am ok, very well. Knock on wood, just fine... Very beneficial [was] the change. Since 2008, 19 September 2008 [she laughs]... Yes, it couldn't have been better, very well...

It appears that all residents of the CCUs in this research felt that they found "asylum" in the community. Some even considered the CCU as their home, whereas others wished to return at some point to their parental home or move to independent living. For all residents however getting transferred from the mental health hospital to CCU signaled a new beginning. Mrs. Aggelopoulou's comments, resident of the hostel, are characteristic:

**R:** I am not 10, I am 4 [years old].

**I:** Do you feel 4?

**R:** No, I am. I stayed in Dromokaition for 5 years, I died in there, that is why they took me out... I feel that I was born again. A new life [began], first in the old hostel and then here.

In conclusion, the relationship of residents with staff members appeared to be good, however residents faced difficulties at first in getting used to a structured daily life with certain rules, in contrast with the relaxed daily life they had experienced in institutions. This shows that the notion of Thirdspace is not always in accordance with the notion of Firstspace: although the living conditions in the CCUs were clearly improved in relation to hospitals, residents did feel pressured at first. Issues concerning pharmaceutical treatment and psychotherapy were clearly improved in relation to hospital: the residents' insight and understanding of systematic administration of drugs and participation to psychotherapy



were increased in most cases. The majority of residents felt safe and protected and seemed to have found “asylum” in the CCUs. Some even considered the units as their home, whereas others considered it as a temporary home, a transitional stage before moving to a more autonomous way of living. Some however still believed that their former house was still their home.

# DISCUSSION

## Chapter 11: Discussion of results

### 11.1. Introduction

This chapter draws together some of the cross-cutting themes that have emerged from residents' experiences of deinstitutionalisation from mental health hospitals to community care units. Firstly, the chapter considers recommendations for mental health practice in Greece, based on differential experiences of the notion of "asylum", both in institutions and in CCUs. The chapter further addresses conceptual issues discussed in Chapter 3, in order to consider how ideas of "asylum" and Thirdspace might facilitate an understanding of the deinstitutionalisation experience. The chapter also considers recommendations for the practice of deinstitutionalisation in Greece, by designating those factors that facilitate a "successful deinstitutionalisation" and those that contribute to an "unsuccessful deinstitutionalisation". Finally, the chapter considers recommendations for future mental health policy implementation in Greece, before concluding with some of the constraints of this study and how these can be addressed in future research not only in the Greek context, but in other countries as well.

### 11.2. Recommendations for mental health practice in Greece: Differential experiences of the notion of "asylum"

#### A. Mental health institutions offering temporary asylum

As it has already been stated in Chapter 1, the notion of "asylum" entails one's sense of feeling safe and protected. Judging by the problems that public mental health institutions face in Greece, with old and neglected buildings, skeleton staff and difficult living conditions, and based on the descriptions of CCUs staff members about life in mental health hospitals, it would only be natural to assume that residents in this research

sample did not easily find asylum in mental health hospitals during their years of hospitalisation.

That which is impressive is that when the question was raised with the participants themselves, there were only six residents who responded that they did not feel safe and protected during the course of their therapy. Those who responded in this manner were mostly afraid of other patients in the same ward and were overwhelmed with anxiety that they may be attacked. Their fear had to do with the fact that their physical wellbeing was being threatened and also with the possibility that someone in the ward would steal their personal belongings.

Interestingly, the majority of residents felt that they did find an “asylum” in the institution. There appears to be a great difference between residents’ accounts and staff members’ comments and this could be due to the following reasons: 1) selective memory from residents, partly due to the retrospective nature of their description of the period they were in institutions, which tends to neutralise negative experiences (Baddeley et al, 2009); 2) residents giving accounts in such a way as to portray themselves as “good patients” through avoiding criticism of the mental health institutions services and staff; 3) overemphasising of negative features of mental health institutions by CCUs’ staff, in order to stress the difference between the two settings; 4) overemphasising by CCUs’ staff members of the brutality of the institutions in order to portray themselves as compassionate and caring and the residents as vulnerable people in need of their care and support.

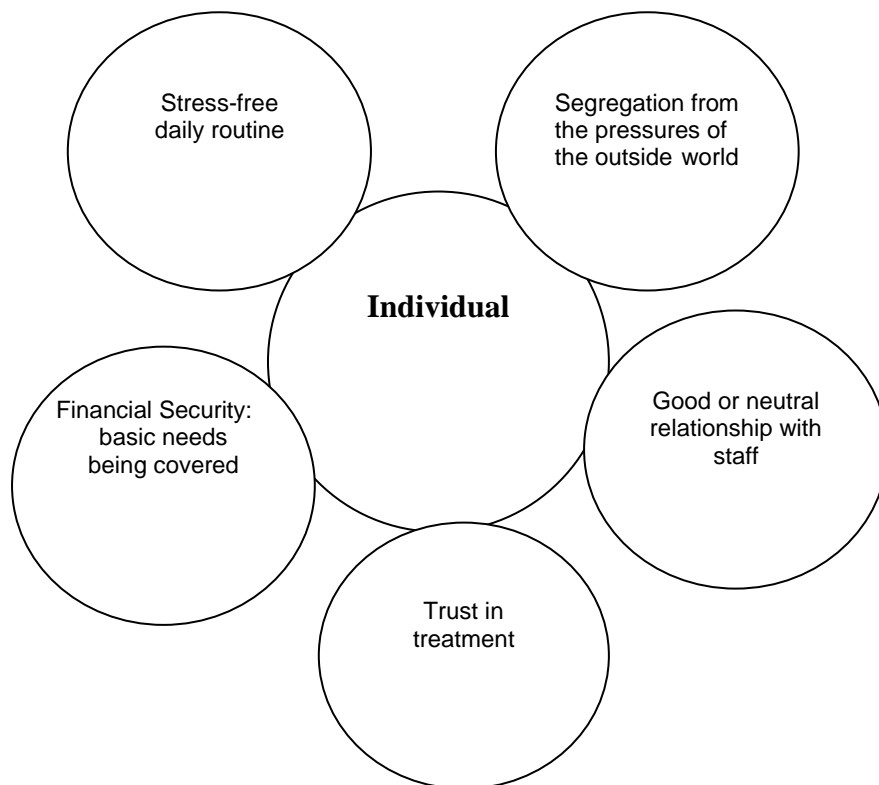
However, the striking difference in perception supports that the notion of Thirdspace – the lived experience of residents – can be very different from the perception of either visitors or staff members. It appears that the physical fabric of the institution – the Firstspace – is of far less importance for residents than the notion of Thirdspace, meaning their own lived experience.

