



(formerly titled 'Living with Serious Mental Illness: An Ethnographic Study')

## **research progress report**

**produced by**

**The Living Project Steering Group**

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# 1. Introduction

The Living Project commenced on the 1<sup>st</sup> of May, 2003<sup>1</sup>. Undertaken to document the everyday lives of people with serious mental health problems resident in community settings, the project provides insights into how the medical and social ambitions of 'community care' are experienced day-in-day-out.

During the past twelve months, 52 men and women with serious mental health problems from the South London area have shared aspects of their lives with the principal researcher. Some have opted to share select experiences or perspectives. Others have talked at greater length about the achievements and challenges encountered. Many have literally taken the principal researcher into their lives, letting him accompany them over days, weeks, or months as they manage everyday life in the community.

This annual report summarises progress and emerging findings from the first 12 months of The Living Project. Describing key project milestones, successes, and difficulties, the report also draws on initial observational, interview and photographic data from the field to highlight emerging lines of argument and consequence.

## 2. Background

The aims, objectives and methodology of the project are described in the original study proposal. However, to briefly summarise:

- Despite the extent and scale of community care in the UK, there is a paucity of research on the everyday lives of people with mental health problems living in the community.
- In addressing this gap in knowledge, this study primarily employs an *ethnographic* research methodology (Box 2a), although select quantitative methods are also employed.
- The study is being conducted in the *Lambeth area* (although participants live across South London). Contact with individuals has initially been facilitated through the First Step Trust (FST) project in the area, FST Lambeth. However, participants are now increasingly meeting with the research team outside of this setting (Box 2b).
- The study represents an innovative collaborative partnership between FST and The Royal College of Psychiatrists (Box 2c).

The research is on-track in terms of timetable and expenditure. Significant achievements have been made in the fieldwork (*Section 3*), and emerging field observations have identified some important issues (*Section 4*). Although challenges have been encountered during the first 12 months (*Section 5*), procedures have been put into place to overcome these. Minor changes have been made to the original study timetable ( *Section 6*).

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<sup>1</sup> Formerly titled 'Living with Serious Mental Illness: An Ethnographic Study', this was changed after field-work began simply to make it easier to explain what the project was about to potential participants.

### **Box 2a – ethnographic research**

Ethnography offers a 'different lens' through which to understand the lives of people with mental health problems living in community settings. In contrast to quantitative approaches, ethnographic research:

- studies behaviour in context (i.e. by working in the environments in which individuals live and operate, rather than in artificial settings such as interview rooms)
- is conducted over lengthy periods of time (i.e. trying to form long-term relationships and to document changes in individuals' lives over considerable periods)
- draws on a range of methods (i.e. not relying on one method – such as interviews – but also employing other techniques to increase the robustness of research findings)
- tries to see the world 'through the eyes' of research participants (i.e. trying to document the meanings, understandings, values, beliefs, and perceptions that individuals hold).

The Living Project combines ethnographic research techniques with selected qualitative and quantitative research methods (network mapping, brief surveys, existing data source reviews, rapid assessments).

### **Box 2b – geographical coverage**

Participants for The Living Project are being recruited from individuals who either live, work, or use services (generic and specialist, social and clinical) in the Lambeth area of South London.

Lambeth is the largest of the inner-London boroughs, with a population of 286,170. Incorporating the diverse areas of Brixton, Streatham, Clapham, Norwood and Waterloo, 34% of Lambeth's residents are from ethnic minorities (after English, the main languages spoken are Yoruba and Portuguese). Unemployment in Lambeth is almost twice the national average.

Initial recruitment for The Living Project has been undertaken through The First Step Trust. However, the research has followed participants as they undergo their daily activities, including domestic settings, mental health and generic services, shopping outlets, benefit and employment offices, places of religious worship, public places (including pubs, parks, and transport routes), and contexts in which participants meet with friends, family members and associated health professionals. This has taken the research team across the South London area.

