

Experiences with early intervention in schizophrenia:

An ethnographic study of assertive community treatment in Denmark

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Abstract

The thesis presents a person-centred ethnographic study of individuals' experiences following first-episode psychosis as they received treatment and support from the OPUS early intervention programme in Copenhagen, Denmark. It describes individuals' struggles to come to terms with overwhelming experiences during their psychosis, and their engagement in identity work as they reconstructed individual life projects. Examining individual-society relations, it is a study of health and social policy in practice, from an existential and cultural phenomenological perspective.

The researcher took an active membership role – as evaluator – in the programme, and fifteen key informants described their situations and experiences during in-depth interviews and through written narratives. The longitudinal design allowed for individuals' changes in attitudes and life circumstances to be described, and for a dialogical approach.

The study explores the community intervention programme from the recipients' perspectives, examining individual processes of transformation in the event of serious psychiatric diagnosis. It describes their social roles in their relationship to treatment staff, their views on medication, and the workings of the therapeutic interventions through psycho-education, multiple-family groups, and social skills training groups. Processes of recovery are analysed as symbolic healing. The OPUS organisation, as well as the general Danish welfare system and the labour market, determined the life choices available to these individuals and their possibilities for social integration. Informants' experiences of mental illness and mental healthcare constituted existential crises in which their senses of ontological security were suspended as their lives were disrupted. While some informants chose a strategy of 'sealing over' their experiences others 'integrated' them in various ways: either by dogmatically endorsing one particular explanation or by combining different systems of explanation from the cultural repertoire in a creative analytical and theory-building work of *bricolage*. Re-establishing a sense of biographical continuity – connecting the individual's past, present and future – was crucial to each person's sense of self and experience of recovery.

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Chapter One

Introduction

This thesis presents an ethnographic study of individuals' experiences with early intervention in schizophrenia. The study was carried out from April 1998, and over the following three and a half year period, in the OPUS project, which is located in Copenhagen, Denmark, and which provides assertive community treatment to persons between 18 and 45 years of age following their first episode psychosis. The study presents an inside perspective on mental health care – describing the intervention through individuals' experiences, positioned within a specific historical, cultural, social, and institutional context.

Taking the perspective of recipients of the intervention the study examines a process of transformation. It describes individuals' struggles to come to terms with overwhelming experiences during their psychosis, and their engagement in identity work as they (re-)construct individual life projects. The epistemological position of the study rests on a conceptualisation of the self as a process rooted in the embodied human condition (Csordas 1994a), evolving in a dialectic between the individual and society (Jenkins 1996). Individuals are active and creative agents enabled and constrained by the opportunities of activity, social interaction, and understanding available due to their individual predicaments, the interventions of mental health institutions, and the overall society.

The study presents an existential perspective on mental illness by investigating individual meanings of people with psychiatric diagnoses. Based on ethnographic material and prospective longitudinal individual interviews with fifteen recipients of the OPUS intervention the study provides in-depth empirical evidence demonstrating the workings, benefits, and failings of the intervention, given specific circumstances. The study explores aspects of 'the self' during the course of early intervention in schizophrenia, and it makes a theoretical contribution to the understanding of processes where individual, social, and cultural predicaments and resources facilitate progress in

recovery or lead to detrimental developments. The category of 'schizophrenia' is presumed to be a social and cultural reality in the field of investigation.

The overall policy-directed conclusion which can be drawn from the study is that a time-limited concentrated effort to provide individuals who for the first time experience serious mental illness with support to control and understand their difficulties, and establish individual life projects, does provide valuable resources to (re-)construct for them a useful position in society and a secure sense of self.

This chapter goes on to present the focus of the study, and after considering the reality of mental illness the approach is clarified in relation to the main anthropological and sociological studies in the field. The chapter ends with an overview of the chapters to follow.

Focus of the study

The study follows a general trend in contemporary social sciences of examining *individual-society relations*: how personal organisation and experience relate to sociocultural forms (cf. Cravalho 2001: 205; Hollan 2001; Jenkins 1996). It examines whether and in what ways the relationship with the mental health institution influences the recipients' life situations, social roles, and self-perceptions. This approach is similar to recent attempts in sociological studies of mental health to relocate attention from disease categories to personal experience (Barham and Hayward 1990, 1995, 1998; Estroff 1989), a general perspective in research on health that is suggested by anthropological studies of illness narratives (Becker 1997; Kleinman 1988b). Rogers and Pilgrim (1993: 612) have observed that even if a growing culture of consumerism has led to an increased sociological interest in lay views on physical health, illness and medicine, psychiatric patients are still largely seen as passive victims, and little is to be found in the literature on their views of their experiences. This study seeks to counter this neglect, and, more specifically, it meets appeals for in-depth ethnographic studies of the lives, social circumstances, and experiences of individuals diagnosed with serious mental health problems (Barrett 1996: 303; Barham and Hayward 1998; Cohen 1992a, 1992b; Estroff 1989; Hopper 1992; Lorencz 1992: 259; Sartorius 1992; Sayre 2000: 72; Strauss and Estroff 1989; Warner 1992; Waxler-Morrison 1992).

The study explores two main dimensions: the intervention programme and the experiences of individual recipients. First, the assertive community approach applied in the intervention programme OPUS is an innovative therapeutic and socially regulative technique in the area of mental health care which supplements, and in many cases substitutes for, the earlier means of segregation by incarceration in a state asylum or hospital, famously described by the sociologist Erving Goffman (1961) as a ‘total institution’. Studies have questioned the extent to which in-patients adopted the notion of being ‘mentally ill’ (Estroff 1993; Estroff *et al.* 1991; Sayre 2000; Townsend 1976), but, even so, the individuals had to regulate their social identities to the role as inmates encompassed within the totality of the institutional structure, the restricted space, the techniques of physical enforcement, the social hierarchy, and the strict rules of interaction (cf. Van Dongen 1997). Outside the walls and the rigid social structure of the asylum this study investigates how the new community approach affects the lives and self-perceptions of the individuals who are recipients of the intervention. In areas of social and health policy in contemporary Western welfare societies time-limited intervention programmes are currently widely implemented to supply individuals with ‘treatment’, ‘support’, or ‘help’. Formalised programmatic guidelines, such as ‘treatment manuals’ and ‘protocols’, direct these interventions in a language stressing the control and reliability of the interventions. In the area of health policy the language resembles the discursive paradigm of the clinical trial. In social policy the phrases are increasingly taken from the discourse of management theory, emphasising ‘control parameters’ and ‘personal development’ (Mik-Meyer 2001). But the workings of the intervention, on an individual level, are largely unexamined – the intervention appears as a ‘black box’. The ethnographic approach of this study allows insight into the workings of the OPUS intervention programme, uncovering the mechanisms of the combined social and health policies. In the light of increased international attention given to ‘early intervention in psychosis’¹ (Birchwood *et al.* 2000a, 2000b; McGorry 1995; Spencer *et al.* 2001) the study examines the situation of recipients of such an intervention, simultaneously considering individuals’ responses to having had these extraordinary mental experiences as well as considering the context of their lives and the culture and society they inhabit. This focus of the study is, furthermore, pertinent

¹ The ‘International Early Psychosis Association’ (IEPA) is dedicated to the issue, and can be visited on

due to the obligation of mental health policy to take account of the meaning to the individual of going through ‘the ordeal of becoming a mental patient’ (Barham and Hayward 1995: 156).

Second, as health and social policy provides people ‘in need’ with special resources, support, and treatment, the ‘targeting’ provides them with a social classification which can be stigmatising (Jenkins 2000: 19). To qualify as recipients of the intervention they are identified or ‘objectified’, e.g. by receiving the diagnosis ‘schizophrenia’, which can conflict with their self-perceptions (cf. Estroff 1989: 192; Jenkins 1996, 2000). This study explores identity as negotiated in a social and cultural context (Jenkins 1996), and thereby challenges reified notions of the pathological characteristics of the self in schizophrenia. The *transformation of self* (cf. Csordas 1994a) has been theorised as a social and interpersonal process following the onset of schizophrenia (Estroff 1989, 1993; Estroff *et al.* 1991) and is central to some theorising on recovery from schizophrenia (Davidson and Strauss 1992; Mountain 1998). This study adds to these approaches by providing a detailed ethnographic account of individuals’ experiences in the period following the first contact with the mental health services and focusing on individuals’ reflections and strategies with regard to their life projects²: what they aim to achieve and how they perceive the course of their lives. The study brings *experiential specificity* to the understanding of how the intervention programme affects the participants.

These dimensions of the study are integrated in what can be called a *cultural phenomenology* in the sense, following Thomas Csordas (1994a), that it ‘represents a concern for synthesizing the immediacy of embodied experience with the multiplicity of cultural meaning in which we are always and inevitably immersed’ (*ibid.*: vii). The approach affords individuals’ experiences a central place in the description and analysis of social and cultural phenomena, and it can be understood as ‘a counterweight and complement to interpretive anthropology’s emphasis on sign and symbol’ (*ibid.*: 4; see also 1994c: 10-12). This study does not, however, present an anthropological

the Internet: <http://www.iepa.org.au/>.

² The concept ‘life project’ has previously found use in a British study of how individuals with a history of mental illness cope as they have been relocated from psychiatric hospitals to the community (Barham and Hayward 1995). ‘Life project’ refers to a continuity in the entire life span of an individual, already lived as well as anticipated (see e.g. Csordas 1994d: 285), whereas, for example, ‘life plan’ directs attention towards the individual’s future (*ibid.*: 270, 272, 278).

examination primarily of *bodily* experiences, such as sensations and emotions (e.g. Jackson 1994; Jenkins and Valiente 1994; Low 1994), but seeks a wider consideration of individual, interactional, and institutional aspects of the lives of embodied individuals in the human world (Jenkins 2002: 6, 68-76, 139-46). The study poses the broad research questions: *What does the community mental health intervention programme mean to the recipients, and how does it affect their understandings of themselves?*

Mental illness and identity: A theoretical perspective

Individuals' experiences of and strategies in relation to mental illness are examined in sociological and anthropological studies with attention to the concept of *identity*, highlighting issues of stigma, social role, individual understanding, and the social consequences of psychiatric treatment. The anthropologist Sue Estroff (1993) examined the psychiatric notion of 'chronicity' in schizophrenia and pointed out that it is a result of a process where persons diagnosed and treated as having schizophrenia over time not only are being identified (by others) as being 'schizophrenics', but also identify themselves as such. The diagnosis becomes a dominant characteristic of the person. Estroff writes that 'chronicity consists of a fusion of identity with diagnosis' (1993: 251).

We observe a constriction of social roles and identities to a core of patienthood and disablement, and an engulfment, loss, and often unauthorised but nonetheless demoralising change of self from a person who *has* an illness to someone who *is* an illness or diagnosis (Estroff 1993: 251, italics in original).

Reinforcing the fusion between diagnosis and individual identity and establishing the chronicity of the condition, Estroff asserts that in Western cultures schizophrenia is an 'I am' illness (Estroff 1989, 1993). You *are* schizophrenic, as you are an alcoholic and an epileptic, whereas you *have* cancer and multiple sclerosis. She argues that this difference in terminology and conceptualisation of the varying illness conditions cannot be related to the severity of dysfunction and persistence in time. Instead, she suggests that the difference is due to culturally specific notions of whether blame for the condition can be referred to the individual suffering from it (1993: 257). It is a *moral* issue. The conceptualisation of the chronic condition of schizophrenia is directly related to culturally specific understandings and values (cf. Barrett 1998) and the individuals'

own perceptions of their situations, conditions, and opportunities – but it is also related to the actual social interaction involving the person suffering from the illness condition:

In the West, adults with unresolved, serious illnesses, especially schizophrenia, frequently fail to attain or retain the expected roles of student, employee, spouse, and parent. Thus, the opportunity to experience self and receive self-influencing indications from others that are other-than-illness-related constricts over time. ...//... *The progressive role constriction accompanying chronic illnesses contributes to simultaneous loss of valued, competent-role experiences and an increase in devalued, incompetent roles and experiences* (Estroff 1993: 259, italics in original).

Social interaction and the assumption, or denial, of specific social roles are thus integral to the development of schizophrenia as a chronic condition.

Theoretical developments of the concept of identity have emphasised that identity is not only a social role immersed in a cultural context of meaning. Richard Jenkins (1996) conceptually identifies two core aspects of identity. First, he states that identity is *nominal*: it is social and cultural by being connected to a name, a concept, which is related to a specific social and cultural context. Secondly, identity is *virtual*: it has specific and individual consequences to the person who is carrying it, both by the way it is experienced, felt, and given meaning by that person and by the way the identity is interpreted by others when carried by that particular person (Jenkins 1996: 24).³ The two aspects of identity are parallel dimensions, or two sides of the same coin.

The self is, therefore, altogether individual and intrinsically social. It arises within social interaction. It is constructed within the *internal-external dialectic of social identification*. It draws upon the external social environment of people and things for its content. Even though it is the most individualised of identities – we might call it customised – selfhood is absolutely social. It depends for its ongoing security upon the validation of others, in its initial emergence and in the dialect of continuing social identification (Jenkins 1996: 50, italics added).

This conceptualisation of self and identity draws the attention to interaction between the social processes of categorisation of mental illness and the individual experiences and

³ This distinction is not to be confused with Goffman's (1963) notions of *virtual* and *actual* social identity, which describe the difference between what we, as a first or uninformed impression, perceive of people, and who they 'in fact' are. Whereas Goffman here is concerned with the quality of our perceptions of others, Jenkins's conceptual distinction between *nominal* and *virtual* addresses the difference between social classification and its consequences for the individual.

strategies involved in dealing with this (see also Jenkins 2000). Examining these dynamics, Thomas Csordas (1994a) suggests a theoretical conceptualisation of *self processes*, supported by Merleau-Ponty's concept of the preobjective (Csordas 1994a: 7ff.; 1994c: 7), to define the self as 'the processes of orientation and engagement in which the person becomes objectified' (1994a: 278). The phenomenological notion that *our perception does not start but ends in objects* (Merleau-Ponty 1962: 76, in Csordas 1994a: 7) takes account of the richness and indeterminacy of perceiving and the human inclination to reflect and objectify. That is why phenomenologists suggest that the starting point of analysis has to be rooted in the embodiment of the human experience being-in-the-world.

In a society mental illness can be considered part of the subject, as Estroff argues, but in the critical analysis it is important to recognise that this is a result of a culturally specific process of objectification. The analysis has, in other words, to examine the social and conceptual processes by which an individual is afforded the identity as mentally ill, and not to take it as a categorical point of departure. Supporting this theoretical argument with empirical insight, Barham and Hayward (1998) claim that part of the problem for users of mental health care and treatment is that they, through psychiatric theory and practice, have been deprived of being thought of *as persons* – they have 'to a large extent been lost to the disorder' (*ibid.*: 165). Barham and Hayward assert that '[t]o have undergone a schizophrenic breakdown is to have been dispossessed of one's right to think about oneself as a person. Instead, the person's concerns about himself or herself as person have been made subordinate to an identity as a schizophrenic' (*ibid.*). The authors have argued that social research should get closer to the situations and experiences of the people who are labelled and treated as mentally ill. This suggestion mirrors ideas to reform psychiatric practice (Kleinman 1988a; Strauss 1989).

Barham and Hayward (1990) suggest an approach in which individuals who are users of psychiatric institutions are considered as agents within individual life processes, and where the analytical focus is to describe their situations and experiences (see also Koegel 1992). Taking a theoretical approach, Ian Craib (1998) has emphasised the need in social studies to focus on the process of internal negotiation involved with regard to individual identity – taking the experiences, feelings, and thoughts of the

individual into account. In line with this suggestion, Barham and Hayward (1998) claim that another picture of the users of mental health services appears when the researcher listens to what is being said by the people themselves. They show how Ben, a 'chronic schizophrenic patient', has gone through many stages in his life with different attitudes and strategies towards assuming, rejecting, covering, and accepting an identity as mentally ill. Depending on the situational context, Ben is sometimes identified solely as mentally ill, for example when he acts as a representative for the mentally ill in advocacy work. In other situations he is known by his status as a musician and as a Catholic in the local church, where he plays the organ. In the latter situation his identity as mentally ill is 'a silent part of the self', as Barham and Hayward explain (*ibid*: 169; see also 1995: 124-33, 155).

Theoretical considerations about identity apply generally to the study of individuals as agents within individual life processes, but, more specifically, they are central to the investigation of how individuals create personal meaning out of their experiences the first time they have serious mental problems and receive mental health care. The investigation of individual meaning has been described as an *existential* perspective on mental illness (Mountain 1998: 16, 150). Defining the locus of human life in our embodied existence, being-in-the-world, the philosophical tradition following Merleau-Ponty apprehends human life as suspended between truth and absurdity, meaning and lack of meaning (Grøn 1991: 332ff.). The individual can achieve meaning, and the absurd presupposes the possibility of its turning into something which has meaning. The existential perspective raises questions such as: How do people cope with the experiences of serious mental illness, such as a psychotic episode? What are the implications for individuals of the treatment and intervention programmes offered to help them? Does the experience influence their lives, their future expectations, and their understandings of themselves? To find answers, the existential and cultural phenomenological perspective on self processes (cf. Csordas 1994a) applied in this study directs the analytic focus towards the experiences, interests, and aspirations of the individuals in question, and towards the ways in which they seek to create meaning out of their perceptions and life circumstances, relying on the possibilities or obstacles

provided in their near social and broader cultural and societal⁴ environment. Before commencing this endeavour, I will outline my position with regard to the reality of the phenomenon of 'mental illness' and present an overview of key studies in this field of investigation.

What is schizophrenia?: The reality of mental illness

The World Health Organisation's tenth revision of the International Classification of Diseases (ICD-10) criteria for 'schizophrenia spectrum' diagnoses (WHO 1993) was used to include recipients of the OPUS intervention. The spectrum includes the main groups: schizophrenia, schizotypal disorders, persistent delusional disorders, acute and transient psychotic disorders, induced delusional disorders, schizoaffective disorders, other nonorganic psychotic disorders, and unspecified nonorganic psychosis (*ibid.*: 64-76).

Schizophrenia is described as 'an illness which is characterised by various symptoms, including auditory hallucinations, bizarre and irrational beliefs, disordered thought as manifest in incoherent speech, poverty of affect, and social withdrawal' (Bentall 1990b: xi). While 'florid psychotic' experiences of hallucinations and bizarre beliefs often begin in the early twenties, some endure only one episode, some experience several single psychotic episodes during their lives, and others never fully escape the psychotic perceptions (Asser *et al.* 1997: 27-32). In 1994 the ICD-10 introduced formal criteria to improve replicability of the diagnoses, defining them strictly by symptoms, or clinical appearance, and not aetiology (*ibid.*: 39). Unlike the former diagnostic practice of sometimes waiting up to several years before determining a case of 'schizophrenia' (*ibid.*) the diagnosis should now be given when specified symptoms of mental and behavioural disorders had been 'present for most of the time during an episode of psychotic illness lasting for at least 1 month (or at some time during most of the days)' (WHO 1993: 64).

Tracing the cultural origin of the concept of schizophrenia, the anthropologist and psychiatrist Richard Barrett (1996) found that it developed as an antithesis to the ideal notion of the rational, self-controlled, and autonomous person in Western thought.

⁴ The distinction between 'social' and 'societal' emphasises the difference between the *interactional* aspects of individuals' lives and the *institutional* arrangement of the particular society in which they live and interact (cf. Jenkins 2002: 68-76).

He discovered the dual origin of the concept in the ideology of degeneration and the notion of the split person which prevailed in Western scientific, as well as common sense, thought during the nineteenth century (*ibid.*: Chapter 7). Further, Barrett (1998) has suggested that 'schizophrenia' has cultural meaning as a category of a 'liminal persona' in modern society.

In 1860 the French psychiatrist Morel introduced the term *démence précoce* to describe the situation when a patient suffers a rapid mental deterioration (Barrett 1996: 193). Between 1883 and 1915 the German psychiatrist Emil Kraepelin took up a Latin version of the term, *dementia praecox*, in the course of a series of classificatory attempts to combine diagnosis with prognosis. Hence, the concept developed from a paradigmatic case report to become one of the major classes of psychiatric disease, primarily defined by the notion of degeneration and loss of inner unity (*ibid.*: 207ff.). Throughout the nineteenth century German psychiatric theory, inspired by the philosopher Kant, idealised individual freedom of the will and unity of consciousness. Seeing the 'splitting' of psychic functions as one of the most important characteristics, Bleuler renamed the category *schizophrenia* (*ibid.*: 208).

Mary Boyle has claimed that 'by the first decades of the twentieth century the concept of dementia praecox/schizophrenia appeared to have taken on a life of its own, quite detached from any consideration of its origin' (1990: 18). Following the (blind) professional acceptance of the validity of 'schizophrenia' as a diagnostic category, patients' behaviour and mental states have been claimed to be symptoms of the particular disease syndrome assumed to cause them. The assumed symptoms thus legitimise the particular diagnosis, but, Boyle argued, in a tautological and thus epistemologically invalid fashion (*ibid.*: 14). In her harsh verdict she concluded that 'the concept is as obstructive to attempts to describe links between biological variables and behaviour as it is to attempts to describe links between social/psychological variables and behaviour' (*ibid.*: 20).

In the same collection of critical articles (Bentall 1990a) Richard Bentall examined the problems of validity and prediction attached to the diagnosis of schizophrenia. He claimed that 'it is possible that schizophrenia is not a meaningful scientific concept and that it should therefore be abandoned along with all the other meaningless concepts (for example, the four humors, phlogyston, the luminiferous

ether) which have been cast aside by scientists during crucial periods of scientific progress' (Bentall 1990c: 24). As an alternative he suggested that attention should be directed towards the symptoms of psychosis, and that we, for the time being, are better off discarding efforts to sustain the notion of a particular syndrome, or disease, underlying these symptoms (Bentall 1990c). Barrett, also, suggests that it might be more useful for psychiatric research to 'suspend belief in schizophrenia temporarily' and instead categorise people in a way that is 'less steeped in our cultural history, for example people who experience hallucinations or who manifest thought disorder' (Barrett 1996: 305). Stressing the need to overcome the biological reductionism dominating research on mental illness, Bentall pointed out that in order to improve the situation of individuals diagnosed with schizophrenia a broad understanding of their, often very difficult, life circumstances has to be considered (Bentall 1990d: 294ff.).

Diagnostic uncertainty regarding the category 'schizophrenia' has also been revealed by the psychiatric practice of changing the diagnosis (Asser *et al.* 1997: 41), especially following first episode psychosis (McGorry 1995: 314-9; Birchwood *et al.* 2000b: 93-4, 99). While some diagnostic practices allowed the diagnosis of schizophrenia to be changed if the patient proved to have a more positive development than initially expected (Benjamin 1989: 291), the formal criteria in the ICD-10 system, based on the one-month duration of symptoms, does not facilitate this. Regardless of its shortcomings Barrett observed that in the meantime 'schizophrenia finds its principal use in psychiatry as a working concept that is good enough, more or less, for practical purposes' (Barrett 1996: 255).

The purpose of this thesis is not to examine the validity of the concept of schizophrenia, nor to develop or establish the usefulness of alternative concepts. Schizophrenia is in this thesis an *emic*⁵ concept in the 'local culture' of the psychiatric profession, and has a direct bearing for the research only insofar that it is a category used in a practice of 'administrative allocation' (Jenkins 2000: 18) to include or exclude individuals as recipients of the OPUS project. In this way it establishes a culturally-specific local framework of conceptualisation in the field of investigation. Thus, schizophrenia is conceived as a *cultural and social reality*.

⁵ The concept 'emic' refers to the meaning as understood by people themselves, in contrast to the 'etic' analytical understanding. The pair of concepts originate from linguistics (phonemic versus phonetic) and was introduced to anthropology by Marvin Harris in 1964 (Eriksen 1993: 28).

The psychiatric classification of the individual experience of psychosis as a mental illness will not be challenged in this thesis. In writings on the subject of mental illness in social sciences it is imperative to explicate the stance taken towards the reality – or ontological status – of the phenomenon of mental illness. As Bentall observes, 'arguments about the nature of psychiatric disturbance have become polarised and bogged down in the rhetoric of competing ideologies' (Bentall 1990b: xiv). Much of the animosity in the debate between critical social thinkers and representatives from the biomedical psychiatric profession seems to derive from this polarisation.

Joan Busfield has brought some clarity to the controversy by suggesting that the claim that *mental disorder is a 'social construct'* is presented with two significantly different meanings by critical social thinkers (Busfield 2000: 546ff.). Some merely mean that mental disorder, and the psychiatric classification of 'mental illness', is a social category – 'that it is a product of how humans think about and act in the world'. Others take it as 'an ontological claim that mental disorder is *only* a category and does not refer to any objective reality' (*ibid.*: 547). The latter radical social constructivist position has been taken in some critical writings (e.g. Szasz 1961, 1970), claiming that mental illness is merely a label, or a metaphor, affording illegitimate authority to what, in fact, is a moral judgement of people who are considered deviant in a given society and culture. Alternatively, Busfield adheres to Rosenberg's (1992) notion of the 'social framing' of illness and disease, indicating 'that the way we understand illness varies across time and place, but does not suggest any denial of the material reality of the phenomena that come to be constituted as disease or disorder' (Busfield 2000: 547). I agree with this position, insisting that social and cultural factors influence the course and severity of mental illness in an individual (cf. Busfield 2000: 550), while at the same time acknowledging the relevance of a biomedical perspective in understanding and dealing with mental illness.⁶

Social studies of mental illness, as well as my experience from two years of ethnographic fieldwork, and personal contacts as well as numerous interviews with patients of psychiatry, have convinced me that there is a reality to mental illness, beyond the label and the social classification. Drawing on personal experiences with

⁶ Applying a phenomenological approach highlighting the importance of embodied experience, Thomas Csordas (1994d) has contributed to this debate by pointing out the inadequacy of the single-minded perspectives both of *biologism* and of *sociologism* (*ibid.*: 287).

extreme mental states during dreams, nightmares, and drug-provoked hallucinations, as well as mediated experiences⁷, it is possible for the lay person to empathise with the overwhelming and ‘anomalous’ experiences of a person enduring a psychotic episode. The extremity of the experiences is furthermore apparent by the frequent ability of ‘the mentally ill’ themselves retrospectively to identify situations when they were psychotic and when they were not. There is no doubt that these experiences for the individuals cause significant impairment to their abilities to engage in the normal daily life, not the least social activities. My conviction that mental illness ‘is real’, however, strictly refers to the state and experience of psychosis (cf. Barrett 1996: 305; Bentall 1990c: 24); hence, it is not support for the validity of the category of schizophrenia or the psychiatric classification of any other mental states or human behaviours, which in any given historical time and socio-cultural setting are claimed to be mental illness.⁸

Critique of the biomedical model of mental illness

Anthropological studies of health and the treatment of human illnesses – specialised in the discipline of medical anthropology (see e.g. Helman 2000) – distinguish between the concepts of ‘illness’ and ‘disease’ (Kleinman 1988a: 7; 1988b: 3-6). *Illness* refers to the patient’s perception, experience, expression, and pattern of coping with symptoms, and suggests an analytic perspective on the phenomenological experiences and sensations of the individuals suffering from these conditions. *Disease* refers to the way practitioners interpret illness in terms of their theoretical models of pathology, and suggests an analytic perspective on the local professional interpretative attempt to name and understand the experiences and sensations of the individual through the diagnostic practice and system of categorisation immersed in cultural symbols and institutionalised conventions. A third distinction is made in the concept of *sickness*, which Kleinman has defined as ‘the understanding of a disorder in its generic sense across a population in relation to macrosocial (economic, political, institutional) forces’ (1988b: 6). For

⁷ Insight can be found both in documentary writing, such as Susanna Kaysen’s autobiographical book ‘Girl, interrupted’, and fictional writing e.g. in classical works by Franz Kafka, on delusions and psychotic sensations of paranoia, and Dostoyevsky, who demonstrated insight into psychotic experiences, particularly in ‘Crime and Punishment’ and ‘The Double’.

⁸ See, for example, Manning (2000) for a critical sociological discussion of controversies regarding the classification of personality disorder.

example, how a period of economic crisis affects the occurrence of depression in a population.

The distinction between the concepts of illness and disease helps us to see that the individual *experience* of mental illness is real, but, also, that this experience is immersed in a specific culturally and socially meaningful context, and that the *classification* of the illness experience as a certain psychiatric disease is a specific cultural, social and historical product. The anthropologist and psychiatrist Arthur Kleinman has introduced 'a framework of cultural criticism' (1988a: 4):

From a cross-cultural perspective the fundamental questions in psychiatry – how to distinguish the normal from the abnormal; how disorder is perceived, experienced, and expressed; why treatments succeed or fail; indeed the purpose and scope of psychiatry itself – all are caught up in a reciprocal relationship between the social world of the person and his body/self (psychobiology). For the anthropologist, the forms and functions of mental illness are not 'givens' in the natural world. They emerge from a dialectic connecting – and changing – social structure and personal experience. ...//... *Mental illnesses are real; but like other forms of the real world, they are the outcome of the creation of experiences by physical stuff interacting with symbolic meaning.* (Kleinman 1988a: 3, italics added)

Human life is intrinsically social and infused with cultural meaning. Clifford Geertz (1973) has described it as being in a 'web of culture', while Bourdieu (1990: 52-79), with his notion of *habitus*, has argued that our socio-cultural shaping has to be conceived of as radically conditioning us as individuals. A similar perspective is found in the phenomenological notion that the reality of the experience of life, and the way we are objectified as persons, being-in-the-world, is inseparable from the cultural and social systems (Csordas 1994a, 1994b). Our individual lives and identities are inseparable from our social being and positioning (Jenkins 1996).

The critical perspective in social studies of mental illness as a social construct is in contrast to a common positivistic bias of psychiatrists (Kleinman 1988a: 11; Luhmann 2000: *passim*), expecting the diagnostic classifications to be more or less material objects, which, independent of cultural and social environments, are located and can be identified in the physical world (the human body, brain, or DNA). Kleinman (1988a) emphasised the value of a critical cultural perspective on the practice of psychiatry, with the intent that this will encourage different norms and expectations in

varying cultural contexts being taken into account in the classification of mental pathology. He gives an example of how in many native American groups it is common that a person who has just experienced the death of a spouse can report to be hearing the voice of the dead spouse calling to them as the spirit travels to the afterworld (*ibid.*: 11). He writes that a North American psychiatrist may classify this experience as a hallucination and a symptom of mental illness. But Kleinman cautions: ‘The reification of one culture’s diagnostic categories and their projection onto patients in another culture, where those categories lack coherence and their *validity* has not been established, is a *category fallacy*’ (*ibid.*: 14-15, italics added). He thus points out the importance to psychiatric practice of not just taking account of the reliability of a diagnosis, i.e. whether it can be reproduced independently of the person diagnosing, but also of considering the validity of the diagnostic system, i.e. whether it is applicable to the setting in which it is being used.

Diagnostic practice in psychiatry is, compared to most other medical disciplines, especially problematic because psychiatric disorders are only in part, and only for certain disorders, a result of biological abnormality. There exist no blood tests, x-rays or brain scans to establish the correctness of a psychiatric diagnosis of, for example, schizophrenia. Furthermore, psychiatric complaints can be hard to distinguish from other ordinary kinds of human misery caused by life events such as death, injustice, failure, unemployment, social isolation and physical illness.