As a result, the majority of residents in this research sample felt rather safe and protected while in mental health hospitals, and believed

that institutions provided to them a “temporary asylum”. Still, however safe and protected they felt, they never felt that the mental health hospital had become their actual home.

The notion of temporary asylum that residents experienced in mental health institutions mainly revolved around five axes:

**Figure 1: Notion of temporary asylum provided by institutions**



**1) Financial security:**

The notion of “asylum” appears to be that of a place offering shelter and protection, covering all basic needs of residents while in mental health institutions, including food, housing, heat and clothes.

In the majority of cases, the residents had neither a pension nor any kind of benefit when they were committed to the psychiatric hospital. The positive thing however - as far as their finances are concerned - was that when they were committed to the psychiatric hospital the social services

were mobilised so that they would receive a pension. For the majority of residents, while the procedure for the issue of a pension or a welfare benefit had already been initiated, a long time passed before they could receive the money. In most cases they would receive it long after they had been transferred to community care units. Therefore, during their hospitalisation in the psychiatric hospital, what would usually happen was that their expenses would be covered by the family. In many cases, this money would be enough to cover the residents' needs inside the psychiatric hospital.

Within the sample of residents that took part in this research there were however some residents who felt that the money brought by their parents (or their pension) in the hospital was inadequate. This could be attributed to 3 reasons: a) the dire financial situation that the family of the resident might have been in, b) the lack of management skills of the resident and c) thefts that have been reported to have taken place within the psychiatric hospital. However, with all their basic needs being covered, most residents while in mental health hospitals felt that did not have the same pressuring financial problems that they experienced in the outside world.

## **2) Stress-free daily routine:**

In this research study, a large group of residents mainly enjoyed the leisure activities and social character of the hospital. These residents described a rather monotonous repetitious everyday schedule, with little participation in any occupational therapy programmes. What they seemed to enjoy the most was the social character of the hospital. Most of all, it was the daily activity of going to the hospital's coffee shop, that residents did not want to miss, not even for a single day.

What is very interesting in this group is that most of them did not mention the hospital's everyday life schedule in a negative way, but rather as a daily routine to which they had become accustomed. Though studies on life in mental health institution often describe psychiatric hospitalisation

as a negative, demoralising and in some cases dehumanising experience (Goffman, 1961; Rosenhan, 1973), as the residents from this group have demonstrated, there are also some positive aspects of life in the hospital. A very interesting point is that most residents in this group actually *enjoyed* and *liked* this relaxing everyday life, with not so many stimuli, constituting a stress-free daily routine that did not put any pressure on to them. For these residents the hospital provided a place where they found reasonable comfort and an undemanding life with dignity.

For a second group of residents, participation in occupational therapy was something that they did enjoy, however they wanted to do this from time to time, without undertaking commitments on a daily basis or the obligations of a more stable form of work.

### **3) Segregation from the pressures of the outside world:**

From staff members' and residents' descriptions it seems that residents were used to the specific environment that mental health institutions offered. Despite the fact that most hospitals' buildings were rather old, they were built in very large green areas with a number of places within the hospitals' grounds that residents could visit. Mental health institutions offer outdoor spaces and areas to walk in quiet, green environments, and these may act in many cases as therapeutic landscapes (Gesler, 1996). This secluded and peaceful environment appeared to have a dimension of therapeutic landscape to residents. As a result, a novel dimension for the term "asylum" is that of segregation from the pressures of the outside world in a peaceful environment, which offered the opportunity to residents [while in mental health institutions] to follow their own schedule, without being bothered or pressured to work or to participate in any activities they did not wish to.

### **4) Good or neutral relationship with staff:**

Several residents and especially those who have been recently institutionalised usually mentioned that they had good or neutral

relationships with the psychiatric clinic's staff without much elaboration. In some cases, the residents reported that they perceived the relationship with staff as very good and this had helped them to realise the need to stay in the psychiatric hospital and the need for treatment. These kinds of relationships were not rare, but at the same time they were not easy to develop within the asylum environment of the psychiatric hospital. When and if these developed, however, it was a factor that helped the residents.

All this of course does not mean that things were always smooth and easy between residents and staff members of institutions. In a few cases, residents mentioned that they were constrained in certain occasions, because of their aggressive behaviour. This could be attributed to the lack of staff, training, institutionalisation of staff, burn out, and controlling relationships that are developed within the asylum between staff and patients.

What is striking though again, is the difference between residents' accounts and CCUs' staff members' perception: according to staff members of Klimaka, some residents in hospital were so neglected and so deprived of any human contact that they were completely withdrawn and silent. According to Klimaka's staff members, the indifference of hospital's staff both towards the residents' reactions and the proper administration of their medicine also had an impact on the course of their treatment.

It is very important to emphasise that these derogatory comments about mental health hospitals were only made by Klimaka's staff members and not by residents themselves. This once again shows the great difference between the notion of Firstspace – the physical dimension of a place, Secondspace, i.e. the relationships developed in a space, with the notion of Thirdspace, which is the lived experience of residents.

#### **5) Trust in treatment:**

About two thirds of the thirty residents who participated in this study, did not know what kind of pharmaceutical treatment they were receiving while in mental health institutions, although in most cases they believed

that the pharmaceutical treatment was helpful for them and they had faith in the prescribing process by the hospital's psychiatrist. Although some of them did not know the names of the drugs they were receiving while in hospital or the active substance they contained, at the same time they recognised the drugs of their everyday treatment from the morphology of the pills they were getting.

It seems from residents' comments that although they had faith in the prescription of the doctor, at the same time they themselves did not have any particular say in the configuration and shaping of the pharmaceutical treatment that was ordered for them.

About one third of the residents who participated in this study were *fully aware* of the drugs they were receiving while in hospital. What is impressive is that again most did not know *why* they were receiving those drugs as far as SMI is concerned, and they could not influence the changes that were happening to their treatment or the prescription process in any way. Still though, they had faith in the prescribing process.

Lastly, it should be mentioned that only a small number of residents ever received psychotherapy while in mental health institutions, but for those who did it was beneficial to them.

## **B. Community Care Units offering temporary and permanent asylum**

The majority of residents of all four units of Klimaka felt safe and protected, and seemed to have found "asylum" in the CCUs, with all the basic parameters of their life being improved. A very interesting parameter that appears to be different in relation to the residents' previous life in mental health institutions is that a fairly big percentage of the residents – nineteen of thirty residents - felt at home in the CCUs. Two subcategories can be found within this population: 12 residents felt that the CCU was their permanent residence, while for 7 of them it was their temporary one, a transitional stage before moving on to more autonomous living conditions. Some however still believed that their former house was still



their home. As a result, CCUs appear to offer an “asylum” more permanent in nature than mental health institutions did.