### **Box 2c – an innovative partnership**

First Step Trust (FST) is an organisation providing real work experience and employment opportunities for people with mental health problems. The Living Project is linked with the Lambeth branch of FST, one of sixteen FST work projects in the UK providing gardening, IT, catering, printing, carpentry, removals, and painting and decorating services. ([www.fst.org.uk](http://www.fst.org.uk)).

The College Research Unit is part of The Royal College of Psychiatrists and is dedicated to improving services for people with mental health problems through rigorous research ([www.rcpsych.ac.uk/cru](http://www.rcpsych.ac.uk/cru)).

### 3. Achievements

This section elaborates (and also supplements) the tasks listed in the Annual Progress Report form.

#### *Gaining access to First Step Trust*

Negotiating, obtaining, and maintaining access is fundamental to the success of The Living Project. Whilst as co-applicants, FST provided an 'entry-point' through which initial contact could be made with people with serious mental health problems, this did not come with a 'guarantee' that individuals would participate in the research. Instead, relationships and trust had to be both established and built upon (an ongoing process) with those people using FST. To achieve this, the principal researcher has regularly participated in the FST working day (undertaking contract gardening, removals, painting and decorating, printing, leaflet delivery, cleaning, and furniture restoration), as well as joining in social activities. As illustrated in Box 3a, this strategy has involved firstly engaging in conversations about the work-at-hand, moving secondly to discussions of individuals' experience of wider community living, and then thirdly to negotiating meeting individuals outside of FST and observing other settings of importance to them. This process can require significant investments of time. Importantly, all research has been undertaken openly, and with participants' awareness and consent.

#### *Access to other sites*

Research undertaken at FST has provided important insights into the *meaning of work* in the lives of people with serious mental health problems, and the role that such organisations play in *facilitating social inclusion*. However, other meanings, organisations, and sites feature in individuals' community lives outside of work. One of the methodological aims of the project was to 'snowball' out of FST to gain access to such settings. This has been achieved, with the researcher, for example, visiting people in their own homes, accompanying them as they use mental health and generic services, participating in leisure activities, assisting with shopping and domestic chores, observing their use of benefit and employment offices, attending places of religious worship, and meeting friends, family members and associated health professionals (see Box 3b).

#### *Orientation assessments*

A rapid assessment has been conducted of the social and policy context, and international literature has been reviewed on the everyday lives of people with mental health problems (attached as an appendix).

#### *Fieldwork achievements: interviews and observation*

More than 425 hours of observation, 19 formal interviews (taped), and a larger number of informal interviews (not taped) have been conducted with research participants. Participants have people with serious mental health problems, and their friends, family, and health and social professionals. Observational data (and key aspects of informal interviews) have been recorded in written and electronic field-notes.

Emerging findings and strands of argument from this fieldwork are outlined in Section 4.

### Box 3a – an example: developing participant and researcher relationships

Developing a relationship with Clinton took nine months, and is still ongoing. At the outset of the research **in May**, staff advised that Clinton was an extremely private man, but one whose life would be of interest to the study. Initial attempts to talk with Clinton by the principal researcher were brushed off. However, **by July**, the researcher had undertaken several gardening and decorating jobs with Clinton, and had begun to discuss Clinton's experience of FST, as well as his previous employment and background. These conversations continued throughout **August, September and October**, although Clinton continued to decline invitations by the researcher to meet-up 'outside of work'. In **November and December**, an effort was made to spend further time with Clinton, and by **January 2004** (some nine months into the project), Clinton invited the principal researcher to his home.