Whether an individual’s experience or behaviour is categorised as a symptom of a mental illness is also in a more profound and direct way related to the specific culture, society and historical time. Diagnostic criteria are not permanent, but negotiated and disputed. At present two different diagnostic systems are used in the Western world: the earlier mentioned ICD system of the WHO and the American Psychiatric Association’s ‘Diagnostic and Statistical Manual of Mental Disorders’ (DSM). The two diagnostic systems have, over time, appeared in respectively ten and four different versions. Cross-cultural psychiatry has demonstrated that the appearances of psychiatric disorders are specific to certain areas: such as ‘semen loss’ in South Asia (Kleinman 1988a: 15) and possibly ‘agoraphobia’ and ‘anorexia nervosa’ in the West and among the Westernised elites of developing countries (*ibid.*: 3). The cultural shaping of mental conditions is acknowledged in the ICD-10 guidelines where culture-specific disorders

are described (WHO 1993: 176-87). History, too, teaches us to be cautious. The fact that the American Psychiatric Association classified homosexuality as a mental illness until the year 1973, speaks for itself (Busfield 1986: 55; Luhrmann 2000: 223).

It has been observed that in contemporary societies social problems are increasingly being medicalised (De Vries *et al.* 1983; Helman 2000: 114-7; Kleinman 1988a: 9). An example is alcoholism, which in Western societies was earlier considered a sin or moral weakness, but is now designated a mental disorder; likewise a wide range of experienced problems of daily living are called stress syndromes (Kleinman 1988a: 9). Even if genetic factors and physiological processes can be proven to be involved in the aetiology and course of an illness, Kleinman argues that medicalisation 'is an alternative form of social control, inasmuch as medical institutions come to replace legal, religious, and other community institutions as the arbiters of behaviour' (*ibid.*).

Medicalisation may in some situations authorise useful social change that is otherwise politically unacceptable. In America the disability system has redistributed income in a situation of economic downturn by medicalising problems of poverty, under- and unemployment and worker alienation (Stone 1984, in Kleinman 1988a: 9), and the medicalisation of mental illness is a strong political argument for the allocation of scarce resources (Estroff 1993: 270ff.). On the other hand, the process of medicalisation may trivialise or deny social problems by individualising the problems experienced by the individuals. And medicalisation can be used for political ends, an extreme example of which was the practice in the former Soviet Union of diagnosing political dissidents as mentally ill, so that they could be pacified by isolating and disciplining them in prison hospitals (Kleinman 1988a: 10; Manning 2000: 634).

Studies of diagnostic procedures question the prevalent positivistic assumption inherent in psychiatric notions of mental illness (Ingleby 1981; Kleinman 1988a; Jenner, Monteiro and Vlissides 1986; Luhrmann 2000). Psychiatric diagnosis is an interpretative social event, where questions of mental illness are determined and defined by a powerful social actor, the psychiatrist, on the basis of the individual's social behaviour, i.e. actions and verbal or otherwise explicit communications of the individual's inner sensations and experiences. Given the lack of any objective, physical criteria of identification, the practice of psychiatric diagnosis of mental illness is therefore potentially a disputed area. Psychiatrists generally acknowledge this basic

quality of the diagnostic procedure by referring to its 'phenomenological character', going back to the work of the German philosopher and psychiatrist Karl Jaspers (Jenner, Monteiro and Vlissides 1986).

While some argue that the psychiatric diagnosis represents an especially qualified form of 'ethnopsychology', due to the formal procedures of diagnosis and peer monitoring (Bowers 1995: Chapter 5), the actual use of this ideal formalistic procedure has been questioned by empirical evidence. Tanya Luhrmann (2000) has demonstrated that the personal experience of the psychiatrist plays a significant role in the determination of the diagnosis. The diagnostic practice is not a straightforward formalistic procedure, but a complex affair more to be likened with the mastery of a game, where judgements are intuitive to the competent player.⁹ In support of this observation it is acknowledged within the psychiatric profession that there is considerable inconsistency in diagnostic practices, even within a limited cultural and geographical area. For example, medical researchers on the OPUS trial study observed different 'diagnostic cultures' between hospitals and stressed the need for special 'research diagnostic criteria' when comparing outcomes from various therapeutic interventions (Jeppesen 2001: 65).

Another critical sociological perspective on mental illness has been provided by studies describing psychiatric classification as an institutional exercise of power to make moral judgements of deviance (Becker 1991[1963]; Lemert 1952). Michel Foucault has contributed to this perspective with his observation of how power is exercised through the institutional creation of knowledge (1977), and his historical demonstration in 'Madness and Civilisation' (1967) of how psychiatry made 'madness' an object of a moral discourse of salvation through individual responsibility, and introduced a scientific discourse of treatment through scientific medicine. The notion that 'power is everywhere and nowhere' is, however, too imprecise, when adapted from

⁹ In support of this observation Palmer (2000) has argued that a hybrid discipline of 'clinical sociology' should be developed to explicate the internal sociology of the psychiatric practice, creating awareness about the shared, tacit skills used by psychiatrists when diagnosing. Kleinman (1980: 109) has made a similar observation by distinguishing between theoretical and clinical types of practitioners' explanatory models, and by pointing out the need to study the latter in the West.

his study of 'the history of ideas' to specific social interactions (Barrett 1996: 104, 300; Burkitt 1991: 109; Turner 1994: 42-3).¹⁰

The formalistic approach to classification of mental illnesses in psychiatry has been criticised not only for being incorrectly so labelled, and for expressing a suppressive force of power, but, also, for missing out in 'clinical value' by pursuing the aim of 'objectivity' (Kleinman 1988a; Rogers and Pilgrim 1993: 627; Sayre 2000: 72). The Scottish psychiatrist R. D. Laing is famous, and in some social settings notorious, for his rejection of the formalistic approach and for his appeal for an interpretative phenomenological approach to understanding the individual experience of mental illness (Laing 1969). David Ingleby (1981), too, launched a direct attack on the formalistic approach in what he calls 'positivist psychiatry'. He located the problem of psychiatry in the aspiration within the discipline to imitate the positivistic approaches of the natural sciences. The predominance of the positivistic ideal of the natural sciences has political implications when applied to psychiatry (as well as to other human and social sciences), since it proposes a particular relationship between humans, society, and nature. The critique is similar to the above mentioned one regarding medicalisation. By locating mental problems as an illness within the nature (or biology) of the individual, it is possible to identify the particular individual as deviant or ill, and the problem can be dealt with by manipulating the individual (using isolation, therapy, or medication). This represents a conservative political view, since the institutions and practices of the society and culture remain unquestioned in the process. Ingleby and Laing both suggest that the formalistic view of mental illness as a malfunction to be located in the individual should be replaced by an interpretative approach which considers the individual in his or her relation to the social and cultural context.

Mental illness as a social phenomenon

Studies in social epidemiology have found significant social variation in the distribution of identified cases of mental disease in a population, with regard to age, gender, marital status, immigrant status, ethnicity, class, and socio-economic status (see Busfield 1986: 57-64, 2000: 548-551; Clare 1976: 203-210; Pilgrim and Rogers 1999: 25-99). For example, the higher occurrence of cases of schizophrenia in the lowest socio-economic

¹⁰ This observation supports Terence Turner's (1994) argument that Foucault's theoretical project,

groups has been explained both as a consequence of the decline in social status frequently experienced by people enduring severe mental illness, and, with causal effect in the opposite direction, by the psychological stresses created by the more difficult circumstances and events in the lives of people with lower socio-economic status (Busfield 1986: 62ff.; Clare 1976: 204ff.). Others have argued that the difference might be related to variance in the values and perceptions of what constitutes 'abnormal' behaviour between the middle-class and the lower-classes in society (Heller *et al.* 1979), and that the socio-economic status of the patient influences the type of treatment provided (Hollingshead and Redlich 1958, in Busfield 1986: 63ff.).

Busfield (2000: 551) has observed that the position of social epidemiological research has been weakened due to the present hierarchical ranking of the sciences, favouring a biological perspective on mental illness. But this is, also, due to a hostile attitude of some sociologists who view the work of social epidemiologists as insufficiently grounded theoretically. Busfield claims that this critique is largely unjustified and that it 'has tended to undermine rather than strengthen the case for the need for adequate attention to social factors in any examination of the aetiology of mental disorder' (*ibid.*). She argues that the critical and the social epidemiological approaches should be regarded as complementary.

Whole societies have been subjects of research on the occurrence of mental illness in the population. Cross-cultural studies concerned with outcomes after first incidence schizophrenia have found that there is a better prognosis for people diagnosed with schizophrenia in traditional or non-industrial societies than in the so-called 'developed countries'. Compared to outcomes from Western studies Warner (1992) refers to studies showing substantially higher recovery rates from schizophrenia in samples from regions as varied as Mauritius (Murphy and Raman 1971); Hong Kong (Lo and Lo 1977); Chandigarh, India (Kulhara and Wig 1978); Sri Lanka (Waxler 1979); Agar, India; Ibadan, Nigeria; Cali, Colombia; and Taipei, Taiwan (WHO 1979).

The assumption that traditional, non-industrialised societies could offer a better cultural and social environment for, and response to, people with severe mental health problems has been questioned (Cohen 1992a, 1992b). Cohen argued that the undisputed findings were due to a biased idealisation of non-industrial societies (1992a: 54). The

basically, lacked ideological criticism and supported the political *status quo*.

strength of the critique is supported by historical evidence. At the time of the development of psychiatry as a medical discipline, which primarily took place in the imperial Germany in the late nineteenth century, it was a widespread assumption that 'modern culture' or 'civilisation' established conditions for human life which had a harmful effect on 'the nerves' or the mental health (Roelcke 1997). This early sociological perspective on the aetiology of mental illnesses was, however, progressively overruled by a biological, Darwinist perspective focusing on issues of physical impairment, influences of a bad hereditary stock or 'low-life', and racial characteristics (*ibid.*). From this perspective the social and cultural contexts of individuals suffering a mental illness were ignored or, at best, taken for granted, and instead modern scientific psychiatry addressed the notion of the strengths of the individuals in 'the struggle for existence' (*ibid.*: 389; cf. Barrett 1996: 208). In the biological understanding social aspects related to mental illness or health became biologised by trying to find some 'germ' or bio-chemical dimension, such as the consumption of alcohol, related to modern life in the growing cities. But there still remained a critical 'development pessimistic' notion that modern life had the effect of creating a higher proportion of people suffering from mental illnesses with more severe outcomes.

Even if the historical background cautions us to idealise non-industrial 'traditional' societies, ethnographic evidence provides convincing arguments for looking into the effects of specific social organisations and cultural values with regard to the development and course of mental illness. The anthropologist Nancy Waxler (1979) pointed to three factors in Sinhalese culture as determining the milder pattern of illness among people diagnosed with schizophrenia in Sri Lanka: firstly, large, tolerant, and strong families to support the individual; secondly, a treatment system based on short-term care that did not give messages to the person diagnosed with schizophrenia which could prolong the illness; and thirdly, a system of beliefs that explained disease in terms of external causation, which had the effect that the individual did not get stigmatised and believed that the mental illness could be cured. Further, it has been suggested that societies can experience an aggravation in the general mental health due to social change and disorganisation (see Scheper-Hughes 2001: 297-301).

Changing from a cross-cultural to an intra-societal perspective, the ‘anti-psychiatry movement’¹¹ of the 1960s and 1970s introduced notions of ‘the schizophrenogenic mother’ and ‘the schizophrenogenic family’, suggesting that the origin of schizophrenia was to be found in a pathological social relation within the nuclear family (Bateson 1972; Laing and Esterson 1964). Along with the idea of the negative influence of emotional overstimulation, or ‘expressed emotion’, Gregory Bateson’s theory of ‘the double bind’ (Bateson 1972) contributed to this micro-sociological aetiological theory of mental illness. In the 1970s the notions were utilised in an anthropological study of the high occurrence of schizophrenia in Ireland (Scheper-Hughes 2001), but subsequently, the *causal* version of the theory has been generally rejected because it was found that it unjustifiably blamed the close family for the onset of the illness. However, a moderated version still claims its importance as a *recovery factor* (Barrett 1996: 248).¹² With the development of de-institutionalisation and community treatment, the family has become a partner of mental health care¹³, and ‘psychiatric science has dominated family treatment and anti-psychiatry by domesticating them into an overarching bio-psycho-social model that reasserts the priority of biology’ (*ibid.*: 247).

Labelling processes: Social role, stigma, and understanding

Another sociological perspective on mental illness was proposed by Thomas Scheff in his book ‘Being mentally ill: A sociological theory’ (Scheff 1999[1966]). Exploring aspects of other- and self-categorisation (Jenkins 1996, 2000), Scheff presented a normalising perspective on mental illness, by relating it to the breaking of rules in

¹¹ The concept ‘anti-psychiatry’ was originally formulated by David Cooper (1967). It has been argued (A. Laing 1994: 137ff., 186ff.), that the notion of a broad ‘anti-psychiatry movement’ was dubious, since many of its prominent representatives, such as R.D. Laing, Franco Basaglia, Thomas Szasz, Aaron Esterson, and Michel Foucault, personally denounced the notion. Even so, they came to represent it due to the significant public interest in left-wing anti-authoritarian ideas in the period.

¹² Barrett has made an interesting observation of the *technical shaping* of research and theory in psychiatry. He argues, that the continuing widespread use of ‘expressed emotion’ (EE) as a variable in quantitative studies of schizophrenia (e.g. Jeppesen 2001) is largely due to the ease with which critical comments can be quantified by counting their numbers during a specified period of time, producing a dichotomous variable (‘low EE’ and ‘high EE’) whose association with relapse can be determined by statistical means (Barrett 1996: 249).

¹³ While it is generally asserted that the partnership between mental health care professionals and relatives works by providing individuals support from the relatives when living ‘in the community’, Estroff has presented an example where relatives, in distrust of the efficacy of the community treatment, entered a

society and a consequent stigmatising labelling by the individual. He claimed that behaviour and sensations by the individual, which otherwise would have passed as trivial or normal, were considered as signs and symptoms of mental illness when expressed or exhibited by a person labelled with a psychiatric diagnosis. In Scheff's own words:

Following Lemert (1951), the original theory distinguished between primary deviance, such as the hallucinations and thought disorder that are taken to be symptoms of schizophrenia, and those same behaviours as they occur in a person who is aware of his or her label as being mentally ill. The theory proposed that much primary deviance is of short duration or of little significance in the life of the bearer. But when people become aware of their label, they may come to play the role of the mentally ill, at first inadvertently, but later, perhaps, involuntarily. In other words, a group of symptoms may be stabilised, through self-consciousness and reaffirmation by others, as a 'career' of mental illness (Scheff 1999: 158).

The theory was highly influential in sociological studies on the subject in the 1970s (e.g. Rosenhan 1973) after which its popularity started to fall (Hannigan 1999:438; Scheff 1999: x), as it was not substantiated by empirical studies (e.g. Gove 1980; 1982).

The notion of a 'career' as mentally ill was introduced by Erving Goffman as a broad sociological concept referring to a particular social stand of a person's course through life (1961: 119), while the more particular concept of 'moral career' refers to the process for an individual of adjusting to a (potentially stigmatizing) social identity (Goffman 1963: 45-55). These concepts direct attention to the strategies and understandings of the 'mentally ill' themselves – resembling the earlier mentioned research focusing on agents within individual life processes (Barham and Hayward 1990). Due to their direct relevance to the approach adopted in this thesis prominent American and British studies following from this research tradition will now be reviewed in more detail.

The concept of career was adopted by Estroff (1981) in her study of how psychiatric outpatients make a living while qualifying as recipients of disability benefit (see also Angrosino 1998; Braathen 1994). Similar dimensions had been explored in the concept of the 'sick role' (Parsons 1951), which describes how an individual situation

coalition with employees of the psychiatric hospital and lobbied to preserve the beds and jobs of the hospital staff (Estroff 1993: 269).

of illness is examined, negotiated, agreed upon, or rejected in a social setting. Within a particular society there is a certain social role allotted to the ill individual, prescribing socially acceptable behavior, and restricting certain activities as well as giving access to certain rights and benefits (Helman 2000: 85). Fox has argued that the sick role provides 'a semi-legitimate channel of withdrawal from adult responsibilities and a basis of eligibility for care by others' (Fox 1968, in Helman 2000: 85).

A British study found that newly assigned psychiatric in-patients were largely happy to assume the sick role, being passive and receiving treatment (Harold-Steckley 1987: 360). The sick role theory did not, however, sufficiently take into consideration the problem of stigma attached to the role as a psychiatric patient (*ibid.*: 405-8). Another study claimed that stigma was related to traditional stereotypes of madness which through socialisation are learned by the individual along with the modern psychiatric view of mental illness (Lindow 1986: 223). Referring to these stereotypes, several informants in the study expressed fear that their sanity would be impugned if others knew of their visits to a psychiatrist (*ibid.*: 379). Hence, individual strategies towards assuming or rejecting a social role, or career, as mentally ill were significantly influenced by their *understandings* of mental illness. In further investigations of this issue, two American studies (Estroff *et al.* 1991; Sayre 2000) identified, respectively, five and six different 'explanatory models' (cf. Kleinman 1980: 104-118) used by psychiatric patients to make sense of their situations and illnesses. Some of these explanations had positive functions for the individuals, by protecting their self-perceptions and self-esteem against the negative stereotypes associated with mental illness (Sayre 2000: 79).

Lindow (1986: 374) discovered a marked difference between newly-referred and long-term psychiatric patients with regard to the understandings they had of mental illness. While the long-term patients, all but one, held a medical psychiatric model when talking about their problems, the newly-referred patients had a more negotiable view of their troubles (*ibid.*: 374ff.). Out of the twenty newly-referred psychiatric patients interviewed, four had initially been 'guided by their GP from a physical to a mental interpretation of their problems' (*ibid.*: 369). Further, Lindow observed that it was a prevalent occurrence that before the actual first contact with a psychiatrist the patient discussed and negotiated the relevance of a psychiatric perspective and intervention

with family and friends. The informants proved to be highly active in the social management of the potentially stigmatising information about themselves (*ibid.*: 263, 390). This empirical finding has been elaborated theoretically by Peggy Thoits (1984) as a dimension in *self-labelling* processes, and has furthermore been acknowledged by Scheff in his later writing (1999: xii).

Estroff and colleagues examined the relationship of self-labelling as ‘mentally ill’ to individual understandings of the nature, cause and course of mental illness among people diagnosed as having major psychiatric disorders (Estroff *et al.* 1991). They found that those who presented a medical/clinical, or a combined medical/clinical and emotional/developmental explanation of their difficulties were most likely to say that they were mentally ill. In agreement with earlier research (Doherty 1975), the longitudinal study showed that over time mental health patients often changed their statements about whether or not they saw themselves as mentally ill (Estroff *et al.* 1991: 339). The study also suggested a general tendency for participants to un-label themselves (as ‘mentally ill’) over the two years the study was conducted. One year after the first interview was conducted, 43 per cent had changed their self-label. Estroff and colleagues speculated that the hospital context could have played an important role in the self-labelling as mentally ill during the first interviews, and that a change of physical and social environment might account for some of the change in attitude (*ibid.*: 359).

Lindow (1986) found that even within the same interview the informant would change his or her model of reference (or language) according to the aspect of psychiatric patienthood being discussed:

For example, in an account of a GP appointment when referral to the psychiatrist was decided, language was often medical. Informants talked about anxiety, depression and physical changes. The insanity stereotype did leap to mind for some informants at this point, but the language was often medical. When it came to describing attitudes to mental disorder in the workplace, aspects of the insanity stereotype predominated, with talk about being ‘screwy’, ‘crazy’ or ‘mental’ predominating (Lindow 1986: 385).

This finding demonstrates a methodological and analytic weakness in the approach taken in the studies by Estroff and colleagues (1991) and Sayres (2000), where a certain ‘explanatory model’ was assumed to be held by any individual at any given time,

without taking into account the situational context and the effect of the interpersonal exchange when presenting the model (cf. Foddy 1994).

The understandings also influenced *information management strategies* (cf. Goffman 1963: 57-128). Harold-Steckley (1987: 393) found that newly admitted patients who saw mental illness as depression or anxiety – a neurotic disorder – were statistically the most likely to tell family, friends, and work colleagues about their experiences. Those most likely to conceal that they had been psychiatric patients were those who had a negative stereotypical view of mental illness as associated with bizarre, dangerous, or unpredictable behaviour.

The research presented in this thesis explores these issues further through an in-depth longitudinal study of the institutional context of intervention as well as of the experiences, strategies, and reflections of newly admitted psychiatric patients as they pursue an understanding of their situations and a redefinition of their roles in society.

Mental health intervention: Consequences for individual life projects

The thesis examines individuals' experiences with serious mental health problems as psychosis, as well as the objectification they encounter as they become recipients of mental health services. Attempts to control, direct, or change the individuals' attitudes and behaviour are investigated within the institutional context of the OPUS project. While paying special attention to the workings of the intervention programme, to uncover its 'black box' mechanisms, the recipients of the intervention are seen as active and creative agents in a wider cultural, social and societal context. This is especially pertinent due to the community base of the intervention. The approach integrates lessons learnt from cross-cultural studies which demonstrated the need to examine the effects of specific social organisations and cultural values with regard to the development and course of mental illness.

The concept of 'schizophrenia' is taken as a cultural and social reality in the field of investigation. The study examines individuals' experiences of mental health problems as they become recipients of the mental health intervention programme. The focus on self processes directs attention to their understandings of mental illness, to their information management strategies, and to their strategies and opportunities with regard to assuming valued or devalued social roles and experiences.

The consequences regarding individual life projects are examined, as the intervention programme initiates a process of transformation whereby the recipients' understandings and strategies are sought to be strengthened, corrected, or changed through various therapeutic techniques. The analytic concept 'life project' is preferred over, for example, 'career' due to this study's existential focus on individuals' experiences and the way these make sense to them in their lives. This reflects this study's understanding of people diagnosed with mental illnesses as active agents, within individual life processes. The approach favours 'agency' over 'structure', in the sense that human interaction is perceived as the basis of pattern as well as innovation in social organisation (Giddens 1984; Jenkins 2002). Therefore, individuals' motivations for their actions, as well as the opportunities and obstacles that they encounter, are at the centre of the investigation. The self is examined as a process of 'continuous becoming' (Csordas 1994a; Jenkins 1996), affected by individual predicaments, societal institutions, and cultural traditions and understandings. This is a study of individual agency and reflexivity in the period following first contact with mental health care, and in the context of socially and culturally specific constraints and opportunities.

Outline of the thesis

The methodology used to carry out this study is presented in Chapter Two. With the researcher taking an active membership role in the field of investigation, the research was carried out as a person-centred ethnographic study. Longitudinal semi-structured interviews with key informants were supplemented by a multiple-method approach, applying different qualitative and quantitative techniques to describe various social settings and the perspectives of actors within the field.

Chapter Three presents an overview of mental health care in Denmark in the broader perspective of historical studies of Western countries. Consequences of the recent development of de-institutionalisation are discussed, with attention to new forms of community treatment and support. The emergence of the innovative OPUS project, offering intensive treatment and support to first-time psychotic persons, is presented.

Informants' experiences prior to their contact with psychiatric treatment are presented in Chapter Four. Stresses in their life circumstances are described, as well as aspects of their psychotic experiences. These descriptions serve to illuminate individual

difficulties which caused the psychiatric diagnosis and the process of admission to institutions of treatment.

In Chapter Five informants describe their experiences of the diagnostic interviews, which served to clarify their symptoms of mental illness at the time that they were included in OPUS. Informants relate their situations shortly after inclusion and their expectations of the intervention as well as of their future lives.

Chapter Six investigates the individuals' treatment in OPUS. The informants' attitudes to categorisations of them as either 'patients' or 'participants' are discussed, and forms of individual support, as well as the relationship with mental health workers, are investigated. The individual effects and symbolic meanings of the use of psychoactive medication are examined.

Chapter Seven describes social and cultural aspects of the intervention in OPUS. Therapeutic work in multiple-family groups and social skills training groups are investigated. As a process of recovery, the intervention functions as symbolic healing, which presents the recipients with an explanation of their experiences and offers a narrative of their transformation back into health. Further, individual strategies of social relations, and the importance of support from the Danish welfare system are described.

Chapter Eight details the informants' understandings of their experiences of mental health problems and their perceptions of themselves. Special attention is paid to the various systems of explanation which informants used to make sense of their experiences, and to describe the ways in which these were utilised. While some dogmatically endorsed either idiosyncratic delusionary explanations or the biochemical and cognitive psychological explanations provided in OPUS, others engaged in a creative work of *bricolage* to combine, for example, spiritual and psychodynamic explanations. The mental illness caused an existential crisis and informants used the available explanations in the cultural repertoire and a new sense of themselves to re-engage in their individual life projects.

Chapter Nine concludes the study by presenting the main findings. Broader perspectives are outlined in a discussion of individual experience, identity, and the transformation of self during early intervention in schizophrenia. Finally, suggestions for further research are made.

Chapter Two

Method

This chapter presents the design of the research to investigate the research questions: What does the community mental health intervention programme mean to the recipients, and how does it affect their understandings of themselves? The study combines ethnographic fieldwork and longitudinal interviews with key informants, presenting a *person-centred ethnography* (Hollan 2001: 48), focusing on the individuals and how their experiences both shape, and are shaped by, social and cultural processes.

After having introduced the background of the research, I will describe the main areas of the method in more detail: the role of the researcher, the ethnographic approach, the interviews with key informants, the use of a multiple-method approach, an outline of the data forming the body of this thesis, and, finally, I describe the way data have been handled and analysed.

Positioning in the field of research

My entry into the field of research was possible due to individual and institutional gatekeepers and facilitators, and it was personally motivated, or biased, by my initial research interests. During a previous research project on individuals' experiences of long-term unemployment in three regions in Denmark (Larsen 1998a; Bach, Larsen and Rosdahl 1998) I became aware of the social policy of arranging *intervention programmes* aimed at specific target-groups. These programmes were training, educating, or morally influencing individuals who were considered at risk of social exclusion. Within powerful institutions in Danish society (such as ministries, unions of employers, and unions of workers) these people were thought of as experiencing problems in adapting to the expectations regarding their individual capability and motivation for being in employment. To ensure the 'right' qualifications and motivations of these targeted 'problem individuals', special intervention programmes, often in the form of activation projects (*aktiveringsprojekter*), had been set up.

With the purpose of studying the attitudes and reactions of the recipients of these interventions I formulated a PhD research project designed as ethnographic fieldwork in an activation project and sent off an application for a scholarship to The Danish Research Agency (*Forskeruddannelsesrådet*¹⁴). Shortly afterwards I was made aware of an interesting job advertisement. The ‘Department for Family and Labour Market’ (*Familie- og Arbejdsmarkedsforvaltningen*) within the Municipality of Copenhagen¹⁵ was looking for a person for the position of co-ordinator and evaluator of an intervention programme in the area of mental health. The OPUS project was described as an innovative project offering intensive treatment and support for young people who were ‘newly-debuting’ (*ny-debuterende*) with a schizophrenic illness. The aim of the project was to offer early intensive medical, therapeutic, and social treatment and support to improve the prognosis (i.e. the future symptoms of mental illness and general life situation) of these individuals. The project was relevant to my interests, seeking to describe and understand the situations and experiences of socially marginalised individuals as they participate in a publicly sponsored intervention programme, so I applied. After a job interview with the two leaders and one of the psychiatrists in OPUS, I was offered the position.

A few weeks later, the PhD research proposal I had sent earlier to The Danish Research Agency was also accepted. I negotiated with all parties involved to integrate the two positions, and, finally, they agreed on a ‘sandwich model’, where the various activities were to take place in separate periods, arranged subsequently like layers in a sandwich. During all of 1998 I would be in OPUS employed as the evaluator, and from January 1999 I would start following courses in the Research Training Programme at the University of Sheffield¹⁶ and receive the scholarship from the Research Agency. Throughout 2000 I would again be working as the evaluator in Copenhagen, and in 2001 I would go back to Sheffield to do the analysis of the data and the writing up of

¹⁴ The Danish Research Agency had three names in my period as a PhD scholarship holder: *Forskerakademiet*, *Forskningsstyrelsen*, and the most recent *Forskeruddannelsesrådet*.

¹⁵ In the following I will, for practical reasons, use the expression ‘the Department’ when referring to ‘The Department for Family and Labour Market’ (*Familie- og Arbejdsmarkedsforvaltningen*) within the Municipality of Copenhagen.

¹⁶ Previous to sending off the application for the scholarship, Professor Richard Jenkins in the Department of Sociological Studies, University of Sheffield, had agreed to be my supervisor on the PhD research. I wished to carry out the research under the guidance of Richard Jenkins due to his ingenious combination of anthropological and sociological approaches in empirical studies of social policy issues (e.g. Hutson

the PhD thesis. The agreement was made in such a way that I would have to produce separate written products for the evaluation and the PhD research respectively. This model was a positive choice on my behalf, since I acknowledged that the two products would have different purposes and audiences.

As the evaluator I had a clearly defined role in relation to the OPUS project, which was my empirical field of investigation. As a member of the staff in the intervention programme I assumed *an active membership role* in the research setting (cf. Adler and Adler 1987: 50ff.), occupying a functional role in the field of research, by my initial involvement in organisational arrangements of the project and throughout by producing evaluation reports (Larsen 1998b; 2000; 2001a; 2001b; Larsen and Feldman 1999), as well as a status report (Larsen 1998c), a paper on the criteria of success for the evaluation (Larsen 1998d), and a few papers on the OPUS intervention, to be presented to the administration within the Department. The evaluation reports were presented and discussed in a steering group of the project, where I functioned as secretary, arranging the meetings and writing minutes.

Additionally, my principal in the Department invited me to join a working group¹⁷ developing a ‘policy for relatives’ in the treatment and services to the mentally ill in Copenhagen. The working group was independent of OPUS, and I joined it as the secretary, writing minutes and arranging practical issues concerning the eight meetings. In addition, I ended up doing most of the writing and editing of the document on the ‘policy for relatives’. Being employed in the Department my principal made it clear to me that this function was expected of me, but I also joined the working group because I was interested in obtaining more general knowledge on issues concerning mental health services and policies within the Municipality. My involvement in this working group was restricted to the year 1998, but on my return in 2000, I joined another working group on ‘user policy’ in the area of services to mentally ill in the Municipality. This time I assumed the role of an ordinary member, presenting and discussing issues to be included in the policy.

and Jenkins 1989), his theoretical work to conceptualise individual-society interaction (e.g. Jenkins 1996, 2000), and his first-hand knowledge of Denmark.

¹⁷ Apart from my principal and myself, the working group consisted of a representative from the health sector, a representative from a user organisation (*Sind*), a representative from an organisation for relatives of the mentally ill (*Landsforeningen for Pårørende til Sindslidende*). Originally, two representatives from

Far from being an unobtrusive, observing 'fly on the wall', my general approach to the field was one of *participant comprehension* (Collins 1984). It was my experience that the active membership role had the advantages of creating a more stable position for me as a researcher in the setting, and generating a higher level of trust and acceptance among the setting members, than could have been expected if I had had a more peripheral role (cf. Adler and Adler 1987: 50, 55). My position as evaluator in the field of research had the further advantage of giving me access to information regarding the principles and ideology directing the treatment and support given in the project. This was both due to my easy access to semi-official publications and due to the possibility of arranging individual interviews with key professional actors in the field, referring to my institutionally internal function as the evaluator.