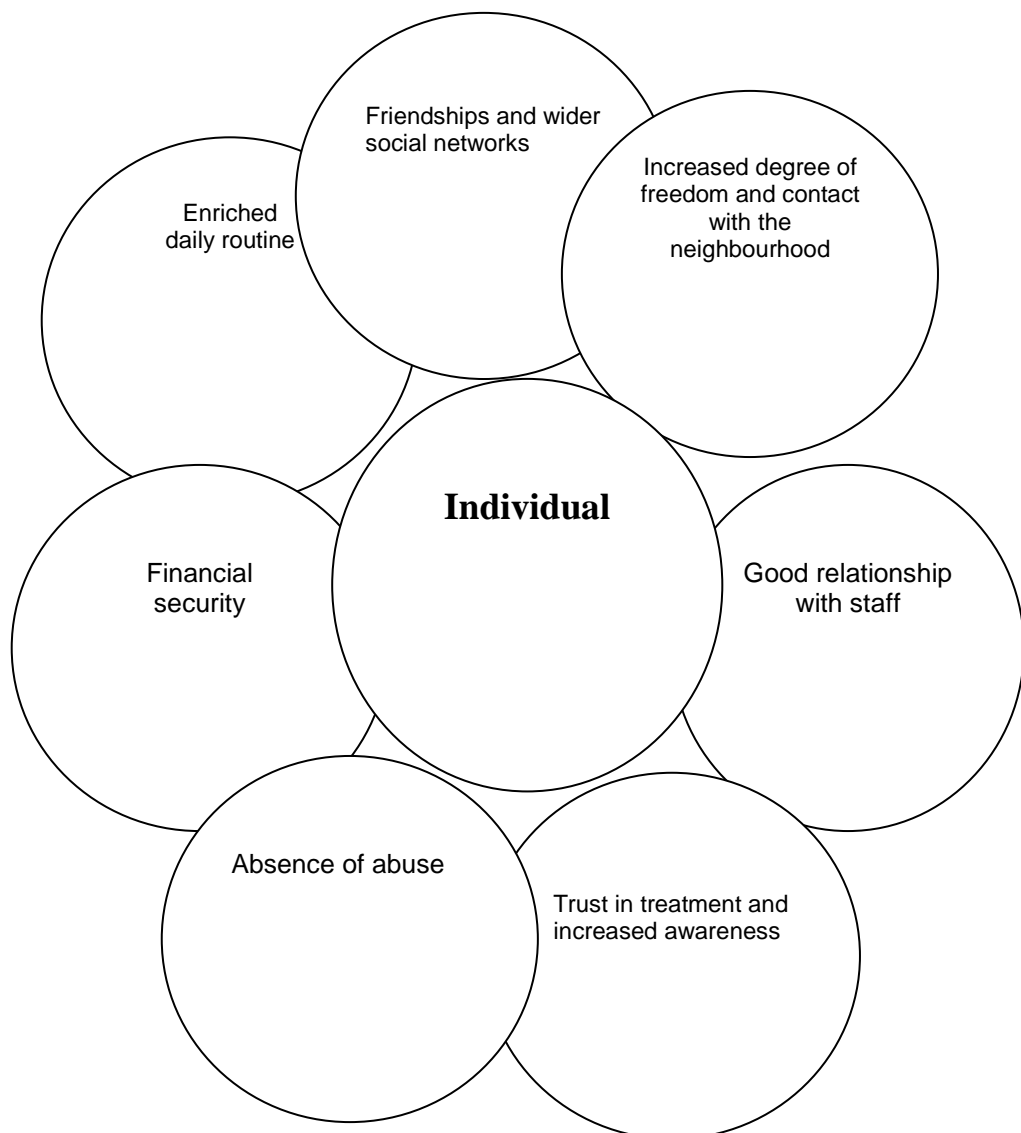
What is again impressive though is the difference between the notion of Firstspace and Thirdspace: one would assume that since residents got transferred to community care units with considerably better living conditions than mental health institutions, the transition would automatically be easy and smooth. The lived experience however of residents shows that the transition had some difficulties for them. What many residents of Klimaka's CCUs found difficult at first, was to adjust to an organised daily programme which had certain rules, and this relates not only to taking care of their personal hygiene, but also helping with the daily chores, and living a daily life with considerably more stimuli than in mental health institutions. After an initial period of adjustment however, residents got used to their new daily programme and became more active. This helped the residents to start taking care of themselves with the aim of becoming as autonomous and self-sufficient as possible. This could potentially help them, especially the younger residents to eventually move on to totally autonomous living conditions.

There appears to be a contradiction between the notion of Firstspace and Thirdspace for two more reasons as well: one would expect that because of the smaller scale of units, and the higher degree of freedom and contact with the neighbourhood, residents would easily find asylum in the CCUs. The lived experience of residents though indicates that this was hindered in some cases by the lack of safety residents felt in certain dangerous neighbourhoods, along with the stigma from the local communities. CCUs in smaller areas such as the island of Aigina, initially faced serious problems. The situation was not easy for residents of CCUs in urban neighbourhoods either: although big cities offered a “blessed anonymity”, at the same time there had been incidents indicating that the stigma associated with mental illness is still prevalent. Progress though has been made in all cases, indicating that for future residents of

CCUs the process of finding asylum in the community could be easier and smoother.

Besides these difficulties, in most cases residents of all four units of Klimaka managed to find asylum in the community, and this notion of asylum revolved around seven axes:

**Figure 2: Notion of temporary and permanent asylum provided by CCUs**



### **1) Financial security:**

One reason why residents felt safe and protected is that they found themselves in a small scale place where all their basic needs – food, water, heating and treatment - were covered. Also, because of the better living conditions that the CCUs offered comparing to the impersonal mental health institutions, the residents felt that their quality of life greatly improved.

A very pleasant fact which shows that there had been considerable improvement during the period of time when residents were transferred to the community care units is that they were able to receive their pension from the Greek Social Security Organisations or other benefits from the Social Welfare. Two residents had an extra income apart from their money they received from the State, through some form of work.

Since all the basic needs were covered by Klimaka, the money residents had went for their personal basic expenses such as buying cigarettes, going out, buying coffee and some personal hygiene things and clothes. Most residents thought this money was enough, in some others of course just enough to cover these needs. Most residents needed during their first months after being transferred, serious help and training in order to learn how to manage their monthly income. The staff, along with the residents, organised a weekly expense planner, which assessed each resident's needs individually. What is impressive is that some residents could not only manage their money well, but they could also help their fellow residents to manage their own money better.