### Box 3b – an example: sites outside of First Step Trust

The principal researcher met Charmaine shortly before she stopped attending FST. After re-establishing contact with Charmaine several months later, the principal researcher accompanied Charmaine as she travelled around a variety of sites in the London area:

*"It was my only way of getting fed", Charmaine said as we walked into the biting wind. We were taking a journey that Charmaine regularly made last year, during a period when she neither received benefits nor a wage. Each day she walked an eight-mile circuit that took in the kitchens of London's homelessness centres, and the shelter of the Imperial War Museum. "I know a lot of people look at me as being a nutter or something", Charmaine observed as we passed the tourists on London's South Bank, "but I don't think they realise how hard it actually is".*

Plate 1: fieldwork with Charmaine on London's South Bank



### *Beneficiary involvement:*

The involvement of beneficiaries is a prominent feature of The Living Project:

- *Strategic:* the research is guided by a steering group of whom *the majority* have ongoing or recent personal experience of mental health problems, or who actively provide care (Box 3c).
- *Dissemination #1:* workers from FST have produced information posters and photographs to raise and maintain awareness of the project amongst the FST workforce.
- *Fieldwork #1:* the ethnographic approach employed in the project has been founded on a close collaboration between participants and the researcher. Given the aim to describe activities, perceptions, and places in detail, researchers and participants often form close relationships over considerable periods of time.
- *Fieldwork #2:* as written accounts develop of the everyday lives of participants with serious mental health problems, the research team show and share materials with participants. This *beneficiary validation* technique both allows materials to be checked for accuracy, and elicits further responses and insights from participants.
- *Dissemination #2:* at the last Steering Group meeting, it was decided that where useful, future presentations about The Living Project would be undertaken jointly between representatives from FST and The Royal College of Psychiatrists.

## **4. Emerging issues**

*Initial* strands of insight and argument have begun to emerge from the field-research. These issues need to be explored further, but illustrate some of the perceptions, coping strategies, and experiences of participants living with mental health problems in community settings.

- *Safe places and social exclusion* – the integration of individuals with serious mental health problems into mainstream communities is a central aim of current mental health policies. However, how do individuals perceive ‘the community? What barriers to social inclusion exist? Could social exclusion ever be a coping strategy? The current research project indicates a potentially fascinating relationship between different places within the community, an individual’s mental health, and wider rehabilitative goals. This includes individuals’ perceiving the community as being comprised of ‘safe’ and ‘unsafe’ places, the existence of different social networks of people with mental health problems (and their advantages and disadvantages in regard to social inclusion), and individuals’ preferences for ‘safe’ over ‘unsafe’ places resulting in self-segregation and social exclusion (Box 4a).
- *‘Being normal’ can be hard work* - in community settings, individuals with mental health problems have reported numerous coping strategies for ‘keeping a lid on the voices’ and controlling unusual behaviours, including using a walkman (to drown out voices), learning anger control techniques, only visiting ‘safe places’, and as in the example (outlined in Box 4b), writing a book detailing instructions on ‘how to be normal’.

### **Box 3c – composition of the Steering Group**

The Steering Group is comprised of 14 people, the majority of whom have direct personal experience of mental health problems, or who provide care to those who do.

#### ***Members from The First Step Trust***

Five workers and two managers from First Step Trust, Lambeth.

One worker and one (of two) chief-executives from First Step Trust, Main Office.

#### ***The Royal College of Psychiatrists***

Director of College Research Unit (psychiatrist)

Two Research Fellows (sociologists)

#### ***Other members***

One representative from the London Development Centre for Mental Health

One representative who is both a carer, general practitioner, and director on FST's board.

### **Box 4a – safe places and social exclusion**

Some individuals in the research have perceived the community as being comprised of 'safe' and 'unsafe' places. Whilst general evaluations of safety have featured (i.e. whether a place is physically dangerous), often these perceptions are founded on a more complex interaction between inner mental states and the external world, with certain geographic places producing specific sensations, thoughts or emotions amongst individuals.

However, in the case of Freddie (below), the identification and existence of a 'safe place' in the community (First Step Trust), poses a different dilemma: when does a 'safe place' become an obstacle to full community integration?