While the role of evaluator presented me with an active and identifiable role in the field of research, my training as an anthropologist provided me with an additional role. These two roles, or identities, attached complementary meanings and functions to my presence in the field. But they also conditioned each other: my degree in anthropology gave me a professional qualification for adopting the role as evaluator, and thereby becoming a member of staff. This situation was different from the other members of staff, who, for example, were trained as either social workers or psychiatrists, and were also adopting these main roles in their functions as members of staff.

My academic training, and the status as an anthropologist that has followed from that, provided a social identification which gave legitimacy to my presence and role as researcher. From the outset of my presence in the field, I described the purpose of my presence within the stereotypical anthropological narrative of 'the explorer in an exotic land' (cf. Jenkins 1984: 148). This not only gave meaning to myself, but also to the actors in the field, whether they were receiving psychiatric treatment and support through the project, or working as staff. When I met a new participant in OPUS together with a staff-member I was thus always introduced by the staff as 'John, our anthropologist', sometimes with the addition, 'He is doing an evaluation of the project'.

Even if the notion of 'anthropologist' is not familiar to all in Denmark, and I have often had to give my version of what it means, both privately and working as a

another user organisation (*Galebevægelsen*) were also involved, but they withdrew since they thought that

researcher, it can quite easily be explained drawing on the narrative of ‘the explorer in an exotic land’. Giving examples of anthropologists doing field research in exotic places and cultures, such as Africa and native America, and drawing on my own previous fieldwork among the ethnic minority Naxi in the Yunnan Province of the People’s Republic of China¹⁸, it has been relatively easy to describe and legitimate my presence as a researcher. Besides drawing a picture which is true to my self-understanding of my role, the explanation has, furthermore, the advantage that people generally meet it with sympathy. It makes the research seem less threatening, by emphasising an *outside perspective* on the immediate social reality, instead of an authoritative objectification. The explanation achieves this by treating the present experienced reality as equal to that of tribal life in Africa or Asia. The ‘gaze of anthropology’ has a remarkable strength by applying a fundamentally curious and investigating perspective on human life and social interaction, and thereby comparing the life which is taken-for-granted and familiar with that which is exotic and incomprehensible. It introduces the possibility of a different way of life, which can seem both amusing and frightening.

The possible parallel to be drawn between the ‘gaze of the anthropologist’ and the ‘gaze of the psychotic’ – calling out the possibility of a different experience of life – had a special positive importance to the acceptance of me as a researcher by psychiatric patients. With the status of an acknowledged researcher and evaluator in the field of research, the relativistic perspective of the anthropologist, ideally ready to apprehend and recognise different dimensions and experiences, has lent legitimacy to the experiences of the psychiatric patients – no matter how psychotic and ‘crazy’. It was my impression that this had an important bearing on some informants’ initial acceptance of me as researcher, and their willingness to participate in the research. The acknowledged legitimacy of the outside, or relativistic, perspective of the anthropological inquiry seems to be particularly important in the field of psychiatry. It can be viewed as a (counter-) authority in a social field, where the power to define which perspectives to be considered as acceptable under normal circumstances exclusively is placed and given legitimacy to the notions and practices of psychiatry as they are endorsed by the staff.

their opinions were not heard within the working group.

¹⁸ The fieldwork in China was conducted in preparation for my MA in Anthropology, University of Copenhagen (Larsen 1995).

Ethnographic study of mental health

Since the researcher was an active member staying over a prolonged period of time in the field of research, the study joins a tradition of 'participant observational' ethnographic studies in the area of mental health. Participant observation is the term commonly used to describe the methodological position of the anthropologist during their fieldwork. Its methodological value is generally acknowledged in studies of societies, cultures or other social constellations where the researcher at the onset lacks general knowledge about the field of investigation, whether it is tribal life in Africa or unknown social environments in the society of the researcher (Hellevik 1991: 114-19). The specific quality is that the researcher is allowed to participate in a *naturalistic* social setting, i.e. it is naturally occurring and not controlled by the researcher, in contrast, for example, to the experimental method. The researcher has the opportunity to observe events and phenomena which are crucial to social interaction in the setting, but could be unnoticed by the social actors themselves, and therefore it is unlikely that they would be accessible by other qualitative methods, e.g. interviews and questionnaires (Patton 1990: 202-5). The method provides an opportunity to obtain an *inside perspective*, while the researcher at the same time is 'a stranger' observing the social setting he or she is participating in.

The concept 'participant observation', however, easily confuses the researcher's varying positions and degrees of involvement in the field of research – or types of membership. Adler and Adler (1987) criticise participant observers acting as 'outsiders' from the fields, only observing and not getting personally involved. This is because they see scientific procedure as a relativist endeavour, since the social interaction makes the researcher's influence on the setting inevitable, and the researcher's personality functions as a major research instrument by obtaining subjectively experienced information to be used as data alongside data obtained from other sources (*ibid.*: 31-2). Therefore, they suggest that in the study of social life a membership role should be adopted by the researcher. Three types of membership role designate the varying degrees of involvement and commitment: the peripheral membership role, the active membership role, or the complete membership role, where extreme instances of complete membership denote what anthropologists term 'going native'.

In studies of mental health, ethnographic researchers have assumed various roles. During the 1950's the sociologist Erving Goffman conducted a study in an American psychiatric hospital 'to try to learn about the social world of the hospital inmate, as this world is subjectively experienced by him' (Goffman 1961: 7). He took the role of staff assistant and did not sleep in the wards, but he avoided sociable contact with staff, did not carry a key (the symbol of staff), and passed the day with patients (*ibid.*). In the tradition of 'culture and personality' studies, Nancy Scheper-Hughes (2001 [1977]) conducted an anthropological community study in an Irish village to perform a 'cultural diagnosis' (*ibid.*: 60) of coming of age, to explain the high occurrence of cases of schizophrenia. She concealed this objective to the villagers as she interacted informally and performed individual psychological tests, while settling down with her husband and children who took up active roles in the community and became her 'prime informants' (*ibid.*: 59-75). By the 1970s, American psychiatric treatment had experienced a development away from the confinement of in-patient treatment (see Chapter Three for a historical review) and the anthropologist Sue E. Estroff (1981) conducted an ethnographic study among clients of a community programme. Estroff sought to blend in with the clients and consciously did not 'behave like staff' (*ibid.*: 5), but she suspected that to them she remained 'an enigma, a friend, or just another strange person who says she's writing a book about them and their treatment programme' (*ibid.*: 6). A more radical approach was taken by Rosenhan and colleagues (Rosenhan 1973), who faked psychotic symptoms and tricked their way into different American psychiatric wards as patients, where they observed the staff's treatment of them. Recently, the anthropologist Tanya Luhrmann (2000) has provided insight into psychiatric staff's perspectives by conducting ethnographic research as a resident in training to become a psychiatrist. And the integrated team approach to the treatment of patients with schizophrenia in a modern psychiatric ward in Australia has been described from the inside by the anthropologist and psychiatrist Robert Barrett (1996).

As the evaluator in OPUS, I could follow the development of the project intensely at the same time as being both a member of staff and at a distance: evaluating the status of the intervention programme and seeking to get insights into the experiences and points of view of the recipients. Since the intervention, from the beginning, was time-limited and experimental, my role as evaluator was *naturalistic* to the empirical

field of research. It was considered important and integral to the operation of the project that it should be closely monitored and assessed, since positive reports from this effort could secure further funding and possibly facilitate a broad and permanent implementation (see also Chapter Three, describing the background of the project).

Applying the general method of ethnographic study might have suggested that the researcher take the role of a recipient of the intervention programme. In this case, however, a number of reasons spoke for refraining from this strategy. A main reason was that I assumed that a major dimension of recipients' situations was their individual experiences of major mental problems (whether as hallucinations, fear, or extreme perceptions). Not experiencing such extreme problems, and not qualifying as recipient of the OPUS intervention, would, from the start, question the validity of generalising the experiences of the researcher as representative of the other recipients' experiences. In such a situation, the focus of the research would automatically have turned to the social influences on the situation, not considering the individually experienced problems the recipients could be assumed to be facing. This would question the validity of the claim to be giving an account of how the recipients experience their situations. Furthermore, difficult ethical questions about conducting the research would have had to be faced, such as whether to conceal or expose the identity as researcher, and to evaluate what impact a likely exposure would have had on the credibility of the role as recipient, in the eyes of staff as well as 'fellow recipients' (cf. Estroff 1981: 3-9, 20-40). Last, but not least, health issues would have had to be considered, regarding whether or not the role as recipient of the intervention programme, and thus 'mentally ill', could have had an undesirable effect on the researcher. The latter issue is considered by Estroff, who gives the advice to refrain from assuming a role as 'mentally ill', due to the possible impact it can have on the researcher (Estroff 1981: 21).

Being employed in the social section of the institutional structure of OPUS, my role as evaluator had a special focus, namely to document and assess whether the project contributed with a specific *social* intervention. In this position I had to report to the principal of the social section of OPUS, who had an office in the main administrative building of the Department, away from the daily work in the intervention programme. The first three months I also had an office there, but on my request I moved to the refurbished offices of the social section of one of the OPUS teams as soon as they

were ready. Together with the three members of staff of that section (an occupational therapist, a psychologist, and a social worker), I participated in the final preparation of the offices: cleaning, painting and arranging furniture and equipment. The office was established in two former small ground-level shops in a residential block in Bispebjerg, in the outskirts of Copenhagen. One of the shops was turned into a common office area for my three colleagues, and in the other, accessible only by using the front doors next to each other on the staircase, I was allotted a personal office next to the meeting room. I requested a separate office since my function as evaluator required me to do a considerable amount of writing, both of data, such as keeping diary notes and handling questionnaires and registration forms, and of reports.

During my longer unbroken periods of fieldwork, I was in daily contact with staff, informally chatting and regularly eating lunch with them, and I participated in the weekly social breakfast-meetings in one team. Furthermore, I participated in common-meetings (*fællesmøder*), when all members of staff and the two leaders, from the health and social sections respectively, met for recurrent educational seminars or to discuss issues of general concern. To fit in with the social staff, I dressed casually (pullovers, shirts, and jeans) and avoided a more formal 'professional' dress-code, e.g. not wearing a jacket. In my first year of fieldwork, in the early period of the project in 1998, I participated in a number of staff meetings where methods of the therapeutic intervention in the multiple-family educational groups and social skills training groups were discussed and rehearsed. I was, however, careful not to engage systematically in too many staff activities since I did not want to present the research from the point of view of the staff in OPUS. If I had arranged a more intense association and systematic daily interaction with the members of staff, I assume that I would have ended up focusing on organisational aspects (e.g. Luken 1982) or on the perspectives of the mental health staff (e.g. Barrett 1996; Luhrmann 2000).

During the year 1999, I was absent from the field most of the time, while I was following the Research Training Programme at the University of Sheffield. In this period, the anthropologist Maia Feldman became my substitute in the function as evaluator. The leader in the social section did not want the position to be empty during my absence, so I arranged that an anthropologist could conduct an ethnographic study of the therapeutic group interventions (Feldman 1999), which I could follow up on my

return. I carefully chose the group interventions since they, as distinct social settings, could most easily be subject to an ethnographic study by another researcher employed for a short term. Returning for two months of fieldwork in the summer of 1999, I worked together with Maia Feldman to conduct questionnaires, five focus group meetings, and analysis and the writing of an evaluation report.

Participating with a specific role and identity inevitably has the consequence that the researcher obtains partial accounts, since affiliation with one group in the setting makes it difficult to get data on other groups in the setting (Adler and Adler 1987; Jenkins 1984: 161). The membership role as evaluator, however, made it possible for me to establish a degree of affiliation with both the staff in OPUS and the recipients of the intervention. It was in the staff's interest that the time-limited experimental project was described and evaluated in order to facilitate further funding and wider implementation. Concerning the recipients, my role as project evaluator gave me the function as a sort of 'advocate', by allowing them to bring forward their experiences and criticisms of the way the project worked.

Apart from relying on my personal observations, sensations, and reflections as a participating fieldworker, an important method of data generating was my access to the observations and reflections of other actors in the field. I used my role as project evaluator to generate a *collaborative* relationship with and attitude towards the aim and conduct of the research – following an open research strategy (cf. Punch 1986). I directly asked the different actors to assist with their insights and knowledge in order for my research to be able to identify the strengths and weaknesses of the project. I pointed out that a more accurate identification in the evaluation reports of positive as well as of negative aspects of the intervention in the project, would make it more likely that these qualities could either be sustained or improved in the future arrangement and implementation of the project. I approached other actors in the field of investigation as my *associates* in the research.

Throughout the course of my fieldwork, I adopted a principle of *dialogue*. It prompted an ethnographic reflexivity which, in an attempt at a double hermeneutic, considered the reflexivity of 'the other', i.e. the informants and the other actors I met in the field of investigation (cf. Csordas 1994a: xi). The study not only considered the cultural context, but the actors' interpretations of their own situations and practices.

Csordas (*ibid.*) argues that it is particularly important to recognise this type of ethnographic reflexivity when much of the background culture is shared between the anthropologist and ‘the natives’. He continues: ‘The dialogue of reflexivities creates an opportunity for data of a richness seldom attainable when one works in a foreign society’ (*ibid.*: xi-xii).

The relationship with my colleagues in OPUS was not always unproblematic – as is often the case when doing research in organisations (Bryman 1988). This is not to say that the role of ‘the sceptical insider’ is unfamiliar to psychiatric institutions. Quite the contrary, Barrett (1996: 303) argues that it is a familiar organisational stereotype. In the first half year, until I presented the first evaluation report, it was my impression that the staff accepted me as a somehow diffuse member of staff, with a function to appraise the work done in the project, but not having any specific significance or value with regard to their daily work. It was only on rare occasions, such as when assisting writing official documents, that my academic competence proved to have any direct value for the daily work of the other staff members. After the publication of my first evaluation report (Larsen 1998b), I experienced a change in my colleagues’ perception of my role. My analytic perspective on the social interaction in general, and my open display and discussion of difficulties experienced among members of staff within the project in particular, was received with difficulty by some members of staff. In particular, I got into trouble for describing frictions and difficulties among staff in one OPUS team as related to a social imbalance caused by a close personal bond between two staff members who prior to their employment in the project were already close friends. Even if it was generally agreed among staff that the friendship possibly had a negative influence on the social dynamics in the team, the public disclosure of this circumstance in the evaluation report was considered improper due to its private nature. This unwelcome disclosure was later mentioned with bitterness on a few occasions, and it was my impression that it caused some degree of unwillingness to collaborate in the research, for example when they did not provide me with (voluntarily) written descriptions of their work in the project. But, luckily, I was never in a situation where all staff members expressed scepticism toward me and my role, nor was I generally restricted from participation in social settings of the research. The only occasion when I

was restricted from participation was on a two-day seminar concerning staff relations and leadership in the project held in the end of my fieldwork period.

As a consequence of the critique following my first evaluation report, I subsequently presented a draft of the reports to the staff members before printing, to allow them to make comments, which I could take into consideration. After the publication of each report, I remained in contact with, or returned to, the field, where I was dependent on the good-will of the staff for the continuation of the research. They remained important *gatekeepers*. Likewise, I had a personal wish to work in a friendly social environment. It continued to be a problem of general concern that leaders and staff were not accustomed to my open presentations and discussions of internal problems in the organisation. But often the writing, which caused concern among staff, was merely a matter of phrasing, and could easily be changed without losing the argument. It was in my own interest that these changes were made, since otherwise they would have had the effect of being ‘noise’ and a distraction from the focus of the presentations. An example of a change of phrasing was when I was criticised for using the word ‘conflict rejection’ (*konfliktsky*) to describe the dominant tendency among leaders and staff in the project, to deal with internal problems by keeping quiet and working for a good morale. The word was perceived as offensive and negative, and instead it was suggested that I should write that a ‘wish to seek consensus’ (*konsensussøgende*) was predominant. I was happy to receive these comments since they often helped me to present the observations and analysis in the reports in a less confrontational and more constructive way, which facilitated a higher degree of attention to the issues described. The strategy of feedback was also applied with regard to my informants; both as a methodological, dialogic principle, as I will discuss in detail below, and as an ethical principle by offering each a copy of the final evaluation report. Some informants read a draft of the chapter in the evaluation report on user assessments, and their comments were incorporated as additional data.

The role as evaluator facilitated the ethnographic study in OPUS, but experiences and observations apart from and outside my formal 37-hour-per-week function as evaluator also had a significant impact on the research. Conducting ethnographic fieldwork is not (just) a 9 to 5 endeavour, and it is not restricted to weekdays. This is probably an inevitable circumstance in all qualitative research, but it

is a distinctive feature of ethnographic study, where the researcher uses and places his or her person as central to the endeavour. The ethnographer places him- or herself in a social role, which is naturalistic to the field of research and has to fall into or adapt to this role in order to accomplish the task. Away from OPUS, in the evening or at the weekend, I thus continued to be ‘an employee in OPUS’ and I started to relate everyday and personal events to issues and problems experienced in this role. Conversations with friends, television programmes, and information from the newspaper were thus integral to my fieldwork experience and they affected and became part of data, reflected upon in my diary.

Interviews with key informants

Within the overall ethnographic approach I followed fifteen recipients of the intervention in OPUS for more than two and a half years – throughout the period of their contact with the project and about half a year after they stopped. The longitudinal design allowed me to follow the individuals’ developments, their changing experiences, ideas and attitudes. It facilitated better knowledge about each individual since the long-term contact made it possible for us to establish a personal relationship. This is of special importance in this empirical field of investigation, where my informants initially, due to psychotic experiences and cognitive deficits following a psychosis or as a side-effect of medication, could have particular difficulties in talking about and reflecting on their lives and experiences. And they could have reasons for being particularly sensitive when talking about personal issues, which could be painful to them.

The person-centred ethnographic approach (cf. Hollan 2001) had the advantage that it allowed the research to illuminate experiences, attitudes, and strategies of individuals as they entered or chose to leave certain social settings. The design took into consideration that individuals are not permanently or statically related to, or fixed within, social settings, but enter and leave these as they either choose or are compelled to. The research design had the consequence that it changed focus, moving away from primarily being concerned with social dynamics within a particular setting. Instead, individuals’ experiences and attitudes were described from the focal point of their individual bibliographical and social situations - they were *agents within individual life*

processes (Barham and Hayward 1990). Due to my participation in various social settings within OPUS, it was possible to supplement my key informants' experiences with the observations I made within these particular settings. It would, however, have been practically impossible if I had participated in all the different social settings, which were central to the various key informants' lives, such as, interacting with their friends and families and engaging in activities of work, education, and recreation. The individual contact based on longitudinally arranged interviews, combined with detailed knowledge of the workings of the particular social settings of OPUS, therefore, constituted an appropriate design for this study.

The qualitative *case study* approach was suitable for the study of individuals' experiences as they participated in the intervention programme (Patton 1990: 99). A case is both a unit of analysis and the focus, or 'heart', of the study. More abstractly, a case can be defined as 'a phenomenon of some sort occurring in a bounded context' (Miles and Huberman 1994: 25). A case in this study is an individual who for the first time experiences major mental problems, and becomes a recipient of mental health treatment and social support. The immediate 'bounded context' of the case is thus the OPUS project. Fifteen individuals who were in similar circumstances, each fulfilling the criteria of a case, formed the multiple-case study. The number fifteen was considered small enough to be practically manageable, and large enough to allow some degree of variability to be presented. By looking at fifteen different cases, similar and contrasting cases could be compared and it was possible to strengthen the precision, the validity, and the stability of the findings (Miles and Huberman 1994: 29). The cases were selected by *criterion sampling*, i.e. to meet predetermined criteria of importance to the study, and *maximum variation sampling*, i.e. to include variation in the data and strengthen visibility of common patterns in analysis (Patton 1990: 169-81). As is generally recommended in qualitative research (Miles and Huberman 1994; Patton 1990), the sample was not chosen so that it would be representative of the background population (i.e. the recipients in OPUS) but it was selected in order to allow systematic in-depth investigation into the variety of individual situations and experiences within the population.

In this purposeful sampling (Patton 1990: 169-81) of key informants, consideration has been given to a number of variables: time of inclusion, gender, age,

OPUS team membership, and OPUS staff allocation. The *time of inclusion* was a crucial sample requirement since a common start-period for the informants allowed the research to follow them prospectively as they went through similar time-stages in their intended two-year contact with OPUS. All informants became recipients of OPUS during the period August 1998 to January 1999. *Gender* was considered as an important social variable to consider in the sampling, because social research often proves this dimension to be of significance. To secure a spread of cases, a variation in the *age* of the key informants was deliberately sought, even if recipients in their 20s dominated the population. Cases were selected to allow an equal representation of recipients from the two *OPUS teams*. Likewise, an effort was made to ensure that the informants had different *staff members*, with different professional backgrounds, as their case managers (or ‘key workers’). These requirements were followed in order to make sure that the cases would not depend exclusively on the treatment and support offered within one specific team or from one particular member of staff. After thorough consideration, psychiatric diagnosis was not considered as a variable in the sampling, since from the beginning of the study there was a concern to avoid the criteria and ‘language’ of the psychiatric profession as an *a priori* key dimension of analysis and understanding of data. Variation with regard to these dimensions is illustrated in Table 2.1 below. Additionally, key informants’ different uses of various forms of treatment as well as psychiatric diagnoses are presented in a table in Appendix A. To secure the anonymity of my informants, pseudonyms have been provided. When OPUS staff are mentioned elsewhere in the text their names have also been omitted. Personal identifiers obvious only to readers with intimate knowledge of OPUS, such as profession and team allocation, have only been omitted in a few cases where information was considered to be potentially discrediting.

Table 2.1: Variation in sample of key informants

		Anders	Birgit	Claus	Dennis	Eva	Frank	Hans	Irene	Julie	Kristina	Lotte	Martin	Namira	Ole	Per
Age at inclusion (years)		24	39	25	29	26	21	29	36	30	28	27	25	20	38	24
Gender	Male	√		√	√		√	√					√		√	√
	Female		√			√			√	√	√	√		√		
Team	OPUS Bispebjerg	√			√	√	√	√	√			√			√	
	OPUS Vesterbro		√	√						√	√		√	√		√
Case manager	Nurse (1)											√				
	Nurse (2)				√				√							
	Nurse (3)		√							√				√		
	Psychiatrist										√					√
	Psychologist	√														
	Social worker (1)					√	√	√							√	
	Social worker (2)			√									√			

The concept of the case study is useful when clarifying technical aspects of the methodological procedure, especially in the set-up of the research design. Henceforth I have, however, chosen to use the notion of key informant, instead of ‘case study individual’. This is because of the technical and positivistic connotations which are apparent in some prominent portrayals of the case study approach (e.g. Yin 1994)¹⁹, and because I, by using the notion ‘informant’, wish to explicate that the overall approach of this research is an ethnographic study based on a phenomenological, naturalistic, inductive and explorative attitude towards the field of investigation.

I arranged the first meetings with my key informants together with the staff in the OPUS teams. We agreed that the best procedure would be for the case manager to inform the potential informant about my interest in meeting them, and briefly to present the purpose of the meeting. If he or she agreed, either a meeting would be arranged by the case manager and the informant, or I would meet the informant together with the

¹⁹ I wish to stress that self-proclaimed ‘case study research’ does not necessarily adopt a positivistic epistemology and methodology (cf. Miles and Huberman 1994; Patton 1990).

case manager on their next appointment. Then, in the presence of the case manager I would present the purpose of our meeting and arrange a meeting time. Following this procedure everybody contacted agreed to meet me.

To meet ethical considerations and in order to establish the formal and contractual character of our relationship I prepared a paper of consent, describing the purpose and character of our meetings. The paper stated that I was an evaluator and PhD researcher and that we would meet for interviews four to five times over a two-year period. The paper also stated that their participation in the interviews as well as the possibility to stop participating in the interview research would not affect their treatment and support from OPUS, and it was guaranteed that they would be anonymous in any publication using the data. Both I and the agreeing key informant signed the paper and I then gave the informant a copy of the paper to keep. I prepared this paper of consent after having seen the material used by the medical researchers on the project.²⁰ I sent a description of my research to the Danish Medical Research Council but got the reply that the nature of the research did not require their approval.

When conducting the interviews, I took care to meet the informants' individual requests regarding the time, place, and form of the interviews. Some interviews took place in the informants' homes, while others preferred to meet in my office or at another OPUS locality. The average interview lasted about one and a half hours. Exceptions were a few of the first interviews, which only lasted about half an hour, and some other interviews which lasted almost three hours. The interviews generally followed the same structure. We began with informal chat which could last from 5 to 30 minutes. I formally started the interview when taking out the paper with my interview guide, notebook, and the tape recorder. Apart from the first interview, the following interviews began with a follow-up of the informant's general situation: what he or she was doing, activities in OPUS, hobbies, work, and studies. As preparation before the interview I listened to the previous interview or read the transcript. This allowed me to ask personal questions, and it signalled my interest in their personal situations. Thereafter, I gave a short presentation of the 'questions of the day'. It was my experience that the presentation made the informants feel more relaxed, since they were prepared for the

²⁰ This inspiration reflects the general trend that the introduction of formal ethical concerns in social sciences is driven by standards developed to protect the subjects of bio-medical research (Punch 1986: 30).

questions to come. The interviews were semi-structured, using what Patton calls *an interview guide approach* (Patton 1990: 283-4), with themes and questions prepared in advance. For each round of interviews an interview guide was prepared, containing questions regarding special key themes. Table 2.2 below provides a schematic overview of these themes. A detailed presentation of the issues examined and questions asked can be found by consulting Appendix B, which includes an English translation of the five interview guides.

Table 2.2: Special themes examined during interviews with key informants

Interview no.	Period of interviewing	Special themes examined
1	Nov. 1998 to Jan. 1999	<ul style="list-style-type: none"> • Situation at start in OPUS • Expectations of OPUS • Reactions in social network • Future perspectives
2	Aug. to Sep. 1999	<ul style="list-style-type: none"> • Assessment of OPUS • How much space/importance OPUS has in life • Contacts with 'normal life' (work and education) • Views on the concepts 'participant' and 'patient' • Whether self-image has been affected • Attitudes in social network to participation in OPUS • Future perspectives
3	Feb. to April 2000	<ul style="list-style-type: none"> • Case manager • Medication
4	Nov. to Dec. 2000	<ul style="list-style-type: none"> • Assessment of OPUS • How much space/importance OPUS has had in life (throughout the period) • Views on leaving OPUS • Understandings of psychotic experiences and mental problems • Future perspectives • Assessment of interviews • Views on participation in the book project²¹
5	Aug. 2001	<ul style="list-style-type: none"> • Assessment of OPUS (retrospective) • Perception of mental illness • Whether self-image has been affected • Social relations affected by participation in OPUS • Consequences of leaving OPUS

Throughout our meetings I sought to follow the natural development of our conversation, by asking the relevant questions when appropriate. I took care to follow up on issues mentioned by the informant, exploring the accounts by ensuring

²¹ I initiated the book project as a forum for my informants to write their personal stories and exchange experiences. It will be described in detail later.

restatements and asking for examples, as is general practice in a semi-structured interview (e.g. Kvale 1997; Patton 1990: 277-359; Spradley 1979). The formal setting of the interview allowed personal questions about sensitive issues to be asked in a non-threatening way. When I finished asking questions about a particular issue, I routinely asked the informant whether he or she had anything to add. I ended the interview by asking about their expectations as to what would happen in their lives, to allow a continuation of the conversation next time we would meet. After I had turned off the tape recorder, we usually continued chatting informally for a while.

My approach to the gathering of information during the interview was that of *dialogical investigation*, enriching the simple question-answer interaction by engaging actively in the understanding of the subject or individual experiences described by the informant. In this way new insights occurred and the consistency of the information was investigated – similar to the Socratic method of dialectic questioning (cf. Larsen 1995). An important difference was, however, that in the dialogic interview the purpose of using that particular method was to bring out information and to understand the informant, not to manipulate the person rhetorically, to end up holding a specific opinion (Kvale 1997: 35). I expressed what Kleinman has called ‘a genuine, non-judgemental interest in the patient’s perspective’ (Kleinman 1980: 106n4). It has been argued that the Socratic method is suited only to the examination of logical consistency in knowledge already possessed, and that it cannot bring forward new facts (Russell 1961: 110ff.). But as a method in qualitative social sciences I argue that it can. The subject of inquiry is the individuals’ experiences and understandings, and data, or ‘facts’, are descriptions of events and meanings as they are individually perceived and interpreted, and negotiated in language. Language is a medium of intersubjectivity which ‘gives us authentic access to experience’ (Csordas 1994a: xii; see also 1994c: 11). The data are generated in the course of the interview – a social situation where perceptions and meanings are presented and negotiated in the process of creating understanding.

In the dialogic interview issues are examined together with the informants in a collaborative reflective effort, not merely brought as ‘raw data’ from the field to be analysed by the researcher at a distance. This strategy is essential in qualitative social research, where understanding of meaning is central to the endeavour. In an interview, a

meeting takes place between two (or more) individuals, and the form and content of the conversation and individual exchange affect the data produced (cf. Foddy 1994). In accordance with this epistemological position I avoid the popular but, in my view, incorrect expression 'data collection', with its inherent positivistic assumption of the existence of data to be collected. The exchange of information, knowledge, and perspectives between individuals is not a simple matter, but reflects, in a small scale, the fundamental nature of human life as social beings. The ideal for the dialogic interview is captured in Hans-Georg Gadamer's notion of 'true conversation' (*eigentlicher Rede*), characterised by the determination by the parties involved to achieve knowledge about the matter at hand (Gadamer 1990: 368-75).

The power imbalance due to the fixed roles of the interviewer, asking the questions and directing the conversation, and the informant, responding to the questions of the interview, has methodological advantages as well as disadvantages. The formal structure of the meeting established a special social interaction, to secure the anonymity and protection of the informant, and allowed the interviewer to probe in detail into problematic aspects regarding the informant's situation, experiences, and opinions. Informal and equal exchange between strangers would rarely allow these kinds of sensitive issues to be revealed. At least in the regular social contexts of the Danish society politeness would generally oblige you not to ask about sensitive matters, and such questions, if asked, would often be fended off with a joke or withdrawal. The potential problem caused by the unequal situation between the interviewer and the informant is that the conversation tends to focus on issues raised by the interviewer. Together with the air of 'efficiency' fostered by the prepared and focused questions this can have the consequence that the interview-situation does not allow sufficient time and 'non talk' for the informant to bring forward issues and themes not thought about as relevant by the interviewer. During the interview I sought to compensate for this shortcoming by systematically asking the informants if they had anything to add to the issues discussed and by showing utmost sensitivity to the responses of informants (cf. Larsen 1998a: 97-107).

By asking questions, and thus, in more than one sense, *questioning* the informant, the interviewer can be put in situations where posing the question potentially can motivate the informant to change the circumstances discussed. The interviewer is

not merely extracting information from the informants. Questions are potentially powerful instruments to awaken or create new understandings and attitudes by providing new perspectives and suggesting the possibility of another state of affairs. I took special attention during the interviews not to offend or in any way hurt or harm the informants with questions that could upset them. I was aware that they were in highly sensitive situations and that I had to be careful which questions I asked, and how I put them. When informants appeared particularly sensitive, I sought to be present in an undemanding way (cf. Scheper-Hughes 2001: 35). But instead of simply avoiding following up on a sensitive issue, I typically asked in a more general or abstract way. This allowed the informants to reply in the way – general or personal and specific – which they found most comfortable. As Estroff (1989: 195) has also observed, the better we got to know each other over the period of investigation the more informants felt relaxed and willing to engage in the dialogical exchange. This was a significant additional advantage of the longitudinal design.

In all interview-based research, the researcher has to address the question of the veracity, or reliability, of the information provided by the informants: are they telling the truth? Interviewing individuals who have been psychiatrically diagnosed as having suffered from an episode of psychosis, thus having experienced hallucinations and delusions, gives this crucial question a special significance. In interviews with individuals with no record of psychosis the problem of informant reliability relates generally to whether the informant is deliberately changing his or her descriptions of personal opinions or account of events in order to achieve a certain goal, either of self-presentation towards the interviewer or in order to influence research results (cf. Foddy 1994). A further question in interviews with individuals who are, or have been, under the influence of psychosis is whether the experiences narrated by the informants, and believed by themselves to be true, did *in fact* happen.

It was, however, my impression that the informants were not ‘florid psychotic’ (i.e. under the influence of active and strong hallucinations and delusions) when I interviewed them, possibly because I met them at a time where the psychosis had faded out and/or the psychoactive drugs had taken effect. Only with two informants, on a few occasions, did I have the impression that their sense of reality was *fundamentally different* to what I considered normal. One occasion was when a male informant

described his experiences of flying to Hollywood and meeting the actor Jack Nicholson. In this particular situation, the informant did not himself believe that it was true; he thought that somebody had arranged it all for him, by placing him in a plane simulator and having an actor pretending to be Jack Nicholson. The informant, however, still was trying to work out how they had arranged to create the illusion of a Californian beach. The explanation of somebody trying to trick him then became part of the psychotic experience, as a delusion that people were conspiring against him. In another situation, an informant explained how her former employers had arranged a conspiracy to harass her. The extreme details of their descriptions and explanations led me to believe that they were a product of their psychotic states. In this sense, I did not 'treat those [informants] whose rationality might be in question as rational', as Lindow explains that she did in her work with patients of a psychiatric ward (Lindow 1986: 359).

But even when informants at certain times suffered from psychotic experiences, there were layers of reality in their experiences which I could treat as such, for example, the reality of their subjective experiences of being conspired against and being harassed. Further, it was my experience that even if the informants believed that there was a conspiracy against them, then it still was possible for them to talk sensibly about daily factual experiences, for example, about talking to their case managers, receiving or rejecting medication, or coming to meetings in OPUS. But, as mentioned, I did not see it as a major problem in the course of my research, since only two of the informants in different situations seemed to be strongly under the influence of psychotic experiences. Had all the informants been in a state of florid psychosis throughout the research, this study would, however, have been very difficult to carry out. In other situations, informants described how they felt and thought during their psychotic experiences, and how they now were struggling to make sense of these experiences. Since the informants then were no longer having these experiences, it did not cause me any problems to distinguish between the psychotic experiences, the meaning they gave to them when they still were under influence of the psychosis, and what it all meant to them at the time the interview took place.

Multiple-method approach and outline of data

The formal context of the interview situation and the fixed and uneven roles of the informant and the interviewer impose some limitations on the interview as a method in social science. The focus allows specific issues to be scrutinised in detail, but it can be at the loss of examining a wider context and dealing with other issues which can be of relevance to the subject in question. By participating in various situations and social contexts in OPUS, I sought to learn about these wider issues, which also made it possible for me to take these issues up in the interview guides.

During the ethnographic study, I sought opportunities to engage in an equal and informal social exchange with the informants, where issues relevant to the focus of my research interest could be touched upon more freely. To find such a social forum was especially problematic in OPUS since it was providing a community service directed at the individual recipients in their personal settings. When they met, it was within the structured constraints of a therapeutic group. The chances of interacting informally with key informants or other participants in OPUS were therefore limited. Partly as a solution to this problem, I came up with the idea of asking my key informants if they would participate in a book project, where they could contribute a story about their experiences of having had serious mental problems and being recipients of the intervention in OPUS.

I presented the idea to my informants at the end of the third interview in the spring of 2000, and initially thirteen of the fifteen key informants were positive towards the idea. In the presentation of the idea I said that such a book would be valuable for other people, since their individual experiences could maybe help other young people who have similar difficulties, as their personal insights could be useful for relatives who want to know what it is like to have mental problems. During regular meetings of the book project group, everybody would give and receive comments on the drafts as a work-in-progress. Some informants were initially intrigued by this possibility to meet other recipients in OPUS, even if they did not feel that they would like to, or be able to, write themselves.

Seven of my informants wrote drafts for the book project, but one, Julie, later decided not to have her story included in the final book. However, they all told me that their individual accounts gave them an opportunity for the first time to tell the full story

as they experienced it. Many chose to write about their situations preceding their mental problems and psychoses, and their experiences during the psychosis and hospitalisation in the psychiatric ward. Interviews touched upon these experiences, but the book project presented a far better opportunity for the informants to describe these difficult experiences and situations. The experiences had often exposed the informants in a way which easily could be felt as humiliating, since highly personal matters were revealed, and they presented themselves in situations where they had been without the protective shield of control of thought, emotions, and actions. By writing about these experiences, and by determining the narrative structure and styles, it was possible for them to regain some control through the representation. In support of this understanding Barrett has shown that clinicians' engagement in writing takes a central place in the therapeutic process of recovery (Barrett 1996: Chapter 5), and he suggests that it could be useful for some psychiatric patients to be actively involved in the process of writing (*ibid.*: 305ff.).

When the informants wrote for the book project, they not only decided the form and content of their accounts, they also decided which parts of the story they wanted to tell and which parts they preferred to leave out. In many respects, this must be considered a weakness in the method as a tool of social research, since it did not allow the researcher to dig into and critically excavate various subjects. But in this particular case, because of the immense sensitivity of the subject, the method was relevant and efficient, since it allowed information to be presented, which otherwise would not have appeared at all. And the method was especially useful in this situation, where the purpose of the study is to examine the individuals' experiences, and not, for example, to assess the psychotic nature and severity of the experiences. Further, the meetings of the editorial group provided an opportunity to discuss the individual accounts, in a form resembling the focus group interview (Morgan 1997), and to ask for elaboration and exemplification in the further writing.

Throughout the year 2000, we had 16 meetings in the book project, always on the premises of OPUS, where I could provide the meeting room next to my office. Generally, the meetings started at 4.30 p.m. and lasted about one and a half hours. The meetings took place in a relaxed and cosy (*hyggelig*) atmosphere. I prepared coffee, tea, and juice and on some occasions one of the informants brought a home baked cake; at other times I brought some biscuits from the shop next door. During 2001, we met four

times in a café. The book project provided a good opportunity to chat in a personal and informal way, and it also provided important new information concerning the experiences of the informants. By the end of my period of fieldwork in 2000, the contributors had contacted a publishing house. During 2001, when I was in the UK, I kept in contact with the six final contributors through an e-mail group we had set up. Finally, in December 2001, the third publishing house we contacted agreed to publish the book (see Larsen 2002).

In Table 2.3 below I present a schematic overview of the contacts I had with each of the 15 key informants.

Table 2.3: Contact with key informants

	Anders	Birgit	Claus	Dennis	Eva	Frank	Hans	Irene	Julie	Kristina	Lotte	Martin	Namira	Ole	Per
Interview 1	√	√	√	√	√	√	√	√	√	√	√	√	√	N	√
Interview 2	√	N	√	√	√			√	√	√	√	√	√	T	√
Interview 3	√		√	√	√	√	√	√	√	√	√	√	√		√
Interview 4	√	N	√	√	√	√		√	T	√	T	√	√	T	√
Interview 5	√	N	√	√	√	√	T	√		√	T	√	√		√
Participation in meeting in book project	√		√		√		√	√	√			√			√
Writing personal story for book project	√		√		√			√	√			√			√
<p>Key for symbols √ = Full participation/face-to-face individual interview using tape recorder N = Face-to-face individual interview using note book only T = Telephone contact only, no proper interview conducted No symbol indicates that no contact was achieved</p>															

The longitudinal data concerning the fifteen key informants receiving treatment and support in OPUS will be presented against the background of the knowledge about the empirical field which I obtained during the ethnographic study. As the evaluator of OPUS I adopted a multiple-method approach combining qualitative and quantitative methods, using a variety of data sources. The aim of the evaluation was to give a broad description and analysis of the institutional implementation of the treatment and support

given in the intervention programme and to present various actors' experiences of, and attitudes towards, the project (cf. Jenkins 1984: 161ff.).

During 2000, I participated as an observer in different social and therapeutic sessions in OPUS. I observed eight meetings between different participants and their case managers (see details in Chapter Six). I participated in three types of therapeutic groups in OPUS: multiple-family groups, social skills training groups, and the informal 'Friday Get-Together'. I took part in twenty-two group meetings held in five different groups. I participated in each group several times to observe regularities and varieties in their respective social organisations and dynamics, and I studied the different groups during the same two-month period to heighten my analytic awareness of similarities and variations between the various groups. In order to identify possible developments and the endurance of institutional structures over time, the study was conducted as a comparative follow-up to the earlier mentioned study by Maia Feldman, who made an ethnographic study of multiple-family groups and social skills training groups as they were practiced towards the end of their first year of implementation in OPUS (Feldman 1999).

I also used other formal methods: individual interviews, focus group interviews, questionnaires, written descriptions, and registration forms. The methods were used on a variety of data sources: medical researchers, leaders of OPUS, staff, recipients of the intervention in OPUS, relatives of the recipients, the case managers, multiple-family groups, social skills training groups, and informal social therapeutic groups. In Table 2.4 the various specific methods used during the ethnographic study in my role as evaluator are presented schematically in relation to the different specific subjects examined. The table is presenting method, data source, and subject of investigation at the same time by combining the method and data sources along the horizontal axis.

Table 2.4: Formal methods used with different data sources concerning specific subjects

	Interviews with key informants	Observations	Questionnaires for recipients	Questionnaires for relatives	Focus groups with recipients	Focus groups with relatives	Focus groups with staff and leaders in OPUS	Written descriptions from OPUS staff	Interviews with OPUS teams	Registration forms filled in by OPUS staff	Interviews with leaders in OPUS	Interview with mental health user organisation	Interview with medical researchers	Interviews with OPUS staff members
Case manager intervention	√	√	√	√	√	√	√	√		√				
Use of medication in OPUS	√		√	√	√	√	√	√						
Multiple-family group	√	√	√	√	√	√	√							
Social skills training group	√	√	√	√	√		√							
Friday Get-Together	√	√												
Social services to recipients in OPUS	√		√	√					√	√				
Collaboration of OPUS with other public service institutions									√					
Overview of psychiatric treatment of key informants										√				
Use and meaning of psychiatric diagnosis in OPUS	√						√						√	
Professional background and expectations of OPUS														√
Institutional history of OPUS											√	√		

Using a variety of methods and data sources in the illumination of a wide range of subjects concerning OPUS, enabled me to provide the different actors' various perspectives, and it provided *triangulation* to increase the validity of the findings (Patton 1990: 187-8). The findings also provided important insights and a general overview of the intervention in OPUS, and the various experiences different actors had

of it. Specific details concerning the various methods and the findings has been presented in the evaluation reports, especially the final three-year report (Larsen 2001a), and will not be scrutinised further in this thesis since they do not form the main body of the data reported here. When I use these data in this study, I refer to the specific reports where detailed descriptions can be found.

Data handling and analysis

Methodology concerns not only the technical and practical ways in which 'raw data' are generated, but also the ways in which these are approached analytically and presented in the research. Until now this chapter has presented only the first part: the process of locating the field of research, gaining access, and the techniques of obtaining and recording information. The remainder of the chapter describes the focus on and selection of the available data, and the handling of these through techniques of analysis and presentation.

Throughout the periods of fieldwork, I noted and reflected on daily events in my diary. I recorded observations, quotations, and reflections of a personal, methodological, and analytic nature. Because of the extended fieldwork period and the wealth of data recorded, I, for practical reasons of file storage and transport, constructed five separate diary files, divided on a chronological basis. Altogether the diary consists of more than 220,000 words, or about 300 single spaced A4 pages. Writing in the diary had an important function, not only to record details of data, but also as a method to reflect in a systematic way about these experiences and their meanings. I did not always manage to record the observations and experiences the same day they happened, and I often had a feeling during fieldwork that I was behind and lacked the time to write sufficiently in my diary. Sometimes several weeks passed before I realised that an event, an observation, or a quotation had to be mentioned and commented upon in my diary. Being in the field, it was sometimes difficult to pinpoint the important events to record, and which events to leave out. In general, I found help in the distinction between 'happening' and 'event' (Hastrup 1989: 17ff.), making the latter the one full of cultural meaning, and the one to be recorded and explained. As Ardener observed: 'In the social space, not everything that happens is an event' (1987: 49). This also meant that a happening several weeks ago suddenly could appear as an event to be recorded, when I

had obtained knowledge or information which presented it with new and significant meaning.

The diary was thus a forum of initial analysis, but it also proved valuable in dealing with field-experiences in a personal, reflective way. Conducting ethnographic fieldwork was demanding, both professionally and personally (cf. Turner 1988: 117ff.). Even if the broader cultural context of the fieldwork, Danish society, as well as the location of my hometown Copenhagen, was familiar to me, the institutional context of psychiatry and experiences with mental illness were 'remote areas' to me (cf. Ardener 1987). In this sense, I was 'a stranger', and the individual experiences as well as the cultural practices that were revealed to me were unfamiliar and in many instances disturbing. Writing in the diary helped me to keep my perspective founded in anthropological and sociological theory and keep a reflective professional distance from the world I was introduced to and the experiences I had. The diary provided a forum for critical distance, what Jenkins (2002: 12) has also called *epistemological objectivity*. I believe that this was crucial for me in order to deal with the experiences and, at the same time, maintain a critical stand towards the psychiatric perspective on mental illness.

Since the interviews with informants provide the main data presented in this thesis, I will, in the remainder of this chapter pay special attention to the way I have handled and analysed these on the way to presenting them as empirical findings. Except for four interviews in which I only used a note book, I used a tape recorder in the rest of the 53 face-to-face interviews with key informants. I experienced technical problems on two occasions due to the possibility of adjusting the tape recorder for various purposes. In my first interview with Kristina, I had pressed the 'dictaphone' button instead of the 'lecture' button, which, unfortunately, had the consequence that the recording was inaudible. In the last half of my second interview with Lotte, I also pressed the button by accident when I started it again after having switched it off when she was talking on the phone. In both instances, I had to rely on my memory to make summarised notes of our conversations, and I took care to mention the important issues again in my following interviews with them.

I transcribed the interviews directly from the recording. During the course of the research, I adjusted the method of transcription from being very close to the words

actually said on the recording to sorting out ‘word-noise’ in the form of word repetitions and words starting sentences never really started nor completed. The editing out of ‘word-noise’ has also been used in situations when one person is uttering small words or sounds to confirm or support and encourage the talking of the other person, often during a more extensive explanation. Both the informant and the interviewer did this. The edited version was not only less time-consuming to transcribe, it was also easier to read. In my judgement, the sorting out of ‘word-noise’ did not exclude any meaningful data for the purposes of the content analysis performed in this study, as it was not radical, and did not alter the ‘feeling of the text’.

It may be important to note that this common ‘messiness’ of the talk could not be explained by a state of mental confusion of the informants. We might not notice it, but it is general to everyday talk, and, especially when we are asked demanding questions, word repetitions and half-started sentences seems to be part of ‘thinking-aloud’. I had a similar approach to editing when transcribing focus groups with OPUS staff, but even so, some members of staff complained that the style of language in the quotations in evaluation reports made them seem unintelligent (Larsen 2001a: 76).

I transcribed the recorded interviews with key informants from the first until the fourth round of interviews. Pressure of time and the focus of the thesis on the period of inclusion in the intervention programme, persuaded me to pay less detailed attention to the interviews conducted in the fifth round, merely relying on the analytic summary noted down immediately after the interview took place.

All quotations presented in this thesis have been translated from Danish to the nearest equivalent English.²² In order to remain true to the original utterances, English concepts have been sought to match the particular words used in Danish. In some instances I have inserted the original Danish word in parenthesis and italics. In the process of translation consideration was taken to preserve the original ‘feel’ of the utterances, thus balancing the nearest equivalent matching concepts with expressions in English which were as close to the Danish as possible. This involved considering whether the quoted person in the particular situation would have been likely to use the English expression. In the quotations, the symbol ‘...’ indicates a pause, ‘...//...’ indicates that material has been edited out, ‘[]’ indicates that explanatory material has

been inserted, while an explanatory text in block letters indicates sound, and inverted commas indicate a quote within the quote.

Analysis of data started as data were generated, as I have indicated in the description of the dialogical character of the interview situation. In order to engage in a dialogue, the interviewer must perceive and seek to understand the information presented by the informant. The 'on-the-spot' analysis continued after each interview with a key informant. Immediately, or as soon as practically possible, I wrote down in the notebook what I perceived to be the key points presented by the informant during our meeting. I also wrote down a description of the setting of the interview: special circumstances regarding the spatial environment of the interview, how the atmosphere was, descriptions of possible interruptions during the interview, and if there was anything special to note about the appearance of the informant. I made these notes partly as 'memory aide', in order for me later to be able to reconstruct details of the context of the interview situation, and, partly, as a first analysis of the information obtained. It is my experience that impressions and analytical ideas arising during the interview are often valuable, and worth recording in order to be used later in a more comprehensive and systematic analysis. The dialogue started in the field of investigation, as data were generated, but continued in the process of analysis as a dialectic, or hermeneutic circle revolving around theoretical constructs and cultural phenomena (cf. Csordas 1994a: x).

The overall approach in the analysis was to present the experiences and attitudes of informants during their period as recipients of the OPUS intervention. This meant that the chronology of their contact, manifest in the data by the sequence of the rounds of interviews, established a framework for analysis. By seeking to describe and explain the variety and patterns of similarity in the experiences of the informants, the general strategy was *cross-case analysis* (cf. Patton 1990: 376). I used the qualitative data handling and analysis software *QSR NVivo*, versions 1.2/1.3, (Richards 1999), and codes and comments within the software were applied in Danish to stay as close to the 'felt' empirical reality of the data. In the analytic process, I used a combination of case analysis and cross-case analysis. The *case analysis* strategy was applied in two different

²² My translations of quotations from Danish to English have been checked by my supervisor, Prof. Richard Jenkins.

ways: during the coding of each interview, or simultaneously transcribing and coding,²³ analytic comments were made in a separate file. In this way, I was able to immediately record the intimate insights into each interview which I obtained during the procedure of transcribing and coding. This ‘case insight’ drew on the recollection of the interview situation and the general knowledge of the person in question to pinpoint issues of special interest related to the individual situation of the informant in the particular situation. These analytic single-case comments, arranged chronologically in a separate file, proved useful during the writing up by enabling me to identify particular issues of analytic relevance related to individual circumstances – avoiding the risk of atomisation of the data by the cross-case approach. Another way case analysis was employed was by the use of my knowledge of each informant to relate particular statements to their general situation. This knowledge of each informant’s personal circumstances and my familiarity with the individual interviews made it possible for me to follow up on specific issues by searching previous or later interviews for comments they had made on a particular issue. The search function in *NVivo* allowed such procedures to be performed swiftly. In this way, all data on each informant were sometimes treated as one case, stretching over time. The transcribed interviews, identified by file names in the format ‘2000.03.31 Anders’,²⁴ were entered as separate documents in a ‘project folder’ in *NVivo*.

The coding²⁵ proceeded with an emphasis on broad *empirical themes*. For example, when coding text sections in an interview transcript where an informant talks about psychotic experiences I would code it as this empirical theme: ‘psychotic experiences’. The use of empirical themes in the coding stage minimised the risk of individualisation and atomisation of the data which would be likely if I had coded by using an emic (*in vivo*) category, based on a particular word and understanding used by the informant to describe and understand that experience, for example that it was ‘magical power’. Further, I avoided using overly theoretical concepts as codes, since they would result in an unfortunate analytic anticipation and, hence, narrowing of the

²³ For reasons of availability of the coding software, interviews in rounds one and two were transcribed and coded separately, while interviews in rounds three and four were transcribed and coded simultaneously. I found the latter approach both time saving and analytically beneficial, since a close ‘feel’ for the data is obtained in the process of transcribing.

²⁴ This structure of the file name made sure that the interviews would automatically be arranged chronologically in the ‘project folder’ and that the particular informant could easily be identified.

subsequent analytical work with the full data. Theoretical codes in the example that I have just used could, for example, have been either 'visual hallucination', 'delusion' or 'making sense of hallucination'. The coding in empirical themes allowed me analytically to return to my informants' experiences with, and different views on, similar phenomena.

I arranged the codes in 'trees' creating a vertical hierarchical interrelation. First-order codes for example were 'Yourself', 'Others', or 'OPUS'. Examples of second-order codes under 'OPUS' are 'OPUS generally', 'medicine', and 'case manager'. Third-order codes under 'case manager' are, for example, 'relation' and 'conversational subjects'. Only rarely were fourth-order codes taken in use when, for example, various types of relations to the case manager were specified in sub-codes. First- and second-order codes primarily functioned to order the codes thematically, while the third- (or fourth-) order codes contained the coded text sections. Under 'node properties' in the software I applied a description of the particular purpose and content to each code and I noted whether the code referred to any particular question asked in one of the interviews. The system of hierarchically-ordered codes evolved, and was continuously revised, as more and more interviews were coded. The procedure in this way contributed significantly to the understanding, and resulting analysis, of the data. Throughout the period of coding interviews I kept a 'log book' where I noted consecutive considerations regarding the strategy of coding, accompanied by regular insertions of full 'node reports' containing descriptions of the structure of the codes and full descriptions of each code. This 'log book' provided a *chain of evidence* to ensure the reliability of the research through a chronological documentation (cf. Yin 1994: 98ff.).

After having finished the coding of all the transcribed interviews, I did not go through the interviews to make sure that the initial coding practice corresponded to the resulting coding structure. It is my contention that the internal consistency of the coding could have been improved by doing so, but I estimated that the procedure would be too time consuming, and that it would not yield a matching outcome in respect to analytic insight and quality. I was careful not to be drawn into the attraction of the formal technicalities of the coding procedure, but kept my analytic attention focused on my

²⁵ *NVivo* operates with 'nodes', but I will follow a more conventional terminology and call them 'codes'.

intimate, and personally experienced, insight into the data. I believe this to be an important and sound priority when conducting qualitative research – to use the technical instruments for what they are, merely instruments to facilitate easier access to, and manipulation of, data, and to maintain the personal insight and empathy with informants in the field as the backbone of the analysis.

Empirical themes were investigated analytically in *NVivo* by retrieving specifically coded text sections across the interviews, using the ‘explore nodes’ function. Reading through these texts, I summarised key themes in each interview on a separate paper. When I wanted to investigate the context of a coded section, the software provided the opportunity with two clicks on the mouse to retrieve the entire interview. In several instances, I found this function very useful, to avoid atomisation of data by the overall cross-case strategy of analysis.

Each interview file was given four attributes in the categories: interview number, pseudonym, gender, and team. The intersection search tool in *NVivo* made it easy to search any selection of documents sorted by attributes. It was, for example, possible to search all text sections in the first round of interviews (*attribute: interview, 1*), coded as related to future expectations (*code: fremtidsperspektiv*). Or, it was possible to see what Hans said about the diagnostic interviews (*code: diagnostisk interview*) in all the interviews with him (*attribute: pseudonym, Hans*). The software also made it possible to check the interviews for comments which might have been overlooked in the coding procedure, by using the ‘text search’ function. For example, Lotte’s involvement in work at different stages could be checked by retrieving all the places the word ‘work’ was used in the interviews with her. This option was used on a few occasions when certain information was missing or when my personal knowledge of the informants spurred me to investigate an issue further.

The hand-written summaries of the coded text sections provided a cross-case overview of the data and made similarities and variations between the informants stand out more easily. In the presentation and discussion, the findings were related to the broader context of the individuals’ involvement in OPUS by drawing on information regarding each individual as well as on additional data generated during the ethnographic study as evaluator of the project. Details could thus be checked and elaborated on by consulting the diary, and the reports generated in my function as

evaluator provided information on various aspects of the intervention in OPUS and different actors' perspectives.

The chronological principle and the general cross-case strategy of analysis and presentation was applied in order to clarify individuals' experiences and processes throughout the intervention, and in order to accentuate similarities and differences in the situations and attitudes of the various individuals.

The person-centred ethnographic approach

This study presents a person-centred ethnographic approach. It combines an ethnographic study as an active member in the intervention programme, and prospective longitudinal interviews with fifteen key informants, from shortly after they were included, throughout their two to two and a half years of participation, until after they left the project. My active role as evaluator of the project allowed access to the field and the use of a broad multiple-method approach, including a variety of qualitative and quantitative methods. While these methods provide useful background information, this study primarily draws on data directly related to the key informants. It examines individuals' experiences in the particularly demanding life situations following the experience of psychosis or other serious mental problems. A dialogic approach involves the informants as active partners, or associates, in the research, and seven of the fifteen wrote about their individual experiences for a book project, although one later withdrew her, leaving six for the final publication.

The qualitative text data were analysed using the software *QSR NVivo*, with attention to variety and traits of similarity in the individuals' experiences and reflections as they were presented over time. Close personal knowledge of the informants and dedication to the integrity of each meeting and interview situation provided the basis for avoiding atomisation of data and meaning in the overall cross-case analytic strategy.

Chapter Three

Mental health care in Denmark

This chapter provides an overview of the recent historical, cultural, and political background of mental health care in Denmark. Specifically, it provides an insight into the policy and services offered and describes the origin and purpose of the community intervention provided in the OPUS project, as an innovative mental health care institution in Denmark.

The de-institutionalisation of psychiatry

Recent history in Denmark has seen significant changes in the treatment and view of the mentally ill, which have followed similar paths to those in other European countries, North America, and Australia. These changes coincided with general structural and ideological processes within Western societies, transforming the role and power of the church and creating modern nation states. Disregarding geo-political borders, professional knowledge has flown between these societies and provided for similar developments in practices of medicine. The historical account of the recent developments in Denmark therefore also draws on the available extensive historical research based on European (largely British) and North American sources.

In the aftermath of the Middle Ages, European countries adopted *institutionalisation* as the dominant way of dealing with the mentally ill – or ‘lunatics’ and ‘mad men’. George Rosen (1968: 159-61) argued that this introduction should be seen in relation to the development of the hospital, which in the Middle Ages was essentially an ecclesiastical institution, its chief role being to help maintain social order while providing for the sick and the needy. These people legitimised the role of the church as a necessary donor and institutional go-between in passing on charity, and Rosen (*ibid.*) argued that the system encouraged begging in society. As the state increasingly gained power towards the seventeenth century, the hospitals came under the control of the state. Given the new bourgeois concern with the economic wellbeing of society, charity was discouraged, and instead the governments took the view that they

‘should use their power to compel all persons capable of engaging in production to do some work’ (*ibid.*: 161). To protect public order, ‘demoralised, rootless groups, bereft of resources’ (*ibid.*: 162), who were seen as displaying antisocial behaviour, became segregated by internment in workhouses or the general hospital, which combined the characteristics of a penal institution, an asylum, a workshop, and a hospital (*ibid.*: 162ff.).

The treatment of ‘the lunatics’ in the asylums varied historically according to the view taken on the nature and origin of madness. In the seventeenth and the first half of the eighteenth century, madness was seen as a loss of an original and natural rationality which could be brought back by education, which in these times meant use of strict discipline (*ibid.*: 170). Andrew Scull has noted that, in this period, the inhabitants in the asylums were seen as wild animals, and they were treated with violence, force, fear, and devices of suppression in order to ‘tame’ them and ‘drive out’ their wildness (Scull 1989: 54-87). Grotesque techniques and machinery, resembling instruments of torture, were developed to enhance the ‘treatment’ which, arguably, also had a moral dimension of punishment (cf. Foucault 1967).

By the end of the eighteenth and the beginning of the nineteenth century, the use of these extreme disciplinary methods in the asylums became outdated as the understanding of madness changed and the notion of ‘mental illness’ was developed (Rosen 1968: 171). A humanistic perception was introduced by the reform thinkers, according to which ‘the lunatic’ was considered a human who needed to be infused with self-control and order (*ibid.*: 88-90). As a consequence, ‘moral treatment’ was introduced in order to re-socialise and bring self-discipline to the patients in the asylums so that they could follow the new civil ideal of the rational individual (*ibid.*). A crucial role in this therapeutic effort was given to the value of work (Rosen 1968: 88ff.). In the new rational and scientific spirit, the idea of treatment and healing thrived, and earlier notions of suppression of a God-given state of madness were rejected. The new ideology emphasised the individual as free, and capable of taking his life in his own hands and changing his destiny (*ibid.*: 91ff.). In early nineteenth-century Europe and the USA, the combination of medical and moral treatment in asylums was almost universally applied as the way to treat, and heal, the mentally ill (*ibid.*: 95-117). Joan Busfield (1986: Chapter 9) has observed that this transformation of asylums into

hospitals, which stressed the need for treatment instead of confinement, and a medical instead of a moral perspective on madness, also functioned to acknowledge psychiatry as a proper medical discipline. Similarly, Foucault (1967) argued that modern psychiatry introduced a technical discourse of treatment through scientific medicine and made madness an object of a moral discourses of salvation through individual responsibility.

Drawing on primary as well as secondary material concerning the USA and the UK, Busfield (1986: Chapter 10) demonstrated that early in the twentieth century, the unanimous positive view of the asylum was abandoned, and a shift towards community care found strong support. In the wake of these changes in ideology, the 1920s saw the introduction of 'open-door' policies in some wards, and systems of 'parole' allowed better behaved patients freedom of the grounds and some freedom to go into the surrounding community (*ibid.*: 332). During the 1930s and 1940s open wards were increasingly introduced throughout the UK (*ibid.*). These changes also meant that relatives and friends now could visit the patients in the wards, and, as Busfield summarises, 'not only did the open-door policies involve an attempt to make asylums more like hospitals and less like prisons, they also involved emphasising the link between asylum and community' (*ibid.*: 333).

During the 1950s, public attention was given to criticism of the asylums as therapeutic environments. Busfield explains:

Many of the new critics were themselves medical superintendents and medical hospital psychiatrists and though the critiques that they offered paralleled in many respects those of the nineteenth century, they gave *a new emphasis to the detrimental psychological consequences of long-term stays in mental hospitals*. It was not just that mental hospitals provided a regime of custody rather than treatment, but that the routine and regimentation, the environmental and social poverty of hospital life were themselves creating additional problems: they were adding insult to injury. A range of terms were used to describe the effects of long term stay on inmates: 'prison stupor', 'prison psychosis', 'psychological institutionalism', 'institutionalization', and 'institutional neurosis'. The critiques drew particular attention, therefore, to the problems of long-stay chronic patients, to the need for more active treatment programmes, and to the need for a physical and social environment with more freedom and more contact with community life. These critiques, therefore, not only encouraged the adoption of open-door policies, they were also associated with *specific therapeutic interventions designed to rehabilitate chronic patients and allow them to return to community life*. Chronic patients were, for instance,

given 'habit training' to encourage them to regain basic skills.²⁶ (Busfield 1986: 335-6, italics added)

In an official British statement from 1957 concerning the treatment of the mentally ill, it was thus stated that '[t]he majority of mentally ill patients ...//... do not need to be admitted to hospital as in-patients. Patients may receive medical treatment from general practitioners or as hospital out-patients and other care from community health and welfare services' (Royal Commission 1957: 5, cited in Busfield 1986: 341).

Andrew Scull's (1977) marxist-functionalist argument that the shift towards community care was economically motivated, in order to save the expenses for the hospitals, has been refuted by Busfield, who criticises him for neglecting ideological motivations (1986: 328-30). Busfield claimed that in the 1950s there was no immediate need to save on the increasing public expenditure, since an equally expanding economical growth and greater prosperity in the period ensured that there was little concern about the increase. She, however, acknowledges Scull's claim that a fiscal crisis of the state may have had an important role to play from the 1970s and onwards, in seeking to minimise public expenditure by reducing the number of hospital beds on psychiatric wards (*ibid.*).

The shift towards community care throughout the twentieth century was primarily carried by a new ideological perspective, even if it may also have been encouraged by economical considerations. Nikolas Rose (1996) has contributed to the debate with an important critical reflection on this development by arguing that the recent political interest in 'the community' represents an ideological rejection of the previous notion of societal responsibility and a concern with citizens' individual responsibilities of their own lives, and that of their family, or other 'community associates'. This aspect is also apparent in the deliberate involvement of 'the family' to share the responsibility for the treatment, support and wellbeing of users of the mental health community services, creating a 'new alliance' between the family and psychiatry (Barrett 1996: 247ff.).

Apart from the ideological aspects, the community approach in psychiatry was based on a therapeutic optimism stimulated by developments in medicine. New anti-

²⁶ Busfield here indicates a reference to two publications: Bennett and Robertson (1955) and Myerson (1939).

psychotic drugs, along with surgical, electro-shock and other physical interventions, made it possible for a greater number of patients to be treated outside the hospital and facilitated earlier discharge of those who did have to be admitted (Busfield 1986: 326). In the 1960s and 1970s there was considerable attention paid to psychodynamic, behavioural, and community orientations, but since the 1980s biological explanations have been the focus of psychiatry, following significant 'breakthroughs' in neuroscientific research and the development of new antipsychotic drugs (Kleinman 1988: 1ff.).

While Britain and the USA have been taking the lead in the development towards community psychiatry (Busfield 1986: 326ff.), Denmark, in the last two decades, has also witnessed significant changes. Large state psychiatric hospitals, which used to dominate psychiatric treatment, have been downsized or closed, and instead outpatient treatment in the community with a more de-centralised and atomised institutional arrangement of treatment and support has been developed. This development is partly due to the above-mentioned advances in medical treatment, which include new effective drugs in the treatment of both psychosis and nervous problems. But there has also been a change in the overall attitude to the mentally ill within society over the period, stressing their rights to 'a normal life' in society (*Amtsrådsforeningen* 2001a: 7). As described in a recent joint publication from the Danish Ministries of Health and Social Affairs (*Sundhedsministeriet/Socialministeriet* 2001), this change has been brought about as a consequence of criticism of the former total institutions as excluded from society in general, characterised by an unfortunate hierarchical structure, with the doctors as the dominating professional group, and offering inflexible and restraining methods of treatment (*ibid.*: 12).

The political determination in Denmark, with a population of 5.2 millions, to diminish the use of psychiatric hospitals can be seen in the sharp reduction in the national number of beds in psychiatric wards from 11,000 in 1976, to 4,200 in 1993, a number which has remained roughly stable since (*Amtsrådsforeningen* 2001: 7). Individual stays in hospital have changed markedly from the mid-1970s to become more short-term. This is clear from the recent years' rapid *increase* in the number of discharges, during which the number of hospital beds has been reduced to less than half. In the same period services offered by institutions outside the hospitals have increased

(*ibid.*: 8). The vast decrease in the number of hospital beds available after 1976 was pushed forward more through political will than on account of a decrease in demand. As a result, many people who formerly would have got a bed in a psychiatric hospital were, in the 1980s and 1990s, put in a situation where they had to manage by themselves, often with social and human tragedies as consequences. It became apparent that new forms of treatment and support had to replace the former total institutions (cf. Barham and Hayward 1995: 142-46).

As a result of this development, a process of 'neo-institutionalisation' of services for the mentally ill began in Denmark in the late 1980s. Similar tendencies in the development of psychiatric services have been seen in other Western countries (McCourt Perring 1994). Initially on an experimental basis, the two first community mental health centres in Copenhagen were opened in April 1989. The purpose of the centres was to give psychotic people, as well as other people with mental health problems, treatment and services, according to the 'seriousness' (*alvor*) of the problem, and depending on the resources available within the centres (Knudsen *et al.* 1992: 20). Community mental health centres have now been widely implemented in Denmark – in Copenhagen²⁷ alone currently twelve centres are operating (*Tilbud til psykisk syge i Københavns og Frederiksberg kommuner* 2000). The rapid development and establishment of centres in the capital reflects a general tendency throughout the country: in 1995 there were 80 centres, and by 1999 there were already 120, allegedly now covering 100% of the country (Jensen *et al.* 2001: 94).

In Copenhagen each of the twelve community mental health centres is associated with one of five general hospitals in the capital. The centres provide ambulant medical and therapeutic treatment to citizens living in the local region (*bydel*) of each centre. The centres primarily offer interventions on an individual basis provided by professionally trained staff: psychiatrists, clinical psychologists, physiotherapists, social workers (*socialrådgivere*) and occupational therapists (*ergoterapeuter*). Nurses often play an important role in functioning as 'contact persons' (*kontaktpersoner*) – or case managers – who meet with long-term users on a regular basis. Some centres provide a day centre, which offers the opportunity for the users to meet with staff and

²⁷ When I refer to Copenhagen I more precisely refer to the municipalities of Copenhagen and Frederiksberg, which are the two politico-regional areas covered by *Hovedstadens Sygehusfællesskab*, the public institution operating the health service in the Danish capital, with a population of 1.2 million.

other regular users and engage in some activities. But in Copenhagen social functions as these are primarily provided in other spatial, institutional and financial frameworks (to be described below).

Since the downsizing and closure of the former large state psychiatric hospitals, a major political focus has been to provide sufficient new community psychiatric services and social institutions to provide the necessary treatment and social support for former in-patients (*Sundhedsministeriet/Socialministeriet* 2001: 12). As the bulk of psychiatric services are no longer spatially and administratively concentrated in the large hospitals, the need has arisen to arrange efficient co-ordination between the different decentralised institutions that provide these services. In 2001, the Danish government set up a cross-ministerial working group, comprising representatives from the Health and Social Affairs ministries and various social and health institutions, as well as from user groups. The purpose of the working group was to come up with suggestions as to how a better co-ordinated service could be provided for the users of mental health services in Denmark. A recurrent theme in the recommendations from the working group was the need for interventions in the health and in the social institutions to establish a common ideological basis. Furthermore, the working group requested an improvement of the communication between the sectors, and that both the users of the mental health services and their close relatives should be involved early on as partners in the intervention (*Sundhedsministeriet/Socialministeriet* 2001).

The emergence of social psychiatry

In Denmark the notion of 'social psychiatry' (*socialpsykiatri*) first appeared around 1990 to refer to the social services in the community to mentally ill persons not admitted to a psychiatric ward (Hegeland 1998: 5). This meaning of the concept is not universal. In English literature, for example, 'social psychiatry' concerns the effects of the social environment on the mental health of the individual and the effects of the mentally ill persons on their social environments (Leff 1993). And when used within psychiatry, the concept generally describes an epidemiological perspective on instances of mental illness in a population seen in relation to specific social variables.

The practice of social psychiatry in Denmark, in the specific Danish use of the term (which will be applied in the following), does not present itself as an alternative to

the medical and therapeutically based interventions in the psychiatric hospitals and the community mental health service. It is suggested as an addition or supplement to fill the space left when the hospitals were no longer in a position to provide total institutions to take permanent or long-term care of persons suffering from mental health problems.

In 1991 the concept was first used officially in the new meaning when the Danish Parliament (*Folketinget*) passed a resolution concerning the social conditions of the mentally ill, and the Danish Ministry of Social Affairs established a steering group regarding social psychiatry (*Følgegruppen om socialpsykiatri*) (Hegeland 1998). Since then, a number of publications in Danish have either discussed the need and possibilities in the development of social psychiatry (e.g. Adolph *et al.* 1996; Andersen 1996; Andersen and Barfod 1998; Brandt 1995, 1996; *Følgegruppen om Socialpsykiatri* 1992a; Kelstrup 1996; Storm 1994; Vendsborg 1996) or presented descriptions, evaluations and recommendations regarding existing interventions in the area (e.g. Barfod and Bo 1995; Bistrup 1993; Bømler 1992, 1996; *Følgegruppen om Socialpsykiatri* 1992b; *Følgegruppen om Socialpsykiatri og socialt udstødte* 1994; Hansen 1998; Lind and Vilstrup 1993; *Socialministeriet* 1994; *Socialministeriet* 1998). The institutional development was further cemented in 1997, when a nation-wide 'Centre of Research and Information for Social Psychiatry' was established, first on a four-year basis, but from 2000 with permanent funding from the Danish Ministry of Social Affairs. On their Internet homepage (<http://www.socialpsykiatri.dk/>, also in English) they present their aims as: 1) to promote the development of social psychiatry in Denmark, 2) to gather, process, integrate, and communicate information and expertise within the field of social psychiatry, and 3) to assist professionals in establishing contacts and networks. The centre contains a specialised library with publications on social work with the mentally ill and papers and reports with descriptions of interventions in different counties in Denmark. With its quarterly publication *Socialpsykiatri*, the centre is establishing a foundation for the emergence of a specialised professional identity for social work with the mentally ill in the community.

This ambition is clear in a recent publication from the centre (Adolph *et al.* 2000), which attempts to unify the previous writings on social psychiatry and define a

basis from which the concept, and the practice of social work it refers to, can develop. In the book the concept of social psychiatry is defined thus:

The social intervention which is given to support people who, as a result of a mental illness, are unable to fulfil their basic social rights within the regular social services. (Adolph *et al.* 2000: 34, my translation)

In the original Danish quotation the word 'offer' is used instead of 'service' which is used in the UK to describe a public intervention to secure citizens' welfare. In Denmark the commonly used expression for a public service intervention *tilbud* (offer) stresses the relational interaction between the provider (as the state, the county, or the municipality) and the recipient: the public institution is *offering* the service to the citizen. Michael Ignatieff has stressed that welfare is about rights not caring, and he pointed out that notions of the 'caring society' evoke 'the image of a nanny state in which the care we get depends on what the "caring professions" think it fit for us to receive' (Ignatieff 1989: 70-1, in Barham and Hayward 1995: 148). The word *tilbud* presents the public institution as a generous provider, and not simply as an institution being required to fulfil the rightful needs and demands of its citizens. In this light, the Danish social welfare system presents itself as a nanny state 'in which entitlements are a matter of moral generosity rather than of right' (Barham and Hayward 1995: 148).

The Danish Ministry of Social Affairs has the responsibility for the general organisation of the social services provided for the mentally ill in Denmark, and is thus the institutional 'crown' of social psychiatry. Based on criteria of residence, the municipalities (*kommuner*) have the immediate responsibility to offer help to the mentally ill, while the larger counties (*amter*) provide more specialised services and are obliged to advise and supervise the municipalities. In practice, the counties and municipalities co-operate to facilitate a variety of services. While the counties have the responsibility to provide medical care, including psychiatric treatment, they also typically provide co-ordination of social and medical psychiatric services to the mentally ill in Denmark (*Socialministeriet* 1998: 91).

In 1998, it was estimated by the Danish Ministry of Social Affairs that around 30,000 people in Denmark (with a total population of around 5.2 mill.) need special social services on account of a mental illness (*ibid.*: 92). It was considered crucial that a

number of varying services meet the needs of each individual, and that the services are provided in such a way that the individual experiences them as coherent and combined. Ideally, the services provide the recipient with the necessary life circumstances and life quality, which make it possible for the mentally ill to live in individual accommodation (*egen bolig*), have contact with other people, have daily work or activities, receive education and training, have interests, get around, receive advice and supervision, and make decisions concerning their own lives (*ibid.*: 94).

The institutional development of social psychiatry in Denmark started in January 1987, when the organisational responsibility for care homes for people with mental illnesses was transferred from the health sector to the social sector (*Amtsrådsforeningen* 2001: 17). The special accommodation arrangements, both as care homes and temporary or permanent communal flats with daily or weekly visiting supportive personnel, have, together with the rapid increase in supportive and recreational services, formed the backbone of social psychiatric interventions. In 1999, around 3,700 people with mental illnesses were provided with specially arranged permanent accommodation, financially supported and administered by the counties (*ibid.*). Apart from these, the municipalities, in recent years, provided around 2,000 temporary accommodation facilities yearly restricted to persons with mental illnesses (*ibid.*: 19). For the years 2000-2002, the Danish state has provided financial support for the development of around a further 1,200 new supported permanent accommodation facilities (*ibid.*: 18).

A fast-growing area of intervention within social psychiatry is the employment of 'support and contact persons' (*støtte- og kontaktpersoner*), to provide individual support and social contact to people with a history of mental illness, who are placed in individual accommodation (i.e. without supportive staff being connected to the place of residence). The provision of 'support and contact persons' has existed since 1976, but in recent years the number of people who were connected to a support and contact person has expanded enormously, from 1,847 in 1997 to 4,067 individuals in 1999. Furthermore, in 2000 3,273 persons with a mental illness received 'social pedagogical support' (*socialpædagogisk bistand*), primarily from special supportive centres (also a rapid increase compared to the 2,308 individuals the previous year, 1999) (*ibid.*: 19).

Generally, this support is directly related to assist the individuals in the specially arranged permanent accommodation (*Socialministeriet* 1998: 105-7).

It has been of significant importance for the development of the social psychiatric services that throughout the 1980s and 1990s there has been a strong political commitment to provide not only subsistence essentials, but also life quality for the mentally ill living in the community. The number of recreational services (*dagtilbud*) providing opportunities for people with a history of mental illness to engage in diverse activities has thus undergone a steady increase since the end of the 1980s, when there were fewer than 500 nationally, to just below 2,500 in 1999. It is expected that this development will continue, as 'more people are supported and receive treatment in their own homes, but still need to engage in a work or activity which is adjusted to the handicap' (*Amtsrådsforeningen* 2001: 18, my translation). A similar expansion can be seen in the increasing number of people who receive 'compensatory special education for the mentally ill' (*kompenserende specialundervisning til sindslidende*). In 1984, 716 persons participated in such educational services per year, in 1999 the number had increased to 3,025 (*ibid.*: 20).

The aim of the institutional and professional emergence of social psychiatry as a distinct practice of social work in Denmark is to enable the former in-patients of psychiatric wards to live a life in the community as close to 'normal' as possible. In the light of this development, the concept of de-institutionalisation, generally used to refer to the closure or downsizing of large hospitals, has to be reconsidered – at least in the Danish context. For it is not the case that institutions are being abandoned totally, rather that some institutions are now being preferred over others. It has been observed, in a comment on the development of psychiatry in Denmark (Brandt 1997: 187), that the new institutions now being preferred are without addresses (*matrikelløse*), that is, there is no space or building where they can be identified. This is, however, only partly true. Social psychiatry also refers to the spatially manifest social services, such as special care homes, social meeting places and sheltered workshops specially set up for people who have a mental health problem (*Familie- og Arbejdsmarkedsforvaltningen* 2000a, 2000b: 29-36; Jöhncke 1998). A British study (McCourt Perring 1994) of the experiences of long-term in-patients in psychiatric wards as they move into new care homes has demonstrated that even if the former buildings of the hospital institution

were left, the 'institution' moved along as organisational structures and caretaker-client relations were reproduced in the new setting. McCourt Perring demonstrated how the residents in the new care homes were kept in a role as dependent and compliant, and that the rehabilitation was *inward-looking*, focusing on the psychiatric facilities as 'a sort of alternative community' (*ibid.*: 174), resembling the in-patients' experiences of the hospital (Lorencz 1992: 297).

To the extent that some former in-patients live in their own flats, and not in staff supported care homes, it is, however, true that interventions offering treatment and support to the mentally ill in the community are less confined within a restricted space. This does not mean that these institutions have no physical and spatial existence, but that they take on another character and meaning, as they reside in administrative centres, meeting places for staff, and only occasionally are used directly by recipients of the services provided, when they come for their weekly conversation or therapeutic meeting. The physical institutions may still be central locations for the staff to conduct their daily work, but – unlike the former hospitals, which were clearly identifiable spatially – the new institutions no longer frame the daily lives of the users. The interventions have not been abandoned and institutions have not disappeared (cf. McCourt Perring 1994), therefore it is incorrect to talk of de-institutionalisation. The *neo-institutionalisation* of mental health services has made the interventions more fluid, less bound to fixed physical premises.

The vast neo-institutionalisation following the de-institutionalisation of psychiatry in recent decade reflected a general political recognition that existing psychiatric services in Denmark did not adequately fulfil the needs of former and present psychiatric patients who were living in the community, outside the psychiatric wards (e.g. Adolph *et al.* 1996; Bømler 1992; Gerlach *et al.* 1996). A special problem arose from the involvement of different public sectors. Even if social services to support the individual were available, very often interventions from the health and social sectors respectively were not sufficiently co-ordinated. It could, for example, be a problem that the social supportive staff necessary to help a person settle down and arrange a new flat were not available at the time the person was ready to leave the psychiatric ward. Or, the social support staff's insufficient knowledge about and access to possible treatment

and support from the psychiatric health sector could prevent a person from receiving the optimal medical treatment.

*Introducing new forms of mental health care in the OPUS project*²⁸

The establishment of the OPUS project has to be seen against the background of the general history of psychiatry and the development of social services in the community for the mentally ill in Denmark. But other factors were also involved in the actual creation and setting-up of the project. Within the Danish health sector there had, since the 1980s, been a growing focus on the possibility of *preventing* illnesses as preferable to *treating* them. In particular, Bispebjerg Hospital in Copenhagen had invested resources in innovative programmes of illness prevention, such as *Sund By* ('Healthy City'), a programme promoting regular exercise, and *Røgfri Årgang* ('Smoke Free Generation'), a programme aimed at preventing smoking. In line with this development, there was a discussion among psychiatrists as to whether it was possible to introduce preventive efforts when dealing with serious mental illness (e.g. Rosenbaum 1992).

In The Danish Ministry of Health it was decided to provide financial support for preventive intervention in mental health. Professor MD Ralf Hemmingsen, who is adviser for The National Board of Health (*Sundhedsstyrelsen*) under the ministry, contacted MD Merete Nordentoft and together, in the spring of 1996, they started to design a project. Drawing on international research on innovative mental health programmes in Australia, Britain, Holland, and Norway, and participating in a conference for psychiatric treatment in Madrid in the autumn of 1996, they developed the design of the intervention and research. They found guidance in a number of international studies which had reported an association between the longer duration of untreated initial psychosis and poor outcomes with respect to schizophrenia (Jeppesen 2001: 8). The design of the intervention was 'evidence based' in the sense that research had proven the efficiency of the treatment. The prime goal of the OPUS project was 'early detection of psychosis' and reduction of the 'duration of untreated psychosis' which was thought to facilitate the best possible prognosis. The project followed the

²⁸ This section is based on information obtained through individual interviews with key actors involved in establishing the OPUS project: from the health sector, MD Merete Nordentoft, from the social sector, Søren Surland and Janne Gry Poulsen, and from the user organisation, *Galebevægelsen*, Claus Bech-Nielsen and Caia Garupi. I have described details in the process in more length in a previous publication (Larsen 2001a, Chapter 2).

growing international interest in providing various forms of early intervention in psychosis (cf. Birchwood *et al.* 2000a; Spencer *et al.* 2001).

Hence, OPUS was set up with the elements of treatment and support which had proved to give the best results: the use of optimal, low-dose, atypical antipsychotic medication, in combination with individual case managers, therapeutic multiple-family groups, and social skills training. The prime goals of the intervention were for the patient to avoid psychotic relapse and achieve 'the restitution of a normal life, including work or education and relationships to family and friends' (Jeppesen 2001: 50). To meet these goals, it was assumed that '[p]atients need help to develop an insight into the illness and its management, including being able to understand and integrate the experience of psychosis, recognise symptoms and early warning signs, comply with treatments, and avoid street drugs' (*ibid.*). The notion of *insight in illness* is generally recognised as a key issue in the psychiatric approach to persons diagnosed with mental illness, since it is a necessity for the persons to accept that they have a problem (i.e. an illness) in order for them to co-operate (or 'comply') with the medical treatment and/or psychological therapy (Birchwood *et al.* 2000b: 99; Estroff *et al.* 1991: 339ff.). An important aspect of the intervention in OPUS was, therefore, to provide the mentally ill with knowledge about their illness and how to deal with it, a therapeutic effort known as *psychoeducation* (McFarlane *et al.* 1991, 1995; McGorry 1995). These efforts were integrated into the overall application of a cognitive psychological therapeutic approach which has proven best suited to improve the prognosis of persons with schizophrenic illnesses (Jeppesen 2001: 24-50).

The ideology of medical treatment, giving optimal, low-dose, atypical antipsychotic medication to minimise side-effects such as involuntary body movements and apathy, was presented along with the increasingly popular etiological model of *stress-vulnerability* regarding mental health problems (Zubin and Spring 1977). The model presents a 'normalising' perspective (McGorry 1995: 325) by suggesting that mental illnesses, as psychoses, are caused by an unfortunate coincidence of social and biographical circumstances and a particular individual vulnerability, based in the biological and psychological composition of the person. Social, psychological, and biological aspects thus all have significance in the development of, or resistance to, mental illness.

Small multiple-disciplinary teams were chosen as the institutional backbone of the treatment and support in OPUS. This was due to good results from the USA using similar teams to provide assertive community treatment (Stein and Santos 1998). Assertive community treatment (ACT) is treatment provided to people with mental illness living 'in the community', i.e. not in a psychiatric ward. It is labelled 'assertive' due to the effort, and responsibility, of the treatment staff to provide treatment and support for the mentally ill, also in periods when they themselves are not able to be active in seeking help, or, even, aware that they need help and treatment. In Denmark these teams have since been labelled *opsøgende psykoseteam*, which literally means 'outreach psychosis teams' (Vendsborg *et al.* 1999). Internationally, there is some inconsistency regarding the naming of these and similar interventions, which, in recent years, have been introduced widely in North America, Europe, and Australia. Currently, the term 'assertive outreach team' is predominant in Britain, and efforts have been undertaken to secure a standardisation of the practices and concepts to distinguish this term from, for example, 'individual case management' and 'crisis resolution teams' (Ford *et al.* 2001). A general trend is that formal standardised criteria are established to secure that the interventions live up to their labels. For ACT it is, for example, a usual requirement that there is twenty-four hour service and that the 'case load' is not higher than twelve patients per staff member.

The intervention in the OPUS project did not fully live up to all the standardised ACT criteria, and it could be argued that 'crisis resolution team' would more precisely characterise the intervention given as a two-year follow-up after the first psychotic episode. Especially since most of the recipients of OPUS were 'detected' and included as they were admitted to a psychiatric ward, and they often spent several weeks or even months there before they were discharged. During the time in a psychiatric ward it was the hospital, and not OPUS, which was responsible for the treatment. However, OPUS staff regularly visited the recipient in the ward and helped them as they were preparing for discharge and to re-enter 'the community'. This was also the case on occasions when recipients were readmitted to a psychiatric ward following relapse. Even if it thus can be debated which is a more correct term to use when describing OPUS, I have chosen 'assertive community treatment' since it originally offered the inspiration, and 'evidence based' scientific legitimation, for the

design and initiation of the intervention programme. However, the combined effort of treatment, therapy and support in OPUS has also been labelled 'integrated psychiatric treatment' (Jeppesen 2001; Jorgensen *et al.* 2000).

The criteria for inclusion in the OPUS trial were that the person should be: 1) aged eighteen to forty-five years; 2) diagnosed as suffering from schizophrenia, schizotypal disorder, persistent delusional disorder, acute and transient disorder, schizoaffective disorder, induced delusional disorder, or unspecified non-organic psychosis according to ICD-10 research criteria (based on 'Schedules for Clinical Assessment in Neuropsychiatry', SCAN version 2.0); 3) have no exposure to antipsychotic medications exceeding twelve weeks of continuous medication; 4) have no mental retardation, organic mental disorder, or psychotic condition due to acute intoxication or a withdrawal state; 5) be familiar with the Danish language, and 6) give written informed consent. The use of ('street') psychoactive drugs was no hindrance for inclusion in OPUS (Jeppesen 2001: 54ff.).

In the spring of 1997, the first descriptions of what came to be the OPUS project were discussed with representatives from the Danish Ministry of Health. The representatives from the Ministry were particularly interested in supporting the programme if the research, or 'trial', would be set up with a randomised controlled design, whereby about half of the included individuals would receive the standard psychiatric treatment and the other half the special treatment in OPUS. Further, some were also randomised to be awarded a place in an experimental 'luxury ward' for young patients with schizophrenia at the psychiatric hospital Skt. Hans, outside Copenhagen. But due to the ward's limited capacity this option was restricted to a more narrow 'catchment area'.

In May 1997, the Social Department (*Socialdirektoratet*) in the Municipality of Copenhagen was contacted and asked to join the intervention programme. The reasons for this offer were pragmatic and economic, since The Danish Ministry of Social Affairs was likely to support the intervention programme financially with the necessary extra funds, but only if a social service institution was involved. The project was to be carried out in the two major urban areas in Denmark: Copenhagen and Århus. In Århus it was no problem to arrange the financial support from the Ministry of Social Affairs, since both the social and the health services were administered by the same institution, the

'Board of Psychiatry and Adult Disability in Århus County' (*Udvalget for Psykiatri og Voksenhandicap i Århus Amt*). In Copenhagen, where social and health services are administratively separated, it was initially suggested that the social section employed a co-ordinator and added extra staff, and that the two sectors could work together on the family intervention and provide information to secure a preventive intervention by early detection (*tidlig opsporing*) of the mentally ill. In an internal paper in the Social Department dated 18th June 1997 the participation was described under the title 'Reach the socially excluded youth before they become crazy - a collaboration project with Bispebjerg Hospital regarding detection and treatment of young psychotics' (*Nå de unge socialt udstødte, før de bliver sindssyge - et samarbejdsprojekt med Bispebjerg Hospital om opsporing og behandling af unge psykotiske*). This paper, and an application to the Ministry of Social Affairs developed during the summer, stressed that the social intervention was independent and a supplement to psychiatric treatment. This first application was, however, turned down, and the Social Department was requested to rework the project description.

In the following months the Social Department contacted an organisation for users of the mental health services called 'The Mad Movement' (*Galebevægelsen*) and invited representatives to join a working group where the intervention in the experimental project would be devised. This practice was in accordance with the popular municipal policy of 'user involvement'. Controversies arose over the suggested experimental set-up of the medical trial, whereby half of the patients would be a control group not receiving the special treatment. In the Social Department this practice contradicted the general policy that all citizens received the same support, depending on an assessment of their needs and the available resources. The representatives from The Mad Movement opposed the randomised design due to similar considerations regarding inequality, and because they saw it as an expression of the perspective and power of the psychiatric profession to treat the patients primarily as objects of their intervention. Considering the need to provide 'scientific proof' within the existing political institutions of authority the design was, however, reluctantly accepted. In a revised application to the Ministry of Social Affairs, completed in October 1997, the staff employed in the social section were connected directly to the programmes of treatment and support developed to provide the 'integrated psychiatric treatment'. The

representatives from The Mad Movement were given only one week to present criticisms and suggestions to alterations in the programme description, which was drafted by the representative from the Social Department. The representatives from The Mad Movement later told me that from this time they increasingly found that their ideas and suggestions, about the institutional structure and the content of treatment and support, were overlooked during the meetings of the working group. Finally, they decided to withdraw from the group, since they saw their presence there as having no concrete bearing on the composition of the intervention. They saw themselves as hostages in the procedure, as political representatives of the users merely functioning to legitimise a treatment of the mentally ill that they could not support.

In the final form the project was given the name OPUS, which originally was an acronym for 'early detection and treatment of young psychotics' (*tidlig OPsporing og behandling af Unge pSykotiske*). It was intended that the name had a musical connotation (due to its use when numbering a musical composition as one of a composer's works), since it was expected that the project would provide a director who could co-ordinate the various psychiatric and social services to create a 'harmonious tune'. The case manager serves this function, to keep continuous and personal contact and to orchestrate the various health and social services provided in the individual's life. The staff were required to build a good personal relationship, or a 'therapeutic alliance' (Spencer *et al.* 2001: 135), with the individual recipient.

By the end of 1997 the first three clinical staff in OPUS were employed: a psychiatrist and two psychiatric nurses, along with two medical PhD students, who were to assist in the conduct of the diagnostic interviews. The rest of the staff were employed during the first half of 1998. Apart from myself, as the evaluator employed by the social sector, eleven full-time staff members were employed to provide services in OPUS: two psychiatrists, three nurses, two psychologists, two occupational therapists, and two social workers. Following regional criteria, two teams were created: OPUS Bispebjerg and OPUS Vesterbro. The social section was concerned that their social intervention should be independent from the health intervention, and had therefore insisted upon separate localities to be provided for the staff employed in the social and the health sectors, respectively. This meant that the two multi-professional teams were divided spatially. The health staff were accommodated in offices in community mental health

centres and the social staff were accommodated in offices established in local residential quarters in the vicinity of each of the community mental health centres.

From the beginning the OPUS project was established with explicit political purposes: to claim the status of psychiatric treatment for illness-preventive efforts, and to improve the quality of the treatment and services for the mentally ill in the community by providing early intervention in schizophrenia. For the social section the participation in OPUS meant that they could be part of innovative work in services to the mentally ill and establish their competence in the field. Due to the financial support provided by the Ministries of Health and Social Affairs, respectively, it could be done at minimal cost for the institutions involved.

The principles of treatment and support offered in OPUS were imported from other Western societies, but the overall value-base of the intervention – focusing on normalisation and social inclusion – was easily appropriated in the context of the Danish welfare model. Although it has been observed that the idea of a specific ‘Scandinavian welfare model’ is something of a myth, based on a normative model of what the welfare state *should* be like (Baldwin 1996), some important features in common do characterise the Danish, Swedish and Norwegian welfare states:

They all emphasize income equalization and a high level of state intervention. Welfare benefits are targeted at individuals rather than families. Income taxes are progressive, social transfer payments are generous, and the public sector is large and decentralized (Torfing 1999: 11-12).

As well as being an example of decentralised and extensive public intervention, the OPUS project reflected, in various ways, Scandinavian egalitarian values of consensus and uniformity (Gullestad 1992; Salamon 1992). The emphasis on including the family in the intervention might, however, be seen as a diversion from the established Danish welfare model – which generally targets individuals only – and may perhaps be explained as a cultural influence from the Anglo-American tradition.

New directions in mental health care

As in other Western societies, mental health care in Denmark has, in the last half of the twentieth century, developed away from segregated institutionalisation towards services offered in the community. As a result, psychiatric hospital wards have experienced a

significant reduction of their service capacity, counted as numbers of beds, and their former long-term functions have been altered to predominantly provide short-term, acute services. These changes have been followed by new forms of institutionalised services provided to the former in-patients of psychiatric wards now living in the community. 'Social psychiatry' is being developed as a professional designation of these social services in Denmark. The process has emphasised the need to co-ordinate services provided by health and social services, respectively.

The OPUS project was established partly as a response to this development, and, partly, to introduce improved forms of treatment to people suffering from serious mental illnesses. By providing early detection and intervention the aim was to prevent or minimise detrimental long-term effects.

Chapter Four

Becoming mentally ill

This chapter introduces the informants of the study and presents their general life situations, as well as the mental problems they endured, prior to their inclusion in the OPUS project.²⁹ Their existential foundations comprised traits of both variety and similarity with respect to their individual circumstances and experiences. A description of their psychotic experiences and problems provides an insight into these extreme sensations and perceptions which is crucial to an understanding when, in later chapters, I examine their efforts, and the difficulties they met, as they sought to recover and re-establish their lives.

The stress of life

Looking back at the time preceding the contact with OPUS, psychotic experiences, and admission to a psychiatric ward, all the informants described their life circumstances as stressful and demanding. The findings accord both with other empirical findings that psychiatric patients report stress and feelings of being overwhelmed in the 'preadmission period' (Lorencz 1992: 265ff.) and with the increasingly popular aetiological model of *stress-vulnerability* regarding mental health problems, as described in Chapter Three. Hence, these descriptions do not make claims about the aetiology of mental illness, and no 'master narrative of illness' is directing the presentation.³⁰

In the period up to the inclusion in OPUS, seven of my fifteen key informants were unemployed, and one, Birgit, who at 39 years was the oldest, received early retirement pension (*førtidspension*). Ole, who was one year younger than Birgit, had been unemployed and receiving social benefit (*kontakthjælp*) for four years. Dennis,

²⁹ To ease the overview of the fifteen informants while reading, the table in Appendix A may prove useful.

³⁰ The presentation in this way differs radically from a case record (Goffman 1961: 134f, 143-7) or a pathogenesis as formulated and used in the psychiatric practice, where a course of events in the

Julie, and Per had been out of work for about a year, Per after having finished his training as a toolmaker. Four years earlier, when he was 26, Dennis had been persuaded by his sister to move to Copenhagen after having been unemployed for a period in his home town in Jutland. His sister was at the time working in Copenhagen and Dennis thought that he might just as well make the move and hope that things would change for the better. After some weeks in the capital, he found a job, but he found it difficult to make friends, and about a year before he was admitted to the psychiatric ward he started to isolate himself further, having lost the job as a care assistant for older people. Julie, at the age of 30, was admitted to the psychiatric ward some time after she had become unemployed because she resigned from her job as manager in a painting and decorating supplies shop.

Claus and Hans were in their twenties. Within the previous year, they had both dropped out of their studies and been unemployed for a period after unsuccessful experiences in various odd jobs. In the first interview, Claus described the torment of the one day he was working in a supermarket, sitting at the cash register.

Claus: Well, I have tried all kinds of things, I have been assistant in a bakery, cleaning assistant, then I have also tried to sit at the register for one day, at the cash register. I couldn't handle that, it was just too hard. ...//... They [the customers] were going to take the ferry and... there they were, screaming and shouting while I was there, 'I just started today, give me a break!', you see. But they didn't care.

JAL: So it was one day you tried that?

Claus: One day I tried that. And I just remember, one day, but I just had these blip sounds [from the scanner in the cash register] in the head, just like this blip, blip, blip... just non-stop. Then I woke up next morning, it was just, 'I am not going down there again!'

Half a year before, Claus had dropped out of his dental assistant training. He had followed the training for nine months, but had come to the decision that it was too hard for him. He found it difficult to keep up with the reading, especially since during the period he felt very tired and had to sleep a lot. He also found the regular trainee placements hard, always having to smile and be polite to the patients. Similarly, Hans found his studies to become a school teacher very demanding. It was especially difficult

individual's life is presented in a form where the illness is the narrative culmination, giving meaning to the succeeding life events (cf. Barrett 1996: 107-142; Lurhmann 2000: 25-83).

to concentrate while reading; he kept on thinking of other things, especially personal problems which increasingly became a burden. He also had social problems with the other students and after a row with some of them he decided to quit his studies. Hans got a job working nights, but it was a very lonely job with few work colleagues to talk to, so it wore him down and eventually he resigned. Because of the periods of unemployment Hans had lost all his personal savings, and he had to borrow money from his parents.

Lotte was the seventh key informant who was unemployed when included in OPUS. She was 27 years old at the time, and had, for several years, lived a life with occasional 'black economy' odd jobs (*sort arbejde*) while remaining in contact with the social benefits system. For a period she had been a cannabis dealer. In her third interview, Lotte explained that she was not at all happy about the opportunities and future prospects she had been offered in Danish society, and the selling of hash had at the time been a way for her to cut through these obstacles and take care of herself.

Lotte: To be completely honest, then I prefer to take care of myself.

JAL: Yes, why?

Lotte: I feel better like that. I think that society stinks. They don't give a damn. ...//... I think that they are complete arseholes. First they put you in school, then you have to hang around there for fifteen years... and then you get out, then you have to live on starvation wages while you slave, and then they put their hand down my pocket to take all the money... they are being used for all kinds of things, they are just being thrown around! You never get anything out of it. I think that it is hopeless. I really can't be bothered with this system, I never could, that was also the reason I became a pusher, you see.

JAL: Because it is another way of living?

Lotte: I don't know, it just happened to be what I wanted, you see, I was in problems up to my neck, then I thought, 'What the hell can I do about it, I have to make a living somehow – it could be a good idea', and then I did it. In present day Denmark you don't have a chance to earn a penny, well you can earn 2000, 3000 [Danish kroner pr. month, equivalent to £170-250] – 2000 if it is a project [benefits working in an activation project], 3000 if you slave seven hours [a day] in some dark basement all winter through, you see. You don't get any money for it, so I thought, 'Fuck you man, you can kiss my arse!'. Then I became a hash seller, pusher.

Of the fifteen, only two key informants were working in regular jobs in the period up to their inclusion in OPUS. Irene, aged 36, was working in a large charity and health related organisation, using her academic training. At 21 years of age, Frank was

the second youngest of the key informants. He had, for several years, been working in a supermarket. In the months before his admission to the psychiatric ward he moved out from his mother's place to his own one-bedroom flat. He had, in the short time, experienced considerable financial problems, to keep up with all the bills and the costs of daily living.

The second largest group, apart from the unemployed, consisted of those informants who were studying or in vocational training at the time before the inclusion in OPUS. Anders, Eva, and Martin were between 24 and 26 years of age, and university students at different stages: Anders was a first-year student of philosophy and economics; Eva was in her third year studying political science, and about to finish her BA; Martin was in his fifth year, and he was scheduled to start writing his final thesis to achieve an MA in Engineering. Kristina was 28 years old and studying to become a teacher of relaxation (*afspændingspædagog*). The youngest key informant was Namira, aged 20, who was in the middle of her three-year training in a large retail store to become a shop assistant. As a Bosnian fleeing the war in the former Yugoslavia, she had received refugee status after arriving to Denmark in 1993 with her mother and older brother.

In the interviews the informants talked about various ways in which they had experienced their general life situations, prior to inclusion in OPUS, as stressful. All described themselves as in a transitory and tumultuous period in their lives – they gave stories of, for different reasons, 'not making it' (cf. Lorencz 1992). For some the transitory status was obvious from the social position they occupied at the time, being unemployed, in education, and/or experiencing financial difficulties. Frank, Hans, Lotte, and Ole all stressed the burden of their financial difficulties at the time. Ole felt particularly insecure about being on the dole and subject to compulsory public initiatives to 'activate' him in work projects. He felt that in the four years he had received social benefits he had been 'thrown around in the system' and he was craving for financial stability, and to be left alone. Claus also felt the pressure; during an interview at the Job Centre he suddenly burst into tears. Julie felt that the responsibility as manager of a shop was overwhelming and even after she had resigned she thought that her employers persecuted her. Eva felt under pressure from her studies as she had come to realise that it would not be possible for her to complete the BA essay she had

been preparing for. But even though the stress should have been relieved by her decision to postpone the examination, Eva explained that the stress continued and accelerated.

In other cases the stress of life was more subtle, related to the individual biography or private predicament. This was most clearly the case for Irene, who, with her good education, secure job, husband, and young child, appeared to be in a stable life situation. Also the staff in OPUS observed this difference in her status, and her individual case manager gave me this advice before my first meeting with Irene: 'I will have to warn you that you will meet your equal.' But regardless of her established social status, during the five interviews, and in her personal account for the book project, Irene has told a story of general insecurity in the direction her life was taking at the time. She questioned whether she should stay in the relationship with her husband, and she was uncertain if she should pursue a career at work or if she should spend more time with her child, in the 'traditional role' as a mother and wife. Kristina also experienced strong emotional tumult in this period. She was passionately in love with a man who was not returning her feelings and sharing her aspirations.

Apart from psychological pressure created by immediate uncertainties, informants also talked about being tormented by distressing experiences they had long ago. Lotte said that she had been abused as a child, and Per described how he needed to talk to a psychologist about the experience, seven years ago, of finding his father dead after he committed suicide. Neither of them felt that they had dealt with these stressful experiences. As a child Lotte was sent to see a psychologist, but she was afraid that he might tell her parents, so she refused to say anything. Per had also seen a psychologist and received bereavement counselling, but, nevertheless, he felt that he had never dealt emotionally with the experience; he had never grieved over his father's death. Further, three of the informants had previously received treatment for mental health problems. Both Irene and Kristina had experienced psychotic episodes and been admitted to a psychiatric ward, Irene once about 10 years ago and Kristina twice, with one year in-between, the first about two years before she was included in OPUS. Anders had, for about one and a half years, received medical treatment for depression.

Apart from the distress caused by social and personal circumstances, five informants talked about mental distress related to frequent use of drugs. For several

years Anders had regularly smoked hash and in the period before he was admitted the psychiatric ward he spent many nights in a 'dust of hash smoke,' philosophising about the world and existential issues. Lotte had smoked hash since she was thirteen, and in recent years she smoked about one and a half grams daily. Per smoked occasionally with the friends he had at the time, who also generally were unemployed. For Frank the use of drugs was also largely social, but he did not stop with hash. At weekends he sometimes used cocaine and on several occasions he took hallucinogenic mushrooms. Likewise, Claus said that he had used drugs primarily when he went out with his friends, and mostly ecstasy, but he had also tried cannabis, acid, and mescaline. In the interviews all five mentioned that their use of these drugs had possibly provoked their psychotic experiences.

When I interviewed Frank in February 2000, more than one year after he had been included in OPUS, he explained that in the beginning, when the psychosis that had brought him into hospital started to fade, he had thought that it was only the mushrooms which made him psychotic.

[At the time I thought:] 'Well, now I have been at the secure psychiatric ward, now I am cured, you bloody don't get crazy from smoking hash. It is only those mushrooms, I have to stay away from them', you see.

But then, after having experienced yet another psychotic episode, he thought otherwise, and he decided to stop taking any drugs. Frank described how the drugs made him hallucinate and feel paranoid. He explained that he used to smoke hash to relax after work and other drugs used to give him a kick when together with his friends.

Frank: Now I haven't smoked for half a year, or taken any drugs or anything for half a year. I can feel that I have got much better, because I also get paranoia, when I take drugs I get heavy paranoia. I think that people are following me on the streets, and things like that. So it's not any good for me. It's not good for me. It has to end now, definitely, I have made up my mind. You see, I don't want to get back to the hospital again, it kind of scares me, that if I take something again, then maybe it will be worse next time. Maybe I will see some visions, some evil visions. I have seen some weird hallucinations, that is what I have to avoid now, you see, and get on with my life. And not waste it on that.

JAL: But there was then also something great about taking the drugs?

Frank: It is more the kick when you take it, with the hash I did it to... after work I came back and smoked a joint or something, and in the weekends I took... it was not every weekend, but two weekends in a row, then we could take some cocaine, some of us. Then we would sit and get each other high, you see, you can say that it made me high.

JAL: So it is also something social?

Frank: Yea, yea. It was! ...//... And it was like that, 'When they do it, then I will also do it', you see, that was how I felt, 'God damn it, I can also do it', you see.

A theme running through many informants' descriptions of the time preceding their inclusion in OPUS is problematic interaction with other people. Some had quarrels with friends, family or people at work or at study, or they thought that people were persecuting them. In these cases the problems could lead to open conflicts, resulting in loss of friends or being fired from a workplace after arguments with the employers. Other informants experienced their social problems in a more introverted form, by feeling very nervous and insecure, and angst when together with other people. These experiences more often resulted in social withdrawal and isolation. The informants felt they were regarded with discontent or suspicion by other people. In particular, those who chose strategies of social isolation had nagging feelings of low self-esteem and thought of themselves as inferior or worthless.

Birgit and Martin talked about severe problems of social angst and low self-esteem. Martin explained how these feelings had grown bigger and bigger since his childhood, increasingly engulfing his life and isolating him from contact with other people, even if, by doing well in his studies at the university and being an active athlete, he appeared to be socially well-integrated. In his account for the book project, he described feeling that he would not be accepted by his peers and that in his teenage years, he thought that he did not have the looks to be liked by girls. He, therefore, did not develop any sexual relationships and this further added to his feelings of inferiority. Martin had deliberate strategies to avoid challenging social confrontation. After finishing primary school, he chose to take his higher education entry exam at a technically-oriented school (*HTX*) instead of the more common general educational school (*gymnasium*), since he expected to encounter fewer social activities at the technically-oriented school. Nevertheless, it was tough for him to get through these years, since at this school they also arranged parties from which he had to excuse

himself. He often used his training for competitions in triathlon as an excuse, both to others and to himself, for staying away from the parties, drinking, and sexual experiments that many of his peers engaged in. But still he craved for these activities and felt guilty and inferior because he could not participate.

Having taken his higher education entry exam, he would have preferred to study a humanistic subject, but again, since he feared the social challenge from his peers, he chose to study engineering. He thought that he would be more easily accepted in the social environment of students of engineering, whom he expected to be a bit socially withdrawn, more like himself. His feelings of personal inferiority, however, continued. The social challenges in his time as a student came not so much from his study as from the student flat he chose to move into, after a period of living alone in a flat. He avoided the regular student parties and was seldom to be seen in the common kitchen, eating bread and honey in his room instead of cooked meals. Eating bread and honey reminded him of a loner he used to visit with his father as a child. It was a good experience for Martin to work part-time as a postman; he felt that the uniform and the positive social role gave him a 'right to be present' and that he was appreciated. But he was ashamed of his social isolation and lack of friends, and he lied about it, even to his parents, pretending to participate in social gatherings. Hence, he secretly spent a few New Year Eves alone in his room in the student flat, hiding in a cave of blankets so that no-one would see him watching television.

The social isolation, and feelings of inferiority and shame tormented him. In the period before he came in contact with OPUS he was often so unhappy with life that he went to sleep, hoping that he would never wake up. He also started thinking about how he could take his own life. One afternoon in the winter he started off to go running. As planned, this time he went for a particularly long run to an isolated beach. He came to the beach, totally exhausted – it was his plan to go into the freezing water. In his exhausted state he expected soon to become unconscious in the cold water, and drown. However, standing at the shore in the early winter darkness, tormented by his dark thoughts, Martin fortunately decided that he would not go through with it.

Anders, Claus, Dennis, Hans, and Irene also revealed that they had thoughts of committing suicide, and Julie came very close to succeeding in her attempt at a point when she was driven to despair and suffering delusions. As others have observed

(Scheper-Hughes 2001: 46-51; Van Dongen 1998), suicide, and planning suicide, can be an individual's attempt to regain control over a life which seems out of control and without hope.

Martin's description of the social isolation he experienced differed from the other informants' descriptions in its predominantly mental character. Even if he did avoid social contact, at the same time he managed to follow a university education, to be an active athlete, and to work as a postman. Dennis talked about a more radical social isolation, locking himself in his flat. Eva and Hans explained that they found it difficult to interact socially. Eva thought that it was because she was bullied as a child, when she stuck out in the school of a provincial town as the 'big-city-girl', having moved from Copenhagen with her parents. Hans said that he used to look down on social activities and instead immersed himself in books. The social isolation was, in this way, chosen by himself, as was the case with Ole, who said that he preferred just to take care of himself, and that he was good at being by himself. For some former psychiatric patients, being 'at a distance' from social life becomes a permanent strategy of 'positive withdrawal' (Corin 1990).

Other informants described social isolation, in the period up to the contact with OPUS, more as a consequence of the problems they were experiencing. Anders stopped having regular contact with family and friends, since he was increasingly absorbed in working out solutions to existential problems and on sleepless nights he often went for long walks by himself. Irene and Kristina also described how their psychotic experiences increasingly absorbed their attention and isolated them socially. Lotte and Per both cut off their friends because their delusions and hallucinations persuaded them to. Frank got into a fight with a gang of youths and had an argument with his employer. And Julie resigned from her job.

Whether it was related to uncertainty in their financial or housing situations, social problems at work or in education, difficulties in their intimate relationships, or general angst in social interaction, the informants at the time before their inclusion in OPUS were in social circumstances which they experienced as burdensome or distressing.

Psychotic experiences

For a man to change his basic, perception-determining beliefs – what Bateson calls his epistemological premises – he must first become aware that reality is not necessarily as he believes it to be. This is not an easy or comfortable thing to learn, and most men in history have probably been able to avoid thinking about it. And I am not convinced that the unexamined life is never worth leading. But sometimes the dissonance between reality and false beliefs reaches a point when it becomes impossible to avoid the awareness that the world no longer makes sense. Only then is it possible for the mind to consider radically different ideas and perceptions. (Mark Engel, preface in Bateson 1972: vii)

As part of the diagnostic requirement to qualify as a recipient of the experimental intervention programme in OPUS, as discussed in Chapter Three, all fifteen informants were psychiatrically assessed as suffering from psychosis, or other mental illness within the ‘schizophrenia spectrum’, at the time of their inclusion. A psychosis can appear as sensory hallucination and delusion. *Sensory hallucinations* are mistaken perceptions of the senses, where a person has the experience of seeing, hearing, tasting, smelling, or feeling things which other people cannot, and which cannot be proven to exist by any method of scientific examination. *Delusions* are false opinions and arguments, for example when a person is of the opinion that he or she is Jesus or a panther, that the devil and the police are conspiring against the person, or that people on the street are persecuting him or her. An important aspect of the diagnostic identification of a delusion is that the belief is idiosyncratic and, for example, not part of an established belief shared by people in a social group or subculture. It is, for example, not in itself a sign of delusion when a member of Jehovah’s Witnesses claims to be among the few chosen by God to enter Paradise at the time of Judgement Day.³¹

Throughout the informants’ descriptions of their psychotic experiences an air of mystery, exoticism, uniqueness, exclusiveness, intensity, and absorption prevailed. Most of all, the psychosis placed the individual in a dense world, full of meaning, with the person at the centre. In his account for the book project Claus describes the feeling:

³¹ See also the discussion of diagnostic validity in Chapter One.

It is a bit strange when you have a psychosis, your senses are sharpened, but at the same time you are numbed. You have an experience of emptiness, and at the same time you are filled with all kinds of emotions. You can't really control anything, it's like you are satiated with emotions.

To describe her experience of the psychosis, Kristina said that it was like being in a film, with yourself playing the main character. It was exiting, intense, empowering, frightening – all at once, or in sequences. The cinematic metaphor seems convincing to describe the subjective sensation of the psychosis. The problem, and the frightening part, is that even if you, at times, feel that you are in the centre of the events, you are not the one writing the script – you maybe feel powerful, but you are not in control. Some informants talked about psychotic experiences where changes in position and mood happened frequently. Frank explained how he at times felt that he had ultimate magical power to make physical objects appear, move out of his body, transform into an animal, manipulate the picture of the television, and call for spirits and ghosts to appear. At other times he felt that he was surveyed by others, people on the street wanted to do him harm, and evil spirits were scaring him, for example by shouting or by making his wardrobe rattle and jump up and down.

Others have given a more uniform description of their experiences, as either negative or positive. Julie described her experiences as purely negative: people were persecuting her by surveying her at work, laughing at her, shouting at her or making strange signals to her, and she had frightening experiences of people staring through her windows, gathering in black clothes in front of her home, and running up and down the staircase in her house. Julie describes these experiences in detail in her account for the book project.

Of the fifteen informants only Kristina said that her psychotic experiences had been entirely good. She described the sensation as flying, as being full of sensations. While she was psychotic, she both felt very happy and very sad, and Kristina explained that she was very grateful that she had had the opportunity to feel so strongly and achieve a kind of deep insight. When Kristina first told me about her very positive experience of her psychosis I was surprised, because the other informants primarily had pointed out negative aspects of the experience. For Kristina the only negative aspect of the experience was to realise that it was not real, as she described in my second interview with her.

JAL: But did you experience it as a problem, when you were psychotic. I mean, when you say that you only felt good, was it then a pleasant experience to have, in that situation, or...?

Kristina: Yes, just at that moment, but then it is evident that you feel bad afterwards, because you discover that you have been ill. And it has been... gone too far, and you feel extremely bad about that afterwards, but just when you are in it, then it is as if you are gliding in the sky.

In her account for the book project, Irene gives a vivid description of the cinematic and fantastical experiences and thoughts she had when psychotic. She believed, for example, that she was involved in a murder story, and, since she knew who the killer was, she called to notify a newspaper. She also thought that she was engaged to Prince Frederik, the future king of Denmark, and that he would come and pick her up in his car.

To Irene and Kristina the psychotic experience was like being in another world, with other and stronger meanings and sensations. Lotte's description of her psychotic experiences was different in that it primarily was a voice speaking to her. Lotte was not quite sure if it was one or two persons speaking, sometimes it sounded as different voices. She explained that the voices became stronger after they had persuaded her to quit her friends. At the time she had been a hash pusher for some time, and she was considering expanding the business, with her own little hash shop. But the voices said to her that she should not do it, and instead find a proper job, and they persuaded her to leave her boyfriend at the time, who was in a rough gang and often beat her up. As a result she lost the common friends they had, and was isolated with her voices. Lotte explained that she was cautious about going out among other people when she had the psychosis, since the voices could make her do and say all kinds of things; she had no control.

Lotte: The psychosis was clever, it made me distance myself from everybody. ...//... When I have got the psychosis I wait a bit to go and see other people, because I know that the psychosis always makes me do something shitty.

JAL: How?

Lotte: It can be statements, it can be actions, it can be all kinds of strange things.

JAL: You feel that you have no control of it?

Lotte: Yea.

In the third interview I had with Lotte, she told me that the psychosis had come back after she had stopped taking the antipsychotic medication. One night she had been working at the hot dog stand when the monotonous ticking sound from the timer for the sausage cooker gave her a strong sensation that the psychosis wanted to come back. Lotte explained that she felt lonely without the voices, but just prior to our meeting she had tried to motivate herself to start taking the medication again.

Lotte: The last few days I have started saying, 'You have to take this shit' [the medication], but worst of all, when the psychosis disappears I feel at least as miserable as when I have the psychosis. So I really don't know what I prefer, psychosis or without psychosis.

JAL: But that was also what we talked about last time, the psychosis makes you lose control, but at the same time there are these voices which you feel support you?

Lotte: I don't feel that they support me, but they grab hold of some things from my childhood which I have completely repressed, some nasty experiences. They then claim that these things are being stored in the back of the head, and therefore your behaviour and things like that, blah, blah, blah... it is as it is. They think that they are kind of a small psychologist who can sit and figure out everything.

JAL: Who is it that thinks that?

Lotte: It is the psychosis.

JAL: Alright, the psychosis tells you that it is like that. What do you think of it?

Lotte: What the hell, I didn't study psychology, I have to admit that, but I bet some of it is right, I'm sure it is.

JAL: So you feel that you somehow can use it in a constructive way?

Lotte: No, I can't really use it, the only thing they say, they say that you are not allowed to forget such nasty experiences, you should not repress it. Even if I thought that it was a brilliant thing I had repressed. They claim that I am not allowed to.

JAL: But then it is actual persons, or actual voices?

Lotte: Yes, it is the same two voices, or one, it is bloody difficult to hear sometimes.

JAL: Yes, yes, is it then something that goes on all the time, or?

Lotte: Yes, it is all the time, it is constant.

The psychosis also persuaded Lotte to stop smoking hash for three months before she was admitted to the psychiatric ward – for the first time since she was thirteen. Lotte believed that the voices were created by 'external forces' (cf. Sayre 2000) – she recognised that she had extraordinary experiences, but she perceived herself as 'psychologically ordinary' (cf. Lorencz 1992: 296). She was not sure who the voices

were, but she had a suspicion that it might have been a young man she once met at a party. She told him that she was considering becoming a hash pusher and he said that it was his dream to join the police force. Lotte had a suspicion that the psychosis might have been his voice.

Other informants reported hearing voices as part of their psychoses, but Lotte's explanation of the psychosis as personalised in a voice, or two voices, communicating with her, giving her advice, and commanding her to do and say things, was exceptional. A more usual experience among my informants was having the feeling that things being said on the radio or on television were specially aimed at them, carrying a special message. Messages could also be more subtly hidden in music or in gestures by actors in films. A young man I met in a social skills training group in OPUS, who was not one of my key informants, explained how, during his psychosis, he could look at a picture and suddenly it would become alive and he could enter the scene it depicted.

Informants told me about other various sensorial hallucinations, but often they found it difficult to differentiate between hallucinations and sharpened or distorted sense perceptions. Anders described how he was able to see in the darkness and how, when walking in the street, he was tormented by the screeching sound from braking buses. Even on cloudy days, Kristina used sunglasses to keep the unpleasant light from her eyes. Frank told me that he, when concentrating and making himself cross-eyed, could make a copy of himself, standing next to him in the mirror. Most likely Frank in this case mistook the visual distortion created by squinting for a hallucination or, rather, magical power.

Apart from Lotte's dialogic experience of being controlled by her voices, and the cinematic experiences of entering another world described by Kristina and Irene, a general feature in the psychotic experiences was paranoia. Feelings of being watched, persecuted, and critically evaluated by other people were strong elements in the descriptions offered by Julie and Frank. In Julie's case the paranoia mixed with a cinematic experience of everything being set up as a conspiracy to persecute her. She thought that her employers were taking and adding money to the cash register, in order to confuse her. She suspected that they had cameras set up in the shop to survey her, and they directed people to come and act as difficult customers asking nonsense questions in order to harass her. She saw meanings and signs in everyday events, for example, when

a man on the street was stepping hard on the ground in front of her, she thought that he was in on the plot to persecute her, and when a taxi driver kept on teasing her by asking if he should go left or right, she realised that he was also part of the conspiracy. Everything linked together, and with the taxi driver she decided that she had had enough, so she refused to pay him. When the police took her to the station she, however, gave in and paid the money for the fare.

The experience of everything being linked together and focused on her was very apparent in Julie's account of her experiences, but it seemed to be a frequent feature also of other informants' descriptions. The feeling of being persecuted and negatively evaluated by other people could, however, be more diffuse. Per described how he could sit with some friends and suddenly get the feeling that they looked down upon him and were laughing at him, and that they all made little winks with their eyes as signs that they were conspiring against him.

Before their contact with OPUS Claus and Birgit had a more or less constant feeling that their neighbours were surveying them. Birgit thought that they were watching her from the flat next door through small holes in the wall, and that they were persecuting her by knocking on the walls and sending smelly gasses into her flat through pipes. To keep out the gasses she blocked the air channel, but she later came to fear that she had possibly thereby caused the death of the woman who lived in the flat above her.

Frank described how his feelings of paranoia were intertwined with megalomania. Frank heard voices taking badly about him and he became very aggressive when he was psychotic. But at the same time he thought that he was immortal, 'number one', chosen by God, that he could write songs and become famous immediately if he wanted to. Frank explained how he could move out of his body and, from the ceiling see himself sitting on the sofa, and in the mirror he could see the double he had created standing next to himself. He heard signs and messages from all places, for example a song was addressed to him, describing him as a black panther. He became the panther. Frank had experiences of possessing magical powers and being able to become God, but he also heard people taking badly about him, as he explained at our third meeting.

But it then also had the result that I thought that I heard from people, and things like that, every time I walked on the street... [they said] 'Well, here he is', and things like that, 'See how he is walking', and things like that. I acted totally cool, you see, I was just walking down the street, and I thought, 'Well yea, fuck that shit!', you see. It had the result that... about believing you can become God, you see, but that was the way I thought, 'Well, but if I became God then it must be because I have a message to people', you see, I thought like that. It then got a bit out of control, you see. ...//... At times it was quite nice, but at times I did not think that it was nice, you see, because I got a lot of comments various places, indirect.

Most informants stressed the unpleasant aspects of the psychotic experiences, that they were terrifying and destructive to their feelings of themselves. But, as with Kristina, Frank pointed out that it was also an extraordinary experience of insight and sublime power, which in some ways enriched him.

I have thought about that it is an experience that no one can take away from me. Even if many won't believe it, they say that it is a tall story. That about believing some things about yourself and be, try to believe that you are God, in your head, that is. ...//... [Talking about taking drugs and getting psychotic] I make my own decisions, but it would be stupid to do it again, to take the drugs again, it would just be stupid to do it again. Because now I have had my lesson, in the sense that I don't need to take drugs. I have had the experience of drugs I need. You see, *I don't think that I ever will get any more wild experience, or better experience, or worse experience*, because I think that I have had the experience I need to have, so I don't need to take it. (Italics added)

Positive evaluations of psychotic experiences are rarely accentuated in research, but this aspect was touched upon in a British study, where people with histories of schizophrenic illness described how they enjoyed aspects of their experiences (Barham and Hayward 1995: 36, 102-10). In the same book one person said that he saw his vulnerability to schizophrenia as part of what he most valued in himself, that the experience 'is not so much an alien intrusion upon his psychological well-being as an exaggeration and distortion of valued ways of feeling and thinking' (*ibid.*: 37). Another young man had a positive experience of religious insight, similar to Kristina's experience (*ibid.*: 117-20). And, in his Australian material, Richard Barrett recorded that a patient in a psychiatric ward said that his delusions made him feel 'good' and 'powerful' (Barrett 1996: 262). Another study observed that some people may actively seek the experience of the psychosis, since it is personally meaningful to them (Sayre

2000: 80). While Sue Estroff demonstrated that some of the people she studied in a community psychiatric treatment programme in America positively chose to 'be crazy', it was primarily because it offered them a recognisable social role (1981: 230ff.). In Estroff's presentation the positive aspects of the experiences are presented as something 'put on', like in a role play. Hence, when discussing medication she mentioned a patient who did not want to lose his '*licence for eccentricity, flights of fancy, and fun*' (1981: 98, italics added).

My material demonstrates that some informants found the psychotic experiences to contain strong elements of positive feelings, such as pleasure, excitement, and powerfulness; and some, especially Kristina, appreciated the sheer intensity of the feelings. However, the informants of this study generally stressed their wish to put the psychotic experiences behind them, even if the experiences might have had strong positive elements. Lotte's ambivalent attitude has been mentioned, but Anders, too, described how he at times longed for the intensity of feeling alive during the psychosis, especially as he felt apathetic and 'as a black hole' in the period after the psychosis had faded.

Frank saw a close similarity between the experiences he had when he was psychotic and his experiences when influenced by drugs. Further, he told how he once swapped similar experiences and sensations with one of his friends who had used various mind altering and hallucinogenic drugs. Claus, who had tried cannabis, ecstasy, and mescaline, also described his psychotic experiences as similar to the experiences he had when using drugs, and how he, at first, was surprised when he had these sensations without having taken any drugs. Frank described it as entering a different world.

You simply experience that you enter a different world, that is what you do, you simply enter the spiritual world. You open some chambers in your brain which say that this chamber I normally can't use, that is, when I am normal. But you can use it when you have taken mushrooms, then you can use this chamber, because the brain is capable of more than you think.

Irene further refined the comparison of the psychotic experience with that of entering a different world:

Many think that you are in a different world when you are psychotic, and in a certain way it clearly is right, and then it is not anyway, because [when psychotic] I do notice what is happening around me. But it is just... that everything is interrelated. Suddenly I see the light, see the red thread, I can relate everything. It is kind of the light of insight. When they play that tune on the radio, then it can be a message, or it can be... or not a message, but it is evident that it is precisely *this tune* they would play, you see. There are interrelations where there never before were interrelations, you see, or where there are no interrelations in the real world, so to speak.

I started this section on the key informants' radically different ways of perceiving reality and their place in it during their psychotic experiences with a quotation from Mark Engel, taken from his introduction to the thinking of Gregory Bateson. I will finish with another quotation from the same text. Keeping in mind the similarity between the psychotic experience and the sensation when using hallucinogenic drugs, as pointed out by my informants, Engel writes with insight about the huge impact on an individual having experienced a radically different reality.

The psychedelics are a powerful educational tool. They are the surest way to learn the arbitrariness of our ordinary perception. Many of us have had to use them to find out how little we knew. Too many of us have become lost in the labyrinth, have decided that if reality doesn't mean what we thought it did then there is no meaning in it at all. I know that place. I have been lost there myself. (Mark Engel, preface in Bateson 1972: viii)

Engel writes about the bewilderment of an individual after having had these extraordinary experiences – what they do to our idea of reality and our notion of our place in the world. But in the situation of the informants for this research, this was not the immediate problem. The psychotic experience was not a drug induced one-off, lasting a few hours, then to be contemplated. To many, over a longer period, it was a constant reality of life – *their* reality. For them the first next step was to stop the continuation of the psychosis – to get back to 'the real world, so to speak' as Irene said. Their route passed through the institution of psychiatry.

Contact with mental health care

My informants came in contact with mental health care in various ways. A general difference was between those who sought help or treatment on their own initiative, and those who were persuaded, tricked, or forced into psychiatric treatment.

Hans and Martin belonged to the first group. Both had personal problems and thought that a psychologist might be able to help them to sort it out. As described above, Martin was experiencing severe problems of low self-esteem and social isolation. The problems had developed in his teenage years and over the years grown worse. At the same time he felt guilty that he had these problems and increasingly saw himself as a bad person. He had not thought about seeking professional help for his problems before he noticed an article in a student magazine, where a psychologist working as student counsellor described the service she was offering and the psychological problems some students were facing. Martin could recognise many of the problems described in the article, and he was surprised that other students had these problems which he had believed were particular for him. It was a relief for him to learn that he was not alone with the problems, and he was encouraged by the statement in the article that these problems could be dealt with by seeing a psychologist.

It, however, cost him a great effort to overcome his anxiety and go to see the psychologist at the student counselling service (*Studenterrådgivningen*). Martin went there in January 1998 and he found some help from the occasional meetings they arranged. It was, however, his failure to accomplish the assignment from the psychologist to eat his meal in the kitchen of the student flat, which convinced him that he 'was a failure' and that he needed to take action to end his life. He also started to come regularly to the student service *Bogstøtten* for young people with mental problems. After coming regularly to meetings with his counsellor for about half a year they decided that he needed more intensive help. Martin especially requested to work in-depth and systematically with specific problems related to his sexuality and his social anxieties, for example about interacting with the other residents in the student flat where he was living. His counsellor arranged for him to go for a screening interview for inclusion in the OPUS project. Hans had a similar experience of first contacting student counselling to talk about the problems he was experiencing in his life at the time; from

there he was sent to talk to a psychiatrist at a community mental health centre, and the psychiatrist sent him to OPUS.

Per and Claus, too, actively sought out psychiatric treatment. After his father's suicide in 1991, Per received bereavement counselling, but even though he kept on seeing the psychologist for about five months, he went through a depression. In 1996 he managed to complete his training as a toolmaker, but afterwards he felt completely debilitated. Having felt like this for about two years, Per came to realise that there was something wrong, and he found the courage to talk to his GP about it. The GP sent him to a psychiatrist, who, after two months of treatment without any improvement, recommended that Per be admitted to a psychiatric ward. But the psychiatrist at the hospital did not think that Per was suffering from any serious mental disorder, and he was thus not admitted.

In the following weeks Per increasingly thought that people were talking badly about him and he started to isolate himself. In the following five or six months his thoughts became increasingly rampant, and he went to the community mental health centre, where he requested to talk to a psychologist. Per thought that his problems were related to his father's suicide; his psychologist agreed, and she believed that he was repressing emotions that he had to express openly. However, the more they excavated the issue during the therapeutic sessions, the worse it became. In the end Per felt that his head was going to explode. After not sleeping for some days he went with his mother to his psychologist, and Per requested to be admitted to a psychiatric ward. He couldn't control his emotions or deal with anything. This time his request was met.

Claus quit his dental assistant training in May 1998, and after a period with successive unsuccessful job experiences and feelings of being surveyed, he had had enough. He found it difficult to control his feelings and when he burst into tears at a meeting in the Job Centre, the bewildered job consultant told him that he could go to see his doctor about his problems; it was like having a broken leg, she said, nothing to be ashamed of. So Claus went to see his GP and they talked about his problems. The situation escalated when Claus went to his aunt's funeral. During the service in the church, he was overwhelmed by his feelings, and he just barely avoided a hysterical laughing fit by concentrating on a point at the altar. On the way home with his family in the car he heard a radio programme, in which a young man with schizophrenia talked

about his life and the difficulties he was suffering. Claus recognised his experiences, such as thoughts of suicide and cutting himself. Home again, alone in his flat, he again thought of suicide. The next morning he decided to seek more intensive help to deal with his problems and he called his GP, who advised him to go to the emergency unit of the psychiatric hospital. Claus went down to the train station to go to Hvidovre, the suburb of Copenhagen with a hospital of the same name. When he arrived at the station, he had to walk along a very long road to reach the hospital. Finally, reaching the reception of the emergency unit, Claus explained that he could not handle anything any longer, and he cried. He went to see a doctor and was given a bed for the night. The next morning he was moved to a youth ward.

Whereas the stories of Claus, Per, Martin, and Hans support Thoits' (1985: 237) argument that individuals may 'self-label' their persistent reactions to stressful life circumstances as indications of mental illness and actively seek professional help, other informants entered mental health care less voluntarily. Dennis related how he was persuaded to go to the hospital, and only reluctantly agreed to stay there. His mother and sister more or less dragged him out of the flat and down in the car to bring him to the ward. When, at the hospital, they told him that he could stay there overnight he tried to resist, but in vain. Dennis explained that he was afraid of going there since he had prejudicial views of people with mental illnesses; mental illness was taboo for him and he did not want to be considered as similar to the mentally ill.

Both Julie and Anders described how they were tricked into the psychiatric ward, where they then were kept against their will. After the episode with the taxi driver, Julie was in distress and had not slept for some days. Together with her partner she cycled to the hospital, where she talked to a doctor and a nurse. The nurse offered Julie a bed at the hospital so that she could rest. In the morning she was told that she was being retained, and to her horror Julie realised that all the doors were locked and the windows were barred. She called her family and in tears she told them that she had been locked up. Anders had a similar experience. At the time he was feeling high and full of energy; he hardly slept and often went for long walks in the night. So Anders decided to pay his GP a visit to tell him that he would not any longer need the anti-depressive medication he had previously been prescribed. The doctor seemed concerned and he asked Anders to come along for a trip to the hospital. In the car it only took a

few minutes to get there. To kill time waiting at the psychiatric ward Anders, with a bat in each hand, played ping-pong with himself against a wall. Eventually, he had a conversation with a doctor, and was asked to stay there for the night.

Both Anders and Per explained that it was when they found themselves in the confinement of the secure psychiatric ward that strong psychotic experiences first really came out. Immediately after the door of the secure ward was closed, Per regretted his decision, and he demanded to be let out. But the staff wouldn't allow that, even though they had said that he was not compulsorily detained. In his account for the book project Per described his thoughts then.

After some hours I understood why: They [the staff in the hospital] were in on the conspiracy, in some hours the secret police will come and get me. It was not just them, they all were in on it, my mother, my grandmother, Poul Nyrup [the Danish prime minister], Bill Clinton, and the CIA, they formed a secret Satanist cartel. I am the son of God to be sacrificed, to be cut open and chopped to pieces. Oops, beware what you think! The Government has placed secret agents at the ward, and they can read my thoughts. The guy who sleeps in the bed to the left of me is to dope me, and the guy from the secret police to the right is watching me to make sure that I don't escape.

Per spent the first week in the secure ward and hated it, since he couldn't go anywhere. At first he thought that the medication was poisonous; but still he took it. He thought about escaping, but even when he went for a walk in the garden a nurse was accompanying him to make sure that he did not jump over the fence. But then he was transferred to an open youth ward, which he much preferred. Here the people were friendly and nice, and he could leave whenever he wanted to. It calmed him down and so he then did not want to go anywhere. While the doctors struggled to find the right type and dose of medication for him, he stayed there for seven months altogether.

Locked up in the ward, Anders became furious with anger and it took four male nurses to hold him down and put him in a straitjacket. He refused to take the medication, but he was being held with force and it was injected in his thigh. It felt like it paralysed the left side of his body, and he couldn't walk properly. After some time in the ward, he managed to open a door with a tool provided by a fellow captive and he ran to freedom. After having enjoyed a cup of coffee and a sandwich at a baker's he returned to the ward; he knew nowhere else to go.

Julie also detested staying in the ward; she was terrified by the fact that she could not leave freely and that she did not know how long she was staying. Like Anders, she did not want to take the medication, and for some time she was successful in cheating the staff by pretending to take the pills. But her deception was revealed after a blood test, and with force she was injected in her thigh. After having been at the ward for about half a year, and plans for her parents to house her after her discharge had been abandoned, Julie had had enough. She felt that the stay in the hospital had demoralised her, and she thought that she would never get out. She went to a nearby train station and jumped out in front of a through train. The next Julie remembered was waking up in an intensive care unit, being washed and getting her bandages changed. One side of her body was full of burns, she had broken her pelvis and an arm, and she had stitches in her head. She had further operations to improve her badly affected vision, but even so she saw poorly and could not read for a long period. When she left the intensive care unit she came back to the psychiatric ward, where she was introduced to OPUS. Altogether she spend almost one year in the psychiatric hospital.

The stories told by Julie and Anders concerning their first contact with mental health care are the most obviously brutal and violent. The experience stayed with them, and it took a long time to get over it, as Anders explained in December 2000, two years after he had been discharged.

It was really violent at the secure ward and things like that, I simply hated people several months after. And I thought back on them, also on my GP, whom I used to quite like. And then they played me that trick, to say that I am voluntarily admitted.

Goffman made a similar observation of the incompatibility between the legally official patient status and the experience of the patient: '[S]ome persons who are glad to come to the mental hospital may be legally committed, and of those who come only because of strong family pressure, some may sign themselves in as voluntary patients' (1961: 124, n9). He therefore suggested the alternative distinction between 'willing' and 'unwilling' psychiatric patients. Goffman's advice is followed in recent research, demonstrating that apparent voluntarily 'informal admission status' in a psychiatric hospital does not always reflect willingness (Harold-Steckley 1987: 209, 406).

Contingencies when becoming mentally ill

In the time preceding contact with OPUS, all the informants experienced psychological pressure related to specific social circumstances or mental experiences – what Goffman (1961: 126) has called ‘contingencies’ in the mental patient’s career. Several had financial difficulties, some had difficult housing situations, some experienced stress in relation to study or work, some were in difficult periods reconsidering their general life situations or intimate relations, and some had mentally overwhelming experiences in relation to taking street drugs. By presenting informants’ situations and experiences in some detail, it has been demonstrated that some of these contingencies could have been different if action had been taken, or if other circumstances had prevailed.

However stressful to the individual, these experiences did not seem to deviate in any particular way from the stressful life situations many people in Danish society encounter without developing psychosis. And there did not seem to be any uniformity in the type or structure of the social or biographical elements which caused this psychological pressure. These contingencies can not, in themselves, account for the development of mental illness. And if some of the individual contingencies had been prevented, there is no certainty whether this would have prevented the outbreak of the psychosis. The material therefore supports the aetiological model of stress-vulnerability to explain development of mental illness as a complex multiple-factor concurrence.

Informants compared the experience of psychosis with that of taking hallucinogenic drugs. It brought them into a different reality, where sensory experiences were stronger and objects and events had different and more dense meanings. Some also experienced possessing magical powers, enabling them to communicate with spirits and assume the shape of an animal. For others the experience was exclusively fear ridden, dominated by feelings of being persecuted. Even if the informants preferred to be without the psychosis, some missed the intensity of the sensations and feelings when psychotic, and one informant pointed out that hearing voices could give comfort and support. The psychosis significantly challenged their everyday experiences of reality and understandings of themselves.

Some informants contacted psychiatric treatment themselves; others were unwillingly admitted to a psychiatric ward. Those who sought out treatment willingly either expected to engage in therapeutic conversations with a psychologist, or they were

tormented by psychotic experiences and requested the hospital as a refuge. Others were unwillingly retained in the psychiatric ward, after having been tricked or gently forced to go there. Some informants described how they experienced that the psychosis first really came out when they found themselves locked in the secure ward. In the ward a few had violent experiences of forced medication by injection and by being held in a straitjacket.

Commenting on what he called the ‘peculiarly retroactive character’ of the pre-patient’s moral career as psychiatric patient, and ‘mentally ill’, Goffman wrote: ‘Until a person actually arrives at the hospital there usually seems no way of knowing for sure that he is destined to do so’ (1961: 134). Goffman did not mean to imply that there was no such thing as mental illness, or that the mentally ill could be cured by closing down the practice and institutions of psychiatry. But the sociologically important point he was making was that when first arriving at the hospital, or becoming a psychiatric patient, the person became socially recognisable as mentally ill. The individual prehistory, and their particular life contingencies at this point, find a direction and point to this status or social role. The awareness of the social dynamics of this process of identification, however, teaches us to be cautious; to keep the focus on the individuals in question, and to see them as actors assuming variable roles within the institutions of society. In the next chapter we will follow the informants as they were included in the experimental project OPUS.

Chapter Five

Inclusion in OPUS

After their first contact with mental health care, either through student counselling, community psychiatry, or admission to a psychiatric hospital, the informants were included in OPUS through a formal screening procedure. This chapter presents the informants' first impressions of this contact and describes their life circumstances shortly after they had been included. Being primarily based on my first interviews with them, it analytically constructs a 'snap-shot', providing a temporal point of reference for their hopes and anxieties, and the dreams they had for their future lives. The presentation further unravels their existential foundations and personal motivations as they encountered the services provided by the community intervention programme.

Getting through the screening interviews

As part of the medical trial, an extensive diagnostic interview procedure screened participants in the project (see the inclusion criteria in Chapter Three). Using structured questionnaires, the behaviour, experiences, thoughts, and emotions of potential participants were scrutinised as symptoms of mental illness, in order to monitor the development and possible improvement or deterioration of their mental states. For each individual the diagnostic screening procedure lasted several hours and was spread over two or three days. The interviewers were medical PhD students involved in the trial, and additional research assistants who had been trained in interview procedures.

When I, in our first meetings, asked my informants if they had found anything difficult when they started in OPUS, some of them mentioned these diagnostic screening interviews. They found the extensive and detailed interviews unpleasant, tiring, and confusing. Others were either indifferent to them or thought that the interviews, apart from being a bit annoying, had also been helpful in clarifying their experiences and sensations.

Ole said that it had been difficult to reveal so many personal issues during the interviews. He explained that there is a mechanism in you that prefers to forget the

experiences you had while you were psychotic. More generally about OPUS, and about the situation of being interviewed by me, he said:

When you then are in contact with the project it is experienced as a part of that situation [that you have been psychotic] – which you wish would go to hell. Then you also wish that you [OPUS and its staff] would go to hell.

This clear explanation by Ole significantly informed my understanding of, as well as my methodological and ethical approach towards, informants who further on would decline from meeting for interviews with me. In particular, it enhanced my understanding of Ole's decision, later, not to meet me again for further interviews, as well as his decision to leave the project. Other researchers have reported that former psychiatric in-patients have given similar reasons for refusing to be interviewed: they did not want to be reminded of 'all that mental patient stuff' (Estroff *et al.* 1991: 334). Hans also left the project within the first year after his inclusion. When I interviewed him about one and a half years after he had participated in the screening interviews, I asked him what he had not liked in OPUS and why he had decided to leave.

She [the interviewer] was quite nice. But she asked, and asked, and asked about all those things, and, as it was, I didn't get anything out of it. And if there just was the smallest thing, then they just went on and on asking and asking as if it was extremely important. ...//... That is not exactly what you need when you have problems because you don't have any work. Then you don't need to get ninety questions about all kinds of... ...//... So, that was also something I was unhappy with [in OPUS]. I should have done something completely different.

And, later in the same interview:

Then you were in the situation where you talk and talk with her [the interviewer]. Then you sit and talk, and then suddenly it is relived, else I would never have thought about it. Never! I don't think so. Maybe I took it a bit too seriously, but...

Both Ole and Hans criticised the screening interviews for putting them in a situation where they had to relive unpleasant sensations or psychotic experiences. It is, however, important to note that Hans did not express this criticism in the first interview. In the first interview, he was critical about the fact that he had to describe his problems to too

many different people and that he was not immediately offered the possibility to talk in depth about them. As it was, Hans, at the time of the first interview, had described his problems in detail to five different people: first a therapist at the student counselling centre, who sent him to a psychiatrist at the community mental health centre, who then referred him to the interviewer who conducted the screening interviews for OPUS; and then in OPUS he talked to two different treatment staff. He had the impression that they were more interested in investigating his problems than helping him to get over them.

You see, the project and things like that... 'We have to find out what it is', that 'We try to find out what his problems are', and like that. I have a feeling that they maybe are not so experienced. It is a bit frustrating when you feel that you *really* have got problems. Then it is *very* annoying that you don't really get to talk about the things you have mentioned. I thought, first time I talked to [the psychiatrist in the community mental health centre], then I really thought that 'Now I will really get to talk about these things', and I don't feel that I have done that yet. And now two months have passed, it is really... it is very annoying. It is!

Martin, too, criticised the fact that too long a time passed before anything was done to address the problems he had mentioned during the screening interviews. In later interviews, he told me that three months passed before the sexual problems he had mentioned during the screening interviews as being particularly disturbing to him were addressed by his case manager. Another problem was that it had not been made clear to him that the interviewer would not be his individual case manager. Martin had had this impression, and was therefore initially disappointed when he learned that this was not the case. When I asked him what he could recommend should be done about the problem, he suggested that a meeting should have been held between him, the interviewer, and his case manager. This could have created a more smooth transition, and at the meeting they could have discussed the issues he wanted to be dealt with and they could, together, have set up a treatment plan. Martin would, in general, have liked feedback from the diagnostic interviews, to find out which conclusion had been reached.

As described in Chapter Four, both Martin and Hans had not experienced previous hospitalisation or other psychiatric treatment, and they came in contact with OPUS through their own active seeking of help. Their particular entry into OPUS

possibly explains their expectations of solving their problems through therapeutic talk, and their disappointment when this expectation was not immediately met.

The third person who had not been hospitalised prior to the inclusion in OPUS, Birgit, was content with the screening interviews overall. She thought that it was a bit confusing, with all the questions, but even so she believed that the interviews were a help to her, since they made her recognise her problems. Among the other informants who commented on the screening interviews this was the general standpoint. However, Eva was confused and angry about a physical test the interviewer had done holding her arm. Eva told me that she did not know what it was about and that she had not been given any explanation by the interviewer. But overall she was happy with the interview.

Eva: She [the interviewer] interviewed me several times. Also that was a help, because I went through some things.

JAL: Yes, in which way was it a help that you went through the questions?

Eva: It was a help in the way that it made that I became more clear. It gave me kind of a clarity.

JAL: Because of the questions she asked?

Eva: Yes

JAL: You, kind of, got a better overview?

Eva: No, I didn't get a better overview of it, but I kind of went through some emotions. For example I could cry together with her. It is very long time since. I only cried twice in the whole time I have been at the hospital.

Anders thought that it was an ordeal to get through the interviews, and that he had found it difficult.

JAL: What is difficult?

Anders: It is to try to answer the questions honestly, without blundering.

JAL: Yes. What are you thinking of when you say that you could blunder?

Anders: Well, not to say how things really are... I should do that.

JAL: So you think it can be difficult in that interview situation to say exactly how it in fact...

Anders: Yes, in the long run it was.

JAL: Yes, was it because it was difficult to tell it to another person, or...?

Anders: No, it was more that... the long-windedness of it, you see.

JAL: Yes. That it was so detailed?

Anders: Yes. Then it is being quantified on the paper. It just becomes numbers and ticks. And it was kind of not that real to be in that situation.

JAL: No. So the unreality of the situation, was it that it became numbers and ticks, that it was quantified in that way?

Anders: Yes, in the long run it was. You see, I think that I kind of lost a bit... honesty.

JAL: In relation to your own, eh, what you said, that you lost your honesty, what you were answering... or what do you mean?

Anders: Well, I didn't answer the questions completely honestly...//... I think that I at some time understated these schizophrenic features in the interview. So... but this does not really belong here [in this interview].

JAL: No, but... I am interested in the circumstances of it. Because, you see, maybe there was a reason that you understated it?

Anders: Yes, I thought that it seemed crazy.

JAL: Yes. Because you thought 'My answer will sound crazy', or what?

Anders: No, you see, she asked about a feature. If I have experienced thought stealing, and then I say 'no'. Like that, almost as a reflex, even if I had experienced something. I think that I could recognise the feeling.

JAL: But then later you have thought about it, that it was wrong that you answered no to the question?

Anders: Yes. And there were more of this kind of questions.

JAL: When you say that you answered no as a reflex in that situation, have you afterwards considered whether there was a particular reason that you answered in that way, or...?

Anders: No, but I think that I wanted to understate it... my illness, that is. I think that psychosis, it sounded at bit more... a bit less crazy than schizophrenia.

After my interview with Anders, he had an appointment with the psychiatrist in the OPUS team, and Anders told me that he had decided that he would tell her how he really had felt and thought during the psychosis, without understating. The reason he gave for now being honest was that he was not satisfied with the medication he took; it made him tired and unmotivated. He thought that if he told the truth about his thoughts and feelings during the psychosis, then the staff in OPUS would be better able to provide him with the right medication.

It was only Anders who disclosed to me that he had not told the whole truth during the screening interviews. It seems, however, likely that his openness about the omission was related to the decision he had already made to disclose it to the team psychiatrist. If this assumption is correct, then it is possible that others during the screening interviews might have, like Anders, understated their symptoms in order 'not to seem too crazy', and, as part of this information management strategy, also refrained from telling me about it. Based on Anders' explanation, their reasons for not changing their minds, to disclose how they really felt and thought, could either be that they were content with the effect of the medication they received, or that they did not believe that

the disclosure would enable the psychiatrist to prescribe them a more precise medication. Naturally, other individual reasons might also apply. This information management strategy, to uphold or protect identity and self-image during the confrontation with the psychiatrist, might explain the general finding in other studies that newly-referred patients at their first psychiatric meetings often seem to be virtually without any symptoms (Lindow 1986: 87-8). It must, however, be emphasised that Anders was not very successful in this strategy of concealment. Even if he made an effort to 'seem less crazy', by keeping quiet about some of his psychotic sensations and thoughts, Anders was, nevertheless, diagnosed within the 'schizophrenia spectrum' target group of OPUS.

Completing the screening interviews and 'qualifying' for OPUS, however, was not enough to actually become a recipient of the intervention. This was because of the randomisation procedure in the medical research design, whereby only about half were offered the OPUS intervention. Some were instead offered a place at a 'luxury ward' for patients with schizophrenia at the psychiatric hospital Skt. Hans, outside Copenhagen, while the rest functioned as the control group for the medical controlled trial. The people in the control group received 'standard treatment', which meant a less intense and regular connection to a community mental health centre, often following a stay at a psychiatric ward. Several informants commented on this procedure of randomisation, which they found strange, a bit like a lottery, but they were happy that they had 'won' participation in OPUS. Only one, Claus, said that he at first had been a bit disappointed, since he, at the time, would have preferred the 'luxury treatment' at Skt. Hans Hospital.

Situation at inclusion

In the period after their inclusion in OPUS, they generally felt that their situations were dominated by sensations of apathy, lack of motivation, boredom, laziness, tiredness, and sadness. And several mentioned that they endured problems of concentration, and that it was difficult for them to structure their days.

Often informants felt introverted; it was difficult for them to talk to other people, and they felt socially isolated. Anders gave an example of what he meant by being isolated and introverted by explaining how he, in social situations, for example at family gatherings, used to be lively and chatty. Now, he was sitting quietly by himself,

preoccupied with his own thoughts, and he was not interested in talking to other people. Later, when Anders thought back to this period, he said that socially he was ‘a black hole’: inactive and killing off the life around him by sucking it in. A psychiatrist at the hospital had described the subjective experience of this state with the expression ‘being inside the dome of a cheese-dish’ (*at være i en osteklokke*), and Anders found that it was a precise metaphor. Other informants, and staff in OPUS, have also used the expression ‘wrapped up in cotton wool’ to describe the same sensation. The sensation was common among participants in OPUS following a psychotic episode, but it could also be a side-effect of the antipsychotic medication, and informants explained that the sensation could be reduced by changing medication or by reducing the dose of the medication used.

During the first interviews with my fifteen informants, I asked them how they generally experienced the situation they were in when they had just started in OPUS. At the time of the initial interview, six of them were in-patients at a psychiatric ward, two of which were on a secure ward; of the rest six had recently been discharged from a psychiatric ward, and three had never been admitted to a psychiatric ward. These differences in their overall life circumstances were significantly related to the individual situations recounted by informants in the interviews.

Without hospitalisation: The three informants who had not been in-patients at a psychiatric ward – Birgit, Martin, and Hans – shared an unfamiliarity with psychiatric treatment, and they had not experienced the encounter with confinement and the use of physical force in the ward. During the first interview Birgit was the only one of the three who mentioned having had psychotic experiences. All three expressed some scepticism about whether they needed and wanted the support and treatment in the intervention in OPUS. Of all fifteen interviewed for the first time, Hans was the one who was most ambivalent. He told me that he did not know what he wanted to do with his life; he had the feeling that he was sleepwalking, that he was lazy, and he needed some help to structure his day. He also mentioned problems of concentration and that he was not seeing many people, and explained that he was isolating himself because he had not arranged his flat properly and therefore could not have guests, since he wanted it first to be ordered and decorated so that it would be ‘attractive’ (*lækkert*). Hans thought that his problems were ‘youth problems’, but that he needed some help to ‘move on’.

All three expressed concern about telling people in their social network about their involvement in OPUS. At the time of the first interview, Hans had not told anybody about it. Birgit had only told her son; she thought that others might have suspected that there was something wrong with her, but she tried to hide it as well as possible. Martin had told his parents and sister just two weeks preceding the interview, which was conducted two months after he was included in OPUS. Originally he did not want to tell them, but his case manager had persuaded him that it could be helpful for him. During their meetings, which happened more than once a week, in the first one and a half months of his involvement in OPUS, he had discussed the issue with his case manager and they had rehearsed how he could disclose that he was having problems and receiving professional help. When he finally told his parents, it was a great relief to him. He explained to me that he now could relax when he was together with his parents, since he did not have to hide that he had problems. Birgit told me that she would not talk about her involvement in OPUS to her family, since she felt that they would not 'believe it'. When I asked her what she meant, she explained that they would not take her problems seriously, and just tell her that she should find a job and get out among people more.

Birgit explained that the difficulty was related to her general 'identity problems', by which she meant that she was not sure whether her experiences and beliefs were right or wrong, and that she could be easily influenced to change her opinion. If she talked about the problems to her family, she foresaw that they would say to her that she really did not have any problems, that it all was her own fault, and that she should pull herself together. To Birgit her problems of hallucinations and delusions were related to her identity problems. She thought that her insecurity about the veracity of her sensations and beliefs, for example whether or not her neighbour was harassing her by knocking on the walls, and whether or not her attempt to avoid the smells by blocking the pipes caused the woman living in the flat above to die from poisoning, was related to her insecurity about who she was. I asked her to explain these identity problems in more detail.

Birgit: It is difficult for me to know, for example, if I am good or if I am evil. What sort of human being I am. It is difficult for me to know if I am in fact...

am I social, or if I am asocial, or if I am evil, or if I am not, or, in general, these are the kind of problems I have with myself.

JAL: Alright, to know who you are, also in relation to others?

Birgit: In relation to the norm. In relation to what is right. For example, if things are a car, or if they are not a car. If there is something wrong with me, or if there is not something wrong with me, or how much there is wrong, and if it is right in relation to what is the norm. Therefore, it is a bit difficult, sometimes, to be me.

This sensation of uncertainty about her own and other peoples' and things' reality and identity can be described as *ontological insecurity* (Giddens 1991: 35-69; Laing 1961: 39-61). Neither Birgit or Hans were sure whether there was something wrong with them. But they had different reasons for not telling their families about their problems. Hans wanted to prevent his family thinking that he had problems; he thought that it would be inappropriate since he, at 29 years old, was a grown man. He also said that he would not like other people to pay special attention to him, as he would not like his relatives to think of him as somebody who had problems.

Hans: I have not told anyone. I do not intend to tell anyone at all.

JAL: No, why not?

Hans: Because, if I explain it, then maybe I will be... reason for being paid more attention, or something, and I don't want that. I am comfortable with people not needing to notice me especially, more than anyone else. Well, it won't help them, it will only make them worry, somehow, and I don't feel bad about it.

JAL: No, you don't feel that it would help you to tell them?

Hans: No, not at all. And it would not help them either, because they would only start thinking about it. And I would not like at all if they would ask me about it: 'Well, how was the meeting with the psychologist?'. Could you imagine that! If you were at home with your mother, or somebody a bit older. I don't feel like talking about this. That is just the way I feel.

JAL: Yes, you think that it is something you don't want to talk to them about, or...?

Hans: Yes, that is the way I feel. I don't feel like getting them involved in this. In my free time and when I am at home with my family, and people like that, then I don't feel like involving them in my problems. Because then they would also tell my grandmother and my grandfather, my uncle and my cousin, and I would not like that.

JAL: No. What do you think it is? What is it you don't like about it, is it that they then talk about you, or...?

Hans: Yes, both that, but also that it would be a bit... It wouldn't be very smart, you see. Then they are asking about you, then 'That is he who...', then I will not be 'That Hans who is studying', you see, then I will become 'That

Hans who has problems', or something like that. And I really don't want to be that.

JAL: No. So it has something to do with identity, in some way, or what?

Hans: Yes.

JAL: When you say that about who you are, you kind of become another person. Or what is it you say? They would talk about you in another way, is that what you think?

Hans: Yes, I would become that, in some way. Yes, in any case, I am afraid to become that. It is more not to be a burden. I don't feel like talking to them about my problems, I just don't feel like that.

JAL: No, but they...

Hans: Maybe they know about it. But I don't care, then they have to know it. I think something has got out, I don't know, maybe you always think that. But I prefer that they don't know a thing about it, I feel best like that.

JAL: Yes, alright. But would it ruin your relationship with them if they knew?

Hans: In a way it would. It would change it a bit. And I can't figure it out, I am not sure if it is positive, because then... It is better that they don't know anything about it. For God's sake, it is not that big a problem.

Hans wanted to deal with his problems with professional assistance provided by OPUS, but without the involvement and knowledge of his family, so they would not think of him as having problems. Birgit's reasons for not involving her family were almost completely the opposite. She wanted to avoid telling her family about her problems because she did not want them to challenge her claim to have problems, and to tell her just to pull herself together. In both cases, dimensions of identity were, however, involved.

Martin's situation was similar to Hans's, but he decided, convinced by his case manager, to tell his close family about his problems and his involvement in OPUS. As can be seen in the end of the quotation above, Hans is also open to considering whether or not it would be positive for him to involve his close relatives. In Martin's case the focused attention of the case manager, convincing him of the benefits, might have been the decisive difference.

The option of telling or not telling the close family was only present for the three key informants who had not been admitted to a psychiatric ward. In the other twelve cases the information had already been disclosed during their hospitalisation. The likely difference in the extent of their individual problems, as well as in the spatial and social reality of their situations during hospitalisation, prevented them from saying, as Hans did, that their problems were really not so great that they had to involve their

close relatives. The fact that these three informants had not been hospitalised thus made it possible for them to consider whether or not something was wrong with them, and for it to be a feasible option for them to refrain from telling anybody in their close social network about their problems. The finding confirms Goffman's observation of the objectifying effect of hospitalisation (Goffman 1961: 134), as well as confirming general aspects of labelling theory (Scheff 1999).

Inside the hospital: At the time of the first interview, six of my informants were still admitted to psychiatric wards. Julie and Kristina were on a secure ward, but Kristina was due to move to the open ward the day after my visit. Julie did not know how long she would be kept in the secure ward. She told me that her situation was uncertain and insecure, and that she found it strenuous to be on the ward. When I asked her what she thought of her present situation, she said:

Well, it can be somewhat tough, to be admitted here at the secure ward. It can be like this, because all the time you think 'When do you get out?', and things like that. The uncertainty, it can make you feel very insecure.

As documented in other studies of in-patients' views (Goffman 1961; Lorencz 1992: 297), she saw the hospital as an institution detached from the surrounding community. Later in the interview, Julie told me that she found it particularly difficult to be parted from her four year old daughter. She also stressed that the uncertainty about when she would be discharged, the indefinite time dimension, and her lack of freedom to do what she want to do, when she wanted to do it, were particularly distressing.

Eva, Dennis, Claus, and Per were all in open psychiatric wards when I interviewed them. Eva had been admitted for just under four weeks and she was, at the time, still quite affected by the psychotic experiences and the antipsychotic medication. During the interview, she therefore soon felt tired and she told me how she found it difficult to talk and concentrate. After we had talked about her future plans, she explained that she had to feel much better before her hopes could be fulfilled. Her uncertainty about whether she would ever feel better dominated her situation at that time.

Eva: I have to become better in talking to people, and I cannot become so tired all the time.

JAL: You become tired?

Eva: Yes, I become tired very easily.

JAL: Why, do you think?

Eva: Because there are too many impressions at one time. I find it difficult to sort out the impressions.

JAL: Yes. So you hope that you can work with this, or become better in it, or?

Eva: I don't know.

Dennis thought that his situation had improved since he came to the hospital. Before, he isolated himself in his flat and was very depressed. When I interviewed him on the psychiatric ward, he told me that he now had more energy (*overskud*) and that he had fewer downs (*nedture*). He was, however, critical about the lack of activities on the ward. Dennis tried to participate in the daily morning run a few times, but he did not have the energy to get up that early to go running. He liked the workshop connected to the ward, but because of the lack of staff, it had been open only a few times. To kill time and to avoid just sitting and getting the old negative thoughts back, Dennis had just bought himself a three-dimensional puzzle, with which he could construct Tower Bridge.

Claus said that he was generally sad about what had happened, becoming psychotic and being in the psychiatric hospital, but that he felt that it was compensated for by being included in OPUS. He explained that he generally tried not to think too much about why he was in the hospital, and just to take one day at a time. Per, too, told me that he did not feel especially good in the situation he found himself in, and that it was difficult for him to be motivated for anything. He, however, found comfort in the belief that new medication might help him to feel better.

In later interviews, and in their writings for the book project, my informants described their experiences in the hospital in more detail. They supplemented the descriptions of overt violence, presented in Chapter Four, by telling about more subtle forms of brutality related to the general social situation, the lack of freedom, and the uncertainty about when they could leave the ward. Eva told me that in the beginning, it was a help for her to be at the secure psychiatric ward, where she could talk to the staff about her problems. As she got better and moved to the open ward, she increasingly felt disturbed by the other in-patients.

It is very disturbing to be at the hospital, because all the other people disturb you all the time. They are also ill, and things like that. Sometimes there are quite dramatic scenes with screaming and yelling and, you see, or people come to you and talk about their illness, and things like that. So, that is not quite... because they are also ill. So that is not so encouraging.

Similarly, Claus, Julie, and Frank later said that they were made ill (*sygeliggjort*) in the hospital. Frank was particularly annoyed that he was under constant observation and that his behaviour was interpreted as indications of illness. When he was happy, the staff claimed that he was psychotic, and when he went to see his father, they said that he was isolating himself. Frank would have liked to have had some support to make his opinion heard; he often had the feeling that the doctors did not care to hear what he had to say. As Eva said, about two years after she had been discharged, in connection to her critique of the psychiatric hospital:

All authority has always been bad for the person who is not possessing it. That's how it will always be.

In an earlier interview, Eva explained that, even if in the end she was not happy staying in the hospital, she thought that the staff were a bit too eager to discharge her. She felt that that they had no real respect for her opinions because they were so used to possessing the definitive authority.

They [the psychiatric staff at the hospital] are so used to being allowed to use force towards people, and things like that, they forget that when you kind of get better... if there is something you want to, and things like that, then it could be that there is a reason for it.

She felt the inequality of power in relation to the staff's 'expert authoritarianism' (cf. Lorencz 1992: 303). Eva, also, described how the physical space of the hospital made her feel humiliated and dishonoured.

Eva: In some way it is humiliating to be at a psychiatric ward.

JAL: Because of that about authority?

Eva: Yes, because of that, but maybe also because you are crammed with so many people together. Under such poor conditions, or not poor conditions, but

in any case a lot of people really crammed together, and you are very close to each other. And in fact I think that it also goes a bit beyond normal limits.

JAL: So it makes you feel a bit devalued?

Eva: Yes, I could well imagine that maybe it is from there this feeling arises. That you kind of feel dishonoured, in one way or another.

Eva likened it to the unpleasantness she would feel if she, over a longer period of time, had to share her room in the student flat with other people. The lack of private space, and freedom to be yourself, would in some way break you down. Another aspect was the lack of activities and not taking care of yourself.

In the first interview, when Claus was still at the ward, he explained that he hoped that he soon would get back home to his flat. He felt that his self-confidence was being ruined by just sitting around, not doing anything and having other people to do all the practical things for him. Claus's statement confirmed the point made by Barham and Hayward (1995: 38) that 'though people may in an important sense feel "better" after a period in hospital the treatment they have received will not of itself help them to pick up the pieces of their lives again and restore their confidence in themselves as viable participants in social life.' In his description of a psychiatric ward, Goffman made a similar observation of the negative consequences to the self-esteem of the in-patients because of the low requirements for their social functioning and the 'mirroring effect' whereby in-patients identify with these (1961: 139). Sayre (2000: 72) has observed that the experience of hospitalisation and diagnosis can confirm the patient's sense of personal failure. Per confirmed the general observation (Spencer *et al.* 2001: 134) that especially in the case of first-episode psychosis treatment and hospitalisation is experienced as traumatic.

In fact it is a trauma to be admitted. For some it can be. It was for me. With all the experiences you have. You have to get over that.

For a long time after Eva's discharge, the perspective of the hospital and the institutions of psychiatry still dominated her life, and she felt that her former role as a patient determined her place in the world. Part of the reason for the dominance and persistence of this understanding she ascribed to the fact that, as a patient, you live at the hospital, and you identify with the people you meet there.

It [the psychiatric hospital] is just an institution, you see, it is not the universe, but you live there, and that is about twenty-four hours a day. And then you start believing it a bit, because you are there all the time. And when you are at the hospital you meet people who almost lived there all their lives. Because it is really severe cases who are at those hospitals.

Eva felt the psychological pressure from the internal-external dialectic of social identification (Jenkins 1996, 2000), whereby the social categorisation and physical placement of her in a group together with other mentally ill made her start identify with them. As she observed, this is especially problematic because of a phenomenon known among health professionals as the 'clinician's illusion' (McGorry 1995: 314), whereby the general prognosis of an illness appears more severe than what is actually the case, because the individuals with the worst outcomes are accumulated in the health services.

Discharged from hospital: At the time of the first interview, Namira, Anders, Lotte, Irene, Frank, and Ole had already been discharged from a psychiatric ward. Compared to the informants who were still in hospital, these six gave the impression of having reached a level of recovery after the psychosis where they were less constrained by thoughts and emotions, and were preparing to re-engage with their lives, to get on with their individual life projects. This, however, was true to varying degrees, and they assumed different strategies towards this aim. Namira and Anders seemed to be in situations which were similar to those of the in-patients. In response to the question regarding their assessments of their situations, Namira and Anders described their problems of concentration and feelings of tiredness, boredom, apathy and introversion. Namira said that the contact with her case manager in OPUS made her feel secure (*tryg*), and that she hoped that she would soon feel better, so that she could reassume her training as a service assistant in a retail store. Anders' primary preoccupation was that his general mental condition would improve, possibly by finding the correct type and dose of medication. He was also concerned to find activities to fill in the time, such as physical training.

Accentuating the need for him to find a way to fill in his time, Anders was adopting an overall strategy similar to those of the other newly discharged informants. When asked about their situations, Lotte, Irene, Frank, and Ole stressed things they had to do, or circumstances concerning their general life conditions which had to be

arranged. The staff in OPUS were seen as having a central role in helping them to get their lives back on track again.

Lotte: Well, it is unpleasant to be in this situation. You see, I am only in this situation because I had a psychosis. When things are bad, then it is quite nice that there is some security, some people who can get you started again.

Similarly, Irene said that she was happy about the support from her case manager in OPUS, and that it made her feel more secure.

When I had to start working again, that was definitely an obstacle I had to overcome. I was very vulnerable to their reactions to how I was going to be dealt with. And I am vulnerable at times when I am very tired. I have noticed that my vulnerability is very related to my tiredness. The more tired I am, the more vulnerable I am. But [my case manager] is very good at noticing this. When we met last time I had a real 'off day' and she could see it at once. And then I tend to put my life in her hands, since I listen to what she says. I would not do anything opposite. So, I am kind of a very good pupil really, I think. But it is meant in a good way, because I want it myself. I want to be in this project because I think that it is the right way to deal with people like me.

She meant that the relative lack of freedom she experienced by following the advice of her case manager was her own choice, and Irene thought that this lack of autonomy was beneficial, given her special situation after the psychosis. Irene explained that it had been difficult to get back to her workplace after having been on sick leave.

You see, it is kind of taboo this illness. It is difficult to know how people will react. I am in the situation that I have a very good job, and a very understanding work unit, and a boss, who also is understanding, and things like that. But anyway it is always a challenge, I think, to be away for two and a half months because I have been mentally ill.

I asked her whether she had felt the taboo towards mental illness in her work place.

I think that it was my own expectations more than it was them. I happen to know that they felt a bit uncertain about me. They anyway were a bit uncertain about me in the start because they thought that I was not like I used to be. I was not the big bubbly creature who came in the door and [would say] 'Listen to this!'. I was, kind of, a bit more quiet and calm.

Lotte and Frank were also working part time at the time of the first interview, and the day after our meeting, Namira was going to start again on her training as a service assistant. Lotte was working odd times in a hot dog stand (*pølsevogn*), to add money to the social benefits (*kontanthjælp*) she also received occasionally. Frank had gone back to his former job in a supermarket, sitting by the counter and stacking shelves. Having left the hospital, Frank went back to live with his mother and younger brother. Before he was hospitalised, he had lived in his own flat for some months, but he was happy now to stay with his mother, since it both was a financial help and convenient and nice, since he was cooked for. When I interviewed him in his free time, a Saturday morning, we were interrupted three times during the hour and a half of my visit, twice by calls on his mobile phone, and once by one of his friends coming by to borrow a music cassette. When I asked Frank if he talks about his experiences and situation with his family and friends, he told me that he preferred not to think and talk about it, since it made him feel bad.

You see, now I have got out [of the hospital]. I prefer to leave it behind me, to think: 'Okay, I have tried to be in this kind of ward,' and things like that, 'I am not doing that again,' ending up in that situation. Well, but I haven't really talked about it with anybody. I have talked a bit about it with my mother.

JAL: So you prefer that it is something other people should not become too involved in, or it is something not to rake up?

Frank: No, I don't think so. Because, you see, if I think too much about it, then I feel a bit bad.

JAL: Yes. So you prefer to leave it behind you and focus ahead?

Frank: Yes.

Ole, too, was determined that things should be done to change his situation. With the help from his case manager, he had applied to receive early retirement pension (*førtidspension* - the Danish state 'Invalidity Benefit'). Ole told me that at the moment he felt very vulnerable and insecure. He hoped that his application for a pension would be accepted, and he expected that his involvement in OPUS would promote this. Ole was confident that the financial support provided by the pension would improve his situation, making it more stable and secure.

It was thus a general theme in the interviews with all fifteen informants that, shortly after their inclusion in OPUS, they experienced their situations as vulnerable and insecure. There was a correlation between the informants' experiences and expectations

of their situations and their involvement in psychiatric treatment: those who before their contact with OPUS had never received psychiatric treatment expressed scepticism towards the benefits of their involvement and they were concerned whether or not to tell people in their close social network about it; those who were in-patients at a psychiatric ward were preoccupied with their current emotional and cognitive difficulties; those who had recently been discharged from a psychiatric ward were engaged in setting up social and financial arrangements for their lives.

First impressions of OPUS

The informants were, at the first interview, generally positive regarding their involvement with OPUS, and expressed expectations that they would be helped and supported to develop and achieve their personal goals. They said that they were at a low point in their lives, but, newly included in OPUS, all, with the possible exception of Hans, felt that they were being helped. Characteristically, some used metaphors of movement to express their expectations of a positive development, such as ‘get going’ (*komme i gang*), ‘move on’ (*komme videre*), ‘progress’ (*fremgang*). One said ‘I feel that I move’ (*jeg føler at jeg flytter mig*).

When I asked if there was anything they found difficult when starting in OPUS, both Hans and Martin said that it was unpleasant to come to meetings in hospital settings. Hans referred to the appointments he had at the psychiatric ward of Bispebjerg Hospital, where the screening interviews had been conducted. He found it very unpleasant to wait in the hospital hall as he thought that he might meet somebody he knew, and he was concerned what they might think of him. Martin expressed a similar concern regarding his meetings with OPUS staff in the office in the community mental health centre at Vesterbrogade. He preferred to meet in the more informal, or less public, offices of the team’s social staff, located on the ground floor of a residential block at Søndre Boulevard, where I was having the first interview with him. But when he came to these premises, he also worried about what people thought of him.

Martin: I have found it difficult to come to these places, because of the location. That place on Vesterbrogade. I thought that it was kind of very public.

JAL: Yes. What about this place [Søndre Boulevard], because there is quite a difference between this place and Vesterbrogade, don’t you think?

Martin: Yes, here it is maybe a bit better, I think.

JAL: Yes. But what you thought was difficult about meeting at Vesterbrogade, you say that it was kind of very public?

Martin: Yes, and because there is something else in the community mental health centre.

JAL: Yes, you didn't feel good about that?

Martin: No.

JAL: Can you explain what it was?

Martin: You see, it was something about if people would see me on the street and think 'What the hell kind of person is he, is he such a... crazy person.'

JAL: Yes. But that [place] was the more public... and kind of more institutional, while this [Søndre Boulevard] maybe is more anonymous, when it is located here?

Martin: Yes, but here I also can get the same feeling.

JAL: Yes, what other people think?

Martin: Yes, like 'What is he doing there, why is he ringing the door bell?', but, you see, that is something... I can swallow it, sometimes.

Some other informants said that they preferred to meet in the informal and less 'public' offices of the social staff in the OPUS teams. In Martin's case, however, it was not only the appearance of the place which bothered him, but more his own thoughts and knowledge that the place was used by a project which offered help to people who had mental health problems. He did not like to be thought of as 'one of those' – 'a crazy person'. Frank, who was included in the Bispebjerg team, said that he felt it a bit unpleasant to come to the community mental health centre at Møntmestervej since he saw a lot of old people at the gerontological day centre in the same building. Frank found it strange that he should be coming the same place as the old people. Both, thus, expressed concerns regarding identification, about who they were socially categorised with (c.f. Jenkins 1996, 2000).

Apart from the premises, Hans was critical of a folder he had received explaining the OPUS project, where the target group was described as 'early detected psychotics'. Hans said that he definitely did not want to be a 'detected psychotic'. In the interview, however, he disclosed to me that he was afraid that there was something wrong with him, and he said that he feared that just thinking that there was something wrong might become self-fulfilling. Hans's prime concern about his participation in OPUS was whether the intervention could help him to solve the 'youth problems' he thought he had. He had expected to receive advice or counselling in talks with psychologically trained and experienced staff, and he was doubtful whether the social worker he had been assigned as case manager could be of sufficient help to him. Martin,

too, had come in contact with OPUS through seeking psychological counselling, and other informants requested psychological interventions. Like Hans, Lotte was sceptical as to whether her case manager, who was a trained nurse, could help her. She told me in the first interview that she had experienced some problems in her childhood, which she would like to talk to a psychologist about. When I asked her what she thought of OPUS, she said:

I haven't really used the place [OPUS] that much. The only thing I would like, it is that it would be more easy to get to see a psychologist than it is. Because now I have asked her [the case manager] if I could get to see a psychologist and it is kind of quite difficult. So, I would like that it was a bit more easy.

When I asked her why she in particular wanted to talk to a psychologist, she explained:

There are some things I could not talk about to somebody, you see. Because there are... you see, I have had some problems since I was small. And I don't talk to everybody about this, therefore I would like to talk to a psychologist about it. Somebody whom I am not going to be in contact with during the next two years, but somebody I maybe can have ten conversations with. That would be it. I would try to see this person, you see.

Lotte explained that she did not quite know yet how she could make the best use of her individual case manager. But at the time of the first interview, she was happy about the help and support she had received up until then, which primarily was related to practical arrangements such as finding a place to live, and talking about her future plans.

I can use her [the case manager] to talk to and get some control and co-ordination in all these things. She can accompany me when I go to different places and support me in different situations. It is like, I have to assemble the situations in my thought, and then present them when she is here. And then, hopefully, I get some support.

Lotte said that she would give it some time and hoped that she would find out what uses she could make of OPUS in general and her case manager in particular. Similarly, other informants have explained that they have had this 'wait and see' approach to OPUS during the first few months, that they gave it some time to find out what use it could be to them.

Of the fifteen informants, four were requesting psychological therapeutic intervention during the first interviews, even if, at the time, it was not formally introduced as part of the services provided in OPUS. Two other informants also mentioned psychotherapeutic intervention. Both Anders and Per told me that they expected to receive psychotherapy as part of the contact with their case managers. This expectation was related to their case managers' professional training as, respectively, psychologist and psychiatrist. Per said that he thought himself as very lucky to have a psychiatrist as his case manager since she could prescribe the medication he needed to keep his psychosis at bay, and give him psychotherapeutic consultations during which he could talk about his father's suicide.

In contrast to the informants who from the start requested therapeutic help or counselling, Birgit said, in the first interview, that she was initially sceptical about her participation in OPUS because she did not think that it could help her to talk about her feelings, sensations, and problems.

JAL: Can you describe what you think characterises the situation you are in now, since you have started in the project?

Birgit: Yes, but it is something to do with how I find it difficult to understand how you can connect theory with practice. It is a bit like: 'How is this going to help?'. That you have to talk to some people.

JAL: Yes. You are a bit doubtful about it?

Birgit: I have been. But I am about to understand better the efficiency of it. But I have found it a bit difficult to see that it should help anything.

JAL: Yes. But you have then maybe experienced that it somehow is useful, a new understanding has appeared, or...?

Birgit: Yes. But it is also a question how much you grasp yourself. That I for example can sit and talk to [my case manager] about how you are, how you think, how you feel. I think that it has a very huge significance. Because you do not talk to other people about this. So I think that it is incredibly good. So I have had some problems solved, I have had the opportunity to talk to somebody, who... some problems I have, which I cannot talk about with anyone else.

Being recipients of the OPUS intervention programme, my informants expected to be helped to get on with, or resume, their lives. In the first interviews, they stressed their expectations that the regular contact and monitoring of their condition would prevent them from experiencing a new psychotic episode, and several remarked that personal contact with their case manager was of particular importance. This made

them feel more secure, both because of the personal relationship they expected it would allow, and because their individual case managers would get to know them well and thus be able to assess their situations better and give them the right treatment.

Along with the possibility of precise medication, Per expressed the hope that his case manager's increasing knowledge of him, also through contact to his family, would allow the case manager to know 'how he was before', and thus be able to determine whether his problems were due to his character, or maybe were caused by depression in addition to his schizophrenic illness. This view was similar to Anders', in connection with his lack of 'honesty' during the screening interview. Both thought that if the staff had the optimal knowledge about them and their problems, then they would be able to give them better treatment and help.

Several informants said that it helped them to be controlled or monitored by the project. Claus, Per, and Frank said that they found comfort from the fact that their case manager would 'keep an eye on them' or 'have control' over their situations, which would prevent them from experiencing a new psychosis. The emphasis on monitoring was confined to some informants who had experienced psychosis and hospitalisation. Martin, who had not experienced this, appreciated another aspect of control exercised by OPUS. He said that the intense contact in OPUS, with weekly meetings with his case manager, helped him to confront his problems. He was, thus, put in a relational situation where he was motivated not to evade (*snige mig udenom*) the situations he found difficult, such as talking to other people in the student flat where he lived. The contact with OPUS created an obligation for him, which he thought would be beneficial to him in the long run. Similarly, Dennis, who at the time of the first interview was in a psychiatric ward, thought that the contact with OPUS could prevent him from getting back to his old routines (*trummerum*) when he was discharged. He anticipated that his case manager would prevent him from isolating himself in his flat and becoming depressed. Informants described how the personal support in OPUS could help them to develop and strengthen alternatives to the life strategy of withdrawal (Corin 1990), recognised as a 'negative symptom' in schizophrenia. Different forms of social control exercised by OPUS were, thus, expected and positively evaluated by the informants themselves.

Likewise, it was a general trend throughout the first interviews that informants expected the staff in OPUS to be the driving force in initiating or arranging their general life circumstances. Anders and Hans were, partly, exceptions. Anders said that he needed to receive medication and advice to keep him from experiencing a psychotic relapse, but in the interview he stressed clearly his need to find out for himself what he needed to do to overcome his problems. It was a considerable problem for him that he was generally apathetic and unmotivated, and that he was introvert. But he thought that it was up to himself to overcome this by deciding what to engage in, either physical training or other activities to kill, and fill in, time. Hans was very ambivalent about the type of intervention he requested from OPUS. On the one hand, he wanted to talk to a psychologist about his problems, but, on the other hand, he was very sceptical about what he felt was the unpleasant interest of the OPUS staff in his private matters.

The active involvement of the case manager was generally seen by informants as a support which could facilitate their personal wishes. Of the six informants who were hospitalised during the first interview, Eva, Julie, and Claus pointed to the help they received from their case managers in their function as an intermediary. Eva described how her case manager supported her in her relations with her family, who she found were dominating her. During the entire first interview, Eva was preoccupied with the influence and pressure she experienced, especially from her parents, whom she thought intervened in her personal matters. The support from her case manager in OPUS made it possible for Eva to carry out her own ideas and wishes, such as finding a school where she could practise playing the flute and helping to arrange the removal when she was discharged. At the time, the support strengthened her and gave her self-confidence.

Julie found that her case manager in OPUS could be a support to her with respect to another powerful group of actors: the hospital staff. Julie had an antagonistic attitude to the staff, whom she saw as her guardians in her imprisonment at the secure psychiatric ward. She was opposed to staying at the ward, because she refused the idea that she was mentally ill. But she viewed her case manager in the OPUS project differently, not as a staff member in the institution of psychiatry, more as a friendly and helpful person from 'the outside'. Thus she said that her case manager was supporting and advocating her case against the ward staff. And the visits of the case manager

provided Julie with freedom, since they together could go for walks in the nearby park and she could accompany her when she wanted to visit her daughter in the kindergarten.

Expectations of the future

Having newly started in OPUS, the informants expressed different expectations of their future lives. Three different types of responses emerged: those who found it hard to imagine their futures at all, those who expected to adjust their lives after the experiences, and those who expected full recovery and resumption of their former lives.

Martin and Dennis most clearly represented the first group. At the time of the first interview they were absorbed by their mental experiences and problems, and their futures seemed out of their reach.

JAL: What do you wish for your future, in general, also in the more distant future? Or how do you see yourself in the future?

Martin: I hope that I will be able to use most of my strength to fulfil some of the dreams I have.

JAL: Yes, which dreams are these?

Martin: It can be... I find it a bit difficult to apprehend now, because my illness, I sort of feel, has made that, it restrains my dreams. So, I have sort of said 'With this illness, what can I achieve without changing myself?'. It sort of limits things. So, I hope that, as I will be recovering, that I can... that is, can allow myself to get some dreams, which are not limited by the way I feel. ...//... I don't feel that I am free to dream now, or to have any wishes for the future.

Martin told me that he had dreams concerning, for example, study abroad, a job, and a family, but that it was painful for him to think about these dreams, since his problems made them unattainable. He had, therefore, stopped thinking about these hopes for the future, and slowly the dreams ceased to exist for him, pushed away by the problems which troubled him. Martin hoped that his participation in OPUS could support him in finishing his studies, and that he would be able to get a job and a good place to live thereafter. He wished to regain a life project.

Dennis, too, found it difficult to relate to what was going to happen in his life. I asked him if he had any plans or expectations regarding his future:

Dennis: No, you see, I haven't thought very much about that. I think more about what is going to happen here and now. And then when I feel a bit better, I will have to find out what I will do.

JAL: Yes. So, you haven't at all had any thoughts about where you will be...?

Dennis: No, because I think, then it becomes far too indefinite to me. It is simply not possible for me to embrace it.

Other informants also expressed insecurity regarding their future lives, especially those who were still in hospital. At the time of the first interview, Claus, Hans, Julie, Kristina, Lotte, Birgit, and Ole said that they expected their lives to change considerably after the mental problems they had experienced. Claus said that it made him depressed to think of his future; he was afraid what it might bring, and, therefore, he just tried to focus on the here-and-now. As he explained:

I am just a bit afraid that I will have a life where you dash in and out of the mental hospital. I kind of fear that. And I really don't want that. That is the last thing I want.

When asked about how he imagined himself in the more distant future, he said that he had a positive image of having a little house in the countryside where he could have a nice and quiet time (*gå og hygge mig*). Claus said that he might receive an early retirement pension and that he could not imagine having a job. He said that he was not good at working, but being made financially secure by the pension, he could maybe have a sheltered job (*skånejob*). Within two years, he imagined that he might be receiving a pension, living in his flat in Copenhagen, and spending a lot of time working out in a fitness centre. Claus told me that he did not see himself getting married and having children, since he was homosexual. At the time he had a boyfriend, who, however, had not seen him at the ward since for a while he had been back in his home country, Iceland.

Julie, Kristina, and Hans had also revised the expectations they used to have for their futures. At the time of the first interview, for Julie, it had been more than half a year since she had been admitted to the psychiatric ward and she was not sure when she was going to be discharged. In the meantime, she had sold her flat and, through the hospital, she had been put on a waiting list for a place in a supported collective for discharged psychiatric patients. She hoped that, within one to two years, she would have

been discharged, and it was her plan to live in the collective for a short while before she could move into an individual flat. Julie was looking forward to being together with her daughter again, whom she would share with her father, from whom she had separated. She said that she then might have a job, possibly using her training as service assistant in a painting and decoration supplies shop.

Kristina was going to make some changes in her life, since she had now learned that she could not engage too much in 'the spiritual'. This meant that she had to give up on both her training to become a teacher of relaxation and her passion for Tai Chi, which she had practised intensively for several years. Kristina hoped that, in the future, she could find a way to have room for the spiritual in her life, but without it taking over and dominating her, as in the psychosis.

Hans said that his original dream was to become a historian, but he had found out that it was not good for him to be sitting by himself too much, since he would start thinking about his problems. Recently, he had problems concentrating, so he would find it difficult to read. He said that it was important to be physically active, to keep his mind from his problems. As he explained:

I have experienced something... therefore I keep having problems with it, and think a lot about it, and I can't really get rid of it, but anyway, it is no use only to talk about it. If I, for example, am water skiing then I don't think very much about my problems, I can't do it, it is impossible then to keep the balance at the same time... [LAUGHTER] for example. And also when I talk to people, and things like that, then I don't think about it, then it is no problem for me. It is more when I am alone, and situations like that. Therefore I don't think that I want to be a historian.

Hans hoped that he, in time, would overcome his problems of concentration so that it would be possible for him to start studying again. Within the next two years, he expected to study a subject concerning society, either Economics, Sociology or Political Science, and that he would have a part-time job at the same time. The job would provide him with some extra money and he stressed that it was important for him to keep active and have social contacts.

I couldn't imagine not having a job. You become an idiot if you only read, if you don't have any contact, any connections, then you become really strange,

or you don't become strange, because I don't become that, but I become sad... boring, that is the word.

Likewise, Birgit, Lotte, and Ole expected that their lives would change more or less as a direct consequence of the problems they had experienced, or the support they received in OPUS. What was special about these three informants was that they anticipated that things would change for the better. They explained how, in previous years, they had considerable mental and social problems, but that they now felt more positive about the direction their lives were taking. They had discovered new life projects. Birgit hoped that in the future she would be more happy and active, getting more out among other people and maybe getting a small sheltered job as a supplement to the early retirement pension she was receiving. Birgit told me that she was not used to seeing many people and that she now was surprised that she had this positive outlook.

I just can't understand that I am so positive, because I never before believed that things could be different than they in fact were. So it really surprises me that I believe in it.

Lotte expected that the future would look brighter. When she was admitted to the psychiatric ward, she was homeless and had considerable social problems in addition to the psychotic hallucinations she was suffering from. When I interviewed her for the first time, she was living in a temporary flat (*akutbolig*) provided by the municipality and had started working on night shifts at a hot dog stand. She expected that after she had taken the antipsychotic medication for one year, she would be free of the illness, and she expected that, within two years, she would have started training to become a veterinary assistant. Before that, she would, however, have to finish basic school exams (*folkeskolens afgangseksamen*). She told me that she would also have to give up her habit of smoking cannabis.

Ole told me that he had been on social assistance for four years, but that with help from his case manager he was now anticipating receiving an early retirement pension within a few months. For Ole this would mean an important improvement in his life situation, since he both would be better off financially and, most of all, it would provide him with more stability and security. With the pension, he could live a quiet and calm life, not being tossed around in the system. He expected that by receiving the

pension, he would be permanently inside the system, or outside the system, depending on one's perspective. By 'permanently inside the system' he meant that he could receive financial support without being questioned and requested to participate in activities arranged by the employment services. By 'permanently outside the system' he meant that by receiving a pension, he would no longer be considered as part of the work force. Ole stressed his ability to live a life without work and to pass time without being impaired by lack of activities, thereby applying the strategy of 'dependent autonomy' that has been documented in research on individual attitudes to long-term unemployment in Denmark (Larsen 1998a).

Irene, Per, Eva, Anders, Namira, and Frank expected to return to the lives and future hopes