Few residents reported financial concerns about the serious economic crisis that Greece is experiencing, which has resulted in cuts in pensions. This however was an issue mainly reported by staff members of the CCUs, who described the concerns that residents expressed to them, both at a microeconomic and a macroeconomic level.

## **2) Enriched daily routine:**

For most residents in all four CCUs of Klimaka, the parameters of daily occupation, participation in occupational therapy and in creative group activities demonstrated significant improvement in relation to the psychiatric hospital. Some residents even went a step further, and developed skills and interests they never had had the chance to develop in the psychiatric hospital. What is even more encouraging is that a small number had a regular job and seemed to enjoy the benefits of this, i.e. the fact that they got paid, came into contact with many people and spent their time in a creative way. Last, but not least, all residents seemed to enjoy the leisure activities offered by Klimaka's CCUs, although some wished for more organised outings and excursions and on a more frequent basis.

## **3) Friendships and wider social networks:**

The number of friendships and social networks that residents managed to establish while in the community care units seemed considerably increased and more developed in relation to what existed while these residents were in the psychiatric hospitals. The development of close friendships appeared to be age and functionality related. Most residents developed friendly relationships and those who did not, could still enjoy the company of the rest of the residents and shared activities. Residents also learned to function as members of a team and they seemed to care for one other.

## **4) Increased degree of freedom and contact with the neighbourhood:**

The degree of freedom that the residents experienced while in the community care units in relation to the time they had lived in the psychiatric hospital was greater and improved. As was previously highlighted, there was no possibility within the psychiatric hospital to be able to go out, so the contact with the neighborhood had been nonexistent. It appears that the residents of the community care units had more freedom than in the psychiatric hospital, for example to go to the

Occupational Therapy Centre which was located close to the units, or go out for a coffee or a walk, along with staff members or friends from the unit. This parameter however was restricted to a certain degree, based on certain conditions: the functionality of the resident, his or her mobility, and the seriousness of the SMI symptoms, along with the safety of the area around the community care unit. Contact with the neighbourhood was also difficult in some cases because of the stigma residents experienced at first, however it seems that the situation became easier as time passed by.

#### **5) Good relationship with staff:**

Another reason that made residents feel that they have found “shelter” in the CCUs was the good relationship that most of them developed with staff members. A critical factor that promoted this was the high staff/resident ratio in the CCUs. Consequently, there was a lot of intensified care and attention, things that they did not have in the psychiatric hospital and they would usually not get if they were at home. The residents had the chance to express any of their needs and they knew that their voice would be heard. The 24 hour presence of the staff who worked in shifts, also created a sense of a steady presence since residents knew that even if something happened in the difficult night hours, someone was there for them. One cannot exclude the possibility that the residents might have tried to give accounts that would portray themselves as “good residents” through avoiding criticism of the CCUs’ services and staff. Still though, the overall impression indicated improved relationships between residents and staff members, in comparison to those developed in mental health institutions. However, at the beginning, there were some frictions between staff and residents, and this was mainly from the difficulty residents experienced at first to get used to a daily routine with certain rules. After this initial transitional period, things became smoother, and most of them managed to develop close relationship with staff.

## **6) Trust in treatment and increased awareness:**

The issue of pharmaceutical treatment and psychotherapy appeared to have several differences – but also improvements – in relation to what the residents had received in the psychiatric hospital. Almost all residents of the units believed that the pharmaceutical treatment was helping them. Moreover, more residents knew the kind of pharmaceutical treatment they were receiving and in fact this number increased as we moved on to more independent living conditions.

This comprehension and realisation along with the insight about the pharmaceutical treatment was very important in order for some residents to experience enhanced autonomy. This in turn facilitated some residents to make a successful transition to more independent living conditions either in the protected flat or living alone outside the unit.

Another positive feature of Klimaka's way of operation was the significant monitoring of the residents from the staff [both doctors and nurses] and the cooperation between the staff and the residents. This close monitoring facilitated immediate treatment of possible relapses, which could happen to residents.

Finally, another parameter that helped the residents greatly and was an integral part in their treatment was psychotherapy. The type of psychotherapeutic approach in the CCUs of Klimaka had a counseling nature and aimed to help residents mainly with daily issues instead of long-term ones. In the CCUs, the framework was such that residents knew that they could visit a psychologist at any given moment and discuss anything that bothered them, when they needed it, without feeling that they were obliged to do so.

## **7) Absence of abuse:**

The majority of residents of all four units of Klimaka felt safe and protected. This came in contrast with the environment of mental health institutions, where in some cases residents mentioned about incidents of abuse by staff and fear for some other patients in the same ward, who

either tried to harm them or to steal their belongings. This parameter seemed to be greatly improved in the CCUs.

In conclusion, based on the lived experience of CCUs' residents in this study, one understands that the notion of "asylum" does not necessarily represent a physical entity (i.e. the building), but in fact a set of social, economic and affective parameters. Findings suggest that "asylum" is not a place, but mostly a set of interrelated criteria which if met or addressed by the mental health care services, "asylum" can possibly be achieved for people with SMI anywhere.

### **11.3. Recommendations for the practice of deinstitutionalisation in Greece: Non-contributory and contributory factors to a successful deinstitutionalisation**

Based on the notion of Thirdspace – i.e. the lived experience- of residents in this study, there appeared to be certain non-contributory and contributory factors to a successful deinstitutionalisation. On the non-contributory side, one factor that created difficulties for some residents when they first got transferred to the community was the fact that they had to get used to an everyday schedule with rules and to a new way of life which involved participation in everyday activities or chores. Secondly, in a few cases, residents found themselves having to share accommodation with people they had little in common with and hence found it difficult to get along with. Thirdly, in some areas, regardless if it was an urban neighbourhood or a small rural area, residents of CCUs found themselves having to deal with the heavy stigma that is associated with SMI in Greece.

On the contributory side certain factors greatly facilitated a successful deinstitutionalisation: A first factor was the change in environment, which the great majority of residents from this research study seemed to enjoy. In this new environment, the pattern of their daily life changed sharply, and they began to participate in daily chores, organised occupational therapy

programmes, trips and excursions; they also seemed to have a greater degree of freedom and contact with the neighbourhood, creating at the same time a new social network. A second factor was the high staff/residents ratio in the CCUs, which enabled staff to spend more time encouraging residents to participate in various activities, helping each one of them substantially. Thirdly, the greater awareness residents had about their drug treatment, along with their participation in psychotherapy, greatly helped residents to better adjust to their new life in the community.

#### **11.4. Recommendations for future mental health policy implementation in Greece**

Based on the lived experience of residents in this study, there are several important lessons for future mental health policy implementation:

**a. There is great need for reinforcement of law for involuntary commitment of patients with SMI to public mental health hospitals:**

All residents that participated in this study were involuntarily admitted to mental health institutions. What is striking is that most residents in this study did not mention at all their involuntary commitment to a mental health institution, and for the residents that did describe the scene, it was an extremely traumatic event. The law explicitly describes the way that involuntary commitment should be carried out by authorities, with the examination of a patient by two psychiatrists and then accompanied to the mental health hospital or mental health unit by specialised psychiatric staff (Law 1992, Article 47)..

In practice, however, it has been found that serious violations have been occurred for the last 23 years. While police interventions should only occur under extreme cases, in reality these interventions have become common practice. Actually due to this type of intervention, side effects have been noted such as: patients are transferred in cuffs/chains as if they were perpetrators, patients are kept in prison for days devoid of their



necessary treatment/medication and police interventions take place in events that no intervention is needed. The Hellenic Psychiatric Association has suggested that EKAB (Emergency Aid Centre) do these types of involuntary admissions. More specifically this should be done either by qualified psychiatric nursing staff or by the Health Centres and their ambulances ([mentalhealthlawblogspot.gr](http://mentalhealthlawblogspot.gr), 18/05/2011). If those services had provided the necessary organisation, then the police intervention would be restricted only in the event of violent acts or destruction inflicted by a patient. As a result, there appears to be a need for serious reinforcement of law, instead of relying on police for involuntary commitment.

**b. Health services need to safeguard the existence of some form of mental health hospital for those who need it:**

From the lived experience of participants in this study, it appears that residents managed to find a temporary asylum while in mental health institutions. A basic element of the notion of “asylum” that mental health hospitals offered and community care units did not, was the element of segregation from the pressures of the outside world. This greatly helped residents in times of crisis to live an everyday life with practically no pressures, but with dignity as well. The segregation from stressful stimuli helped them to calm down and to gradually regain their strength in order to face life in a community care unit. As a result, mental health services should safeguard the existence of some form of mental health hospital or psychiatric wing in general hospitals which can offer to patients with SMI in periods of crisis the element of segregation from the pressures of the outside world.

**c. Families of patients with SMI and of residents of CCUs need additional support and assistance by the state:**

From the lived experience of participants in this study it appeared that in some cases residents experienced financial exploitation by their

family members and/or had tense relationships with them, feeling angry that their relatives had ordered their involuntary commitment to hospital. One reason behind the problems that families faced has to do with the heavy stigma that is associated with mental illness in Greece.

All this shows that families caring for individuals with SMI in the Greek context, either patients in mental health institutions or residents of CCUs, need additional support and aid from the State. Family members experience a lack of assistance and support and as a result, they may feel unable to cope, resulting in great difficulty in any attempt for communication with their ill relative. Although the PanHellenic Family Association for Mental Health (SOPSY) organises support programmes such as counseling groups and support sessions for family members (Kollias et al, 2002), this was not available up until the late 1990s. Even nowadays - particularly during the financial crisis that Greece is experiencing - such efforts need to be reinforced by the State. More importantly, there is a great need for educational programmes for families of individuals with SMI – hospital patients or residents of CCUs - in order to learn the symptoms, treatment and options that both they and their relative with SMI have.

**d. There is a great need for training programmes for SMI for the general public in Greece:**

From the lived experience of residents in this study it appeared that SMI is heavily associated with stigma in Greece, even nowadays. Finding asylum in the community has not been an easy process for residents, especially during the initial phase of operation of certain CCUs, particularly in smaller rural areas. The situation has not been easy for residents of CCUs in urban neighbourhoods either: although big cities offer a “blessed anonymity”, at the same time there have been incidents indicating that the stigma associated with mental illness is still prevalent. As time passes by though, communities seem to get accustomed. However, an intensified educational programme for the general public concerning mental illness

and how to treat people with SMI in general, and residents of CCUs in particular, living in our neighbourhood, could greatly help the change of scenery in Greece. Special seminars should get organised for high school students as well, in order to educate people at a much younger age.

### **11.5. Recommendations for future mental health policy research in Greece**

The main issue this study explored was the notion of “asylum” and what this meant for the residents of four CCUs run by Klimaka. The participants’ lived experiences allowed for the construction of different interpretations of “asylum” and revealed important insights on how we might improve mental health practice and policy in Greece for people with SMI who are about to get deinstitutionalised from mental health institutions to CCUs.

The research focused on the four units’ residents’ and staff members’ experiences of deinstitutionalisation, and it also included the voices of two staff members of mental health hospitals, two officers from the Ministry of Health, and the legal advisor of Klimaka. However, it faced the constraint of not being able to further explore issues that were raised in this research, concerning the difficulties that residents face concerning their relationship with their family members. As a result, it would be very useful at a future research to include the voices of family members of residents of CCUs or of relatives of patients in mental health institutions who are about to get transferred to CCUs, in order to have a clearer and broader picture of the issue of deinstitutionalisation and explore their perspective as well. It would also be useful to include the voices of officers from the Ministry of Finance, in order to draw conclusions about how mental health services will manage to survive through periods of financial crisis, while at the same time best helping residents of CCUs find true asylum in the community.

# CONCLUSION

## Chapter 12: Conclusion of the thesis

### 12.1. Differential experiences of the notion of “asylum” and recommendations for mental health practice in Greece

This research study dealt with a group of residents that were transferred from mental health hospitals to CCUs. The main issue this study explored was the notion of “asylum” and what this meant for these residents. The participants’ lived experiences allowed for the construction of different interpretations of “asylum”.

Firstly, the mental health hospital was perceived as a place offering a “temporary asylum” in periods of crisis, and the notion of “asylum” revolved around five axes: 1) Financial security, with all basic needs being covered in hospital, 2) Stress-free daily routine, 3) Segregation from the pressures of the outside world, 4) Good or neutral relationship with staff and 5) Trust in treatment. Community care units on the other hand, were perceived by residents as places offering temporary and permanent asylum, and this notion of asylum revolved around seven axes: 1) Financial security, with basic needs and pension issues being covered, 2) Enriched daily routine, 3) Increased number of friendships and wider social networks, 4) Increased degree of freedom and contact with the neighbourhood, 5) Good relationship with staff, 6) Trust in treatment and increased awareness, and 7) Absence of abuse.

From residents’ experiences we can conclude that individuals can successfully live in CCUs if the parameters of “asylum” are put in place. It appears that the notion of “asylum” does not necessarily represent a physical entity (i.e. a building), but a set of social, economic and affective parameters. The findings of this research suggest that “asylum” is not a place, but mostly a set of interrelated criteria which if met or addressed by the mental health care services, “asylum” can possibly be achieved for people with SMI anywhere. However, in the midst of the extreme financial

crisis that Greece has been experiencing the past years, the greatest challenge that mental health services are currently facing in Greece is to keep in place all necessary mental health services and provide all necessary conditions that will help individuals with SMI to successfully make the transition from mental health hospitals to a more autonomous life in the community.

Secondly, this study revealed important insights on how we might improve mental health policy in Greece for people with SMI who are about to be transferred from mental health institutions to CCUs, by focusing on the factors that contributed to a successful deinstitutionalisation for participants. A first factor was the change in environment, which the great majority of residents from this research study seemed to enjoy. In this new environment, they began to participate in daily chores, organised occupational therapy programmes and excursions; they also seemed to have a greater degree of freedom and contact with the neighbourhood, creating at the same time wider social networks. A second factor was the high staff/residents ratio in the CCUs, which enabled staff to spend more time encouraging residents to participate in various activities. Thirdly, the greater awareness residents had about their drug treatment, along with their participation in psychotherapy, greatly helped them to better adjust to their new life in the community.

On the non-contributory side, one factor that created difficulties for some residents when they first got transferred to CCUs was the fact that they had to get used to an everyday schedule with rules, which involved participation in everyday activities or chores. Secondly, few residents found themselves having to share accommodation with people they had little in common with and found it difficult to get along with. Thirdly, in some areas, regardless if it was an urban neighbourhood or a small rural area, residents of CCUs found themselves having to deal with the heavy stigma that is associated with SMI in Greece and NIMBYism attitudes. Taking into consideration these factors, which hindered a successful deinstitutionalisation, can help in order to alleviate mistakes of the past.

Lastly, the study revealed recommendations for future mental health policy implementation in Greece, which included: the need to reinforce the Law for involuntary commitment of patients with SMI to public mental health hospitals; the need to safeguard the existence of some form of mental health hospital or psychiatric wing in general hospitals for patients who undergo periods of crisis or relapse; the need to provide additional support to families of patients with SMI and of residents of CCUs; the need for training programmes concerning SMI for the general public in Greece, in order to eliminate the heavy stigma associated with SMI.

### **12.2. Reflections of the researcher**

One of the greatest lessons I learned through this research is that the notion of Firstspace can be strikingly different from the notion of Thirdspace. Findings of this research suggest that the physical fabric of the institution – the Firstspace – was of far less importance for residents than the notion of Thirdspace, meaning their own lived experience. Interestingly, many residents managed to find a temporary asylum within the old, neglected and deteriorated buildings of the mental health institutions. Additionally, one would assume that since residents got transferred to community care units with considerably better living conditions than mental health institutions, the transition would automatically be easy and smooth. The lived experience however of residents showed that the transition had some difficulties for them. What many residents of Klimaka's CCUs found difficult at first, was to adjust to a daily programme which had certain rules, and this relates not only to taking care of personal hygiene, but also helping with the daily chores, and living a daily life with considerably more stimuli than in institutions. After an initial period of adjustment however, residents got used to their new daily programme and became more active, with the aim of becoming more autonomous and self-sufficient.

For all residents in this study, getting transferred from the mental health hospital to CCUs signaled a new beginning. The transition to

community care opened new vistas to their lives, resulting to an enriched daily routine, wider social networks, increased degree of freedom and contact with the neighbourhood and increased awareness concerning their treatment. The ultimate goal of this change was for some of the residents, particularly the younger ones, to move to independent living.

Exploring the notion of Thirdspace in this study was critical in order to reveal the lived experience of residents and draw conclusions about the deinstitutionalisation policy in Greece. Exploring Thirdspace in any field relating to health services is of paramount importance, in order to develop health services that effectively help users. Discovering the hidden knowledge of what really works in health care provision, can lead the way to providing services that really make a difference in people's lives, while at the same time empowering hospital patients, residents of CCUs and service users in general.

### **12.3. Proposals for future mental health policy research**

Although this research focused on residents' and staff members' of CCUs experiences of deinstitutionalisation, it also included the voices of two staff members of mental health hospitals, two officers from the Ministry of Health, and the legal advisor of Klimaka. However, it would also be useful at a future research to include the voices of family members of people experiencing SMI [hospital patients or CCUs' residents], in order to have a clearer picture of the issue of deinstitutionalisation. Literature suggests that family members of hospital patients and/or CCUs' residents also find themselves in the margins of society, experiencing severe difficulties that usually last a life time. Exploring their lived experience is of paramount importance in order to indicate areas that families need help from the state. Helping family members at an earlier stage and more effectively, may help to an earlier detection of SMI, earlier treatment, better compliance by hospital patients and CCUs residents, and hopefully elimination of the heavy stigma associated with SMI in Greece.

It would also be useful in a future research, to include the voices of officers from the Ministry of Finance, in order to draw conclusions about mental health services that will be able to survive through periods of financial crisis, while at the same time best helping residents of CCUs find true asylum in the community.



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## APPENDICES

### Appendix I

#### Tables 2, 3 and 4: List of Participants

**Table 2: List of residents of Klimaka's four CCUs**

<u>Partici- pant</u>	<u>Pseudonym</u>	<u>Male/ Female</u>	<u>Age</u>	<u>Status</u>	<u>Location</u>
1.	Kerkyraios	Male	42	Resident	Psychogeriatric Unit
2.	Papadopoulos	Male	49	Resident	Psychogeriatric Unit
3.	Vlastos	Male	77	Resident	Psychogeriatric Unit
4.	Leonidopoulos	Male	64	Resident	Psychogeriatric Unit
5.	Kalos	Male	54	Resident	Psychogeriatric Unit
6.	Chrysalis	Female	67	Resident	Psychogeriatric Unit
7.	Kostaki	Female	72	Resident	Psychogeriatric Unit
8.	Voskopoulos	Male	71	Resident	Psychogeriatric Unit
9.	Pappas	Female	70	Resident	Psychogeriatric Unit
10.	Colliou	Female	74	Resident	Psychogeriatric Unit
11.	Iraklidou	Female	70	Resident	Psychogeriatric Unit
12.	Georgitzi	Female	87	Resident	Psychogeriatric Unit
13.	Chatzichristou	Female	84	Resident	Psychogeriatric Unit
14.	Barbarigos	Male	43	Resident	Psychogeriatric Unit
15.	Zachou	Female	63	Resident	Protected apartment
16.	Vasilikou	Female	53	Resident	Protected apartment
17.	Monachos	Male	53	Resident	Protected apartment
18.	Kouroupis	Male	50	Resident	Protected apartment
19.	Dimoulas	Male	53	Resident	Boarding House Afaia
20.	Bebekou	Female	36	Resident	Hostel
21.	Dorakos	Male	52	Resident	Boarding House Afaia
22.	Maragaki	Female	58	Resident	Boarding House Afaia
23.	Stonakis	Male	30	Resident	Boarding House Afaia
24.	Louloudis	Male	39	Resident	Boarding House Afaia
25.	Poulakis	Male	47	Resident	Hostel
26.	Aggelopoulou	Female	30	Resident	Hostel
27.	Karamouza	Female	52	Resident	Boarding House Afaia
28.	Marouli	Female	62	Indepe- ndent Living	Under the supervision of the hostel
29.	Ioannou	Female	62	Resident	Boarding House Afaia
30.	Olympiou	Female	38	Resident	Hostel



**Table 3: List of staff members of Klimaka's CCUs**

<u>Particip- pant</u>	<u>Pseudonym</u>	<u>Male/Female</u>	<u>Age</u>	<u>Status</u>	<u>Location</u>
1.	Krinou	Female	-	General Duties Staff member	Psychogeriatric Unit
2.	Gyrla	Female	-	General Duties Staff member	Psychogeriatric Unit
3.	Vidou	Female	-	General Duties Staff member	Psychogeriatric Unit
4.	Lalou	Female	-	General Duties Staff member	Psychogeriatric Unit
5.	Makrypoulia	Female	-	Nurse	Psychogeriatric Unit
6.	Virgouli	Female	-	Nurse	Psychogeriatric Unit
7.	Alikaki	Female	-	Nurse	Psychogeriatric Unit
8.	Galena	Female	-	General Duties Staff member	Psychogeriatric Unit
9.	Vlicha	Female	-	General Duties Staff member	Psychogeriatric Unit
10.	Fotinopoulou	Female	-	General Duties Staff member	Psychogeriatric Unit
11.	Kafetzi	Female	-	Psychologist	Psychogeriatric Unit
12.	Lyrizis	Male	-	Psychologist	Psychogeriatric Unit
13.	Aristaki	Female	-	Head Nurse	Psychogeriatric Unit
14.	Amygdalou	Female	-	Psychologist	Hostel
15.	Makedonas	Male	-	Nurse	Hostel
16.	Boukala	Female	-	Nurse	Hostel
17.	Kastrinakis	Male	-	Chief Psychiatrist/ Head of Klimaka	Klimaka Headquarters
18.	Nitsou	Female	-	Nurse	Hostel
19.	Dimitraki	Female	-	Nurse	Hostel
20.	Sakorafas	Male	-	Nurse	Hostel

**Table 4: List of other participants**

<b><u>Partici- pant</u></b>	<b><u>Pseudonym</u></b>	<b><u>Male/Female</u></b>	<b><u>Age</u></b>	<b><u>Status</u></b>	<b><u>Location</u></b>
<b>1.</b>	Tassos	Male	-	Mental Health Officer	Ministry of Health
<b>2.</b>	Nikolaou	Male	-	Mental Health Officer	Ministry of Health
<b>3.</b>	Alogoskoufis	Male	-	Legal Advisor of Klimaka	Private Law Firm
<b>4.</b>	Koubaraki	Female	-	Psychologist	Dromokaition Mental Health Hospital
<b>5.</b>	Starlis	Male	-	Psychiatrist	Dromokaition Mental Health Hospital

## Appendix II

### **Information Form for residents of community care units run by Klimaka: Deinstitutionalisation and transition to community care in mental illness**

*This study is being undertaken by the researcher Dorothea Lentis, under the supervision of Professor West, Greenwich University, and of Dr. Paterakis, Chief Psychiatrist, Dromokaition Hospital.*

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You are invited to participate in a study about **deinstitutionalisation**. You have been **transferred to a Community Care Unit** and we would like to know **what your feelings are about it**. This will help policy makers to **better plan deinstitutionalisation and transition to community care in the future**.

Your clinician is aware of your selection and has no objection to your participation.

If you decide to participate, we will conduct an interview with you which will last for about forty-five minutes. With your agreement, the interview will be tape recorded. The tape recording will be used only by the researcher and will be destroyed at the end of the study. If you prefer, you may request the tape be returned to you for your own safekeeping.

You are entirely free to choose whether or not you want to participate in this study. **Your decision will not affect your treatment or your length of stay in the community care unit in any way, nor will it affect or prejudice your future relations with the community care unit.**

Should you feel unhappy about participating at any point in time during the research, **then you are free to withdraw and this will not have any adverse effect on you.**

Your taking part in this study will be kept entirely **confidential**. The interview material will be seen only by you and the researcher Dorothea Lentis. Confidentiality will have to be broken only under specific circumstances, i.e. disclosure of abuse or risk of self harm.

It is possible that information from this research study could one day be published, but all names and identifying data will be appropriately anonymised to ensure no one individual can be identified from the data.

Although we cannot promise that you, personally, will receive any benefit from this study, we do hope that this study will give policy makers the chance to plan better deinstitutionalisation and transition to community care for other patients in the future.

We will offer you a copy of this form to keep. If you have any questions, please do not hesitate to ask us. You can do so by contacting the researcher, Dorothea Lentis, phone number: 6932-410744.

**Please note: If you sign the consent form, it means that you have read this information leaflet carefully, you understand what will be required of you in the study and have decided to participate.**

## Appendix III

### Consent Form for residents of community care units run by Klimaka

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Name of researcher: Dorothea Lentis

Phone number: 6932-410744

#### **Study of deinstitutionalisation and transition to community care in mental illness**

I confirm, that I have read and understood the information sheet dated: ..... for the above study and have had the opportunity to ask any additional questions I may have.

I understand that my participation is entirely voluntary and that I am free to withdraw at any time without giving any reason and without my medical care or legal right being affected.

I also do / do not give permission for my interview to be tape recorded.

I also understand that some parts of my interview may be used in future published work, but that this will be anonymised so I cannot be identified in any way.

In signing this form I agree to take part in the above study.

Signature

Date

Time

Name (please print)

---

## Appendix IV

### **Information Form for staff members of community care units run by Klimaka: Deinstitutionalisation and transition to community care in mental illness**

*This study is being undertaken by the researcher Dorothea Lentis, under the supervision of Professor West, Greenwich University, and of Dr. Paterakis, Chief Psychiatrist, Dromokaition Hospital.*

---

You are invited to participate in a study about **deinstitutionalisation**. This will help policy makers to **better plan deinstitutionalisation and transition to community care in the future**.

If you decide to participate, we will conduct an interview with you which will last for about forty-five minutes. With your agreement, the interview will be tape recorded. The tape recording will be used only by the researcher and will be destroyed at the end of the study. If you prefer, you may request the tape be returned to you for your own safekeeping.

You are entirely free to choose whether or not you want to participate in this study. **Your decision will not affect or prejudice your future relations with the community care unit.**

Should you feel unhappy about participating at any point in time during the research, **then you are free to withdraw.**

Your taking part in this study will be kept entirely **confidential**. The interview material will be seen only by you and the researcher Dorothea Lentis.

It is possible that information from this research study could one day be published, but all names and identifying data will be appropriately anonymised to ensure no one individual can be identified from the data.

Although we cannot promise that you, personally, will receive any benefit from this study, we do hope that this study will give policy makers the chance to plan better deinstitutionalisation and transition to community care in the future.

We will offer you a copy of this form to keep. If you have any questions, please do not hesitate to ask us. You can do so by contacting the researcher, Dorothea Lentis, phone number: 6932-410744.

**Please note: If you sign the consent form, it means that you have read this information leaflet carefully, you understand what will be required of you in the study and have decided to participate.**

## Appendix V

### Consent Form for staff members of community care units run by Klimaka

---

Name of researcher: Dorothea Lentis

Phone number: 6932-410744

#### Study of deinstitutionalisation and transition to community care in mental illness

I confirm, that I have read and understood the information sheet dated: ..... for the above study and have had the opportunity to ask any additional questions I may have.

I understand that my participation is entirely voluntary and that I am free to withdraw at any time without giving any reason and without my legal rights as a staff member being affected.

I also do / do not give permission for my interview to be tape recorded.

I also understand that some parts of my interview may be used in future published work, but that this will be anonymised so I cannot be identified in any way.

In signing this form I agree to take part in the above study.

Signature

Date

Time

Name (please print)

---



## Appendix VI

### Tables 5 and 6 with themes from the semi-structured interviews

Table 5	Part 1: Themes concerning the period of institutional care
<ol style="list-style-type: none"><li>1. What were the circumstances leading up to hospitalisation. Length/periods of inpatient stay.</li><li>2. Relationship to home and family, while in the mental health institution.</li><li>3. Relationship with other inpatients. Friends and social networks.</li><li>4. Everyday life, activities, work and occupational therapy programmes in the hospital. Daily schedule-routine.</li><li>5. The participants' experiences of professional care/support within the hospital.</li><li>6. The participants' views about their treatment both pharmaceutical and psychotherapy, in the hospital.</li><li>7. Financial issues relating to life in the hospital.</li><li>8. Religious needs and worshipping in the hospital.</li><li>9. Whether or not there have been particular aspects of life in the hospital that have either created difficulties or have been helpful for participants.</li><li>10. Suggestions for possible changes in any aspect of life in the mental health hospital that could make inpatient stay easier.</li><li>11. Were there any aspects of life in the mental health hospital that made participants feel safe and protected. Notion of "asylum".</li><li>12. Where did participants feel "at home" during the period of institutional care.</li></ol>	

<b>Table 6</b>	<b>Part 2: Themes concerning life in the community care unit</b>
	<ol style="list-style-type: none"> <li>1. For how long have the participants been in the community care unit.</li> <li>2. Relationship to home and family.</li> <li>3. Relationship with other residents in the community care unit. Friends and social networks.</li> <li>4. Everyday life, activities, work and occupational therapy programmes in the community care unit. Daily schedule-routine.</li> <li>5. The participants' experiences of professional care and support within the community care unit.</li> <li>6. The participants' views about their treatment – both pharmaceutical and psychotherapy, in the community care unit.</li> <li>7. Financial issues relating to life in the community care unit.</li> <li>8. Religious needs and worshipping in the community care unit.</li> <li>9. Whether or not there have been particular aspects of life in the community care unit that have either created difficulties or have been helpful for participants.</li> <li>10. Suggestions for possible changes in any aspect of life in the community care unit that can make participants' stay easier.</li> <li>11. Are there any aspects of life in the community care unit that make participants feel safe and protected. Notion of "asylum".</li> <li>12. Where do participants feel "at home".</li> </ol>

## Appendix VII

### Approval letter by Klimaka



Φορέας Ανάπτυξης Ανθρώπινου και Κοινωνικού Κεφαλαίου  
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Contact Person: **Olga Theodorikakou**

*Athens, June 25<sup>th</sup> 2010*  
*Ref. Number: 1082*

Dear Sirs of the Ethics Committee of Greenwich University,

We certify that we [the non-profit organization "Klimaka"] have given permission to Mrs. Dorothea Lentis to conduct at our community care units her research for her PhD degree, titled: " Transition from institutional care to community care for people with SMI in Greece: Construction of notion of "asylum" in community care units".

Through her study Mrs. Lentis will explore the following: 1) how individuals feel about their life in a community care unit, comparing to their previous life in mental health hospitals; 2) what constitutes "asylum" for people with SMI (as a place offering protection and security), and whether or not individuals have been able to find "asylum" in the community after being for at least six months to one year in a community care unit; 3) factors that contribute to a "successful" or "unsuccessful" deinstitutionalization.

Mrs. Lentis will interview with semi-structured interviews all residents of the 3 community care units for people with SMI operating under the aegis of Klimaka in Athens: 1) one psychogeriatric boarding house with 15 individuals; 2) one hostel with 12 individuals; 3) one protected apartment with 4 individuals. In total, she will interview 31 individuals, residing in the 3 units. Mrs. Lentis will also interview all staff members of the three units. We believe that this study can provide valuable insights to the issues of deinstitutionalization and transition to community care in Greece, and can offer valuable lessons for future mental health policy implementation in Greece.

Mrs. Lentis' research will be supervised by Professor West of Greenwich University, and by Professor Meenabeau of Greenwich University. Her study will also be supervised by Dr. Paterakis, Chief Psychiatrist of Dromokaition Mental Health Hospital in Athens, who is her local supervisor in Greece. We are very happy that Mrs. Lentis will conduct her research with us, and we believe that her study can make a valuable contribution to knowledge in the field of mental health services in Greece.