*The thought of leaving FST...concerns Freddie, citing it as "frightening". Freddie says that he knows everyone at FST, and enjoys the work. He says that if he made a mistake whilst on the job at FST, that would be ok. In contrast, in the outside world, he explained that if he made mistakes he would be immediately sacked. Freddie is also concerned that his [past] will count against him if he were to apply for a competitive job.*

Fieldnote extract

### **Box 4b – coping strategies**

"I just want a normal life", was a phrase repeatedly expressed by one participant, for whom daily life involved dealing with the symptoms of her schizophrenia, whilst attempting to find work. In order to try and 'keep the lid' on her symptoms, and to lead a 'normal' life, this individual carried with her a 'book' that she had written which outlined the different things she had to do to look after herself, and the ways in which she could take control over her schizophrenia. Often re-writing and revising sections of the handbook as she sat in one of the chapels of the local Catholic Church, or a nearby McDonalds, this 'handbook' provided means through which she could cope with her schizophrenia, and try and follow a 'normal life'.

- *Money is a divisive factor* – for some individuals, daily living was reported as a financial struggle, whilst for others, money was not reported or perceived as a priority issue, with other factors being identified as more immediate. Service workers interviewed commented on often markedly different levels of benefit received across individuals, with one commenting that “social workers are like lawyers - the better lawyer you get, the more money you’re likely to receive”.

These are a few initial observations (primarily provided to give an example of the type of field-data that has been collected, and the potential strands of argument which may be developed further in project years 2 and 3).

## **5. Challenges: encountered and anticipated**

Challenges encountered, and further challenges anticipated for project years two and three, concern:

- *Recruiting participants* – Individuals participating in the study should reflect not only the constituency of those using the First Step Trust, but also the wider sociodemographic characteristics of other individuals in the Lambeth area with mental health problems. Consequently, the project’s sample is carefully monitored to ensure that women, individuals under 30, people with complex needs (including substance use), and individuals with experience of homelessness are incorporated into the study.

In order to ensure that the last group are represented, an agreement has been reached with the *South Thames Assessment, Response and Training team* (START) who operate an assertive outreach service for homeless individuals with mental health problems in the Lambeth area. The principal researcher will accompany the START team and will be introduced to individuals who could participate in the study. This collaboration will need to receive ethical approval from the Institute of Psychiatry’s ethics board, but it is likely this will only require a chairman’s action, rather than full review.

- *Working across multiple sites and multiple individuals* – This has represented a significant research challenge, particularly given the need to dedicate sufficient time to produce detailed field-notes, and also the often practical difficulties in locating some participants who periodically lose contact with the research team and connecting services.
- *Ethical considerations* – the ethics of ethnographic research pose ongoing challenges, particularly in terms of informed consent and assessments of participants’ potential for self-harm or risk to others. The research team has introduced procedures for monitoring such issues.



**PLATE 2: OBSERVATION AND INTERVIEW IN PARTICIPANT'S OWN FLAT**



**PLATE 3: FIRST STEP TRUST WORKFORCE AND VISITORS (WORK-A-DAY, 2003)**



## 6. Timetable for Project Year 2

Whilst the timetable for Project Year Two remains unchanged, apart from a few minor revisions (underlined below):

Task	Project months	Comments
Undertake interim analysis of data – identify emergent issues and themes (hypotheses), to be followed up in next phase of fieldwork.	13-16	The interim analysis of data will be given priority. However, in order to avoid 'losing' important field-contacts, or damaging existing relationships, some fieldwork will be undertaken during this period.
Present interim findings to management of First Step Trust - elicit feedback and 'member validation'. Comments will be incorporated in the interim report and used to help guide subsequent fieldwork.	<u>17</u> (was month 16 previously)	
Write interim report - summarise interim findings and incorporate user feedback.	<u>18</u> (was month 17 previously)	
Commence Phase 2 of Fieldwork - use same methods as in Phase 1.	<u>19-26</u> (were months 18 and 25 previously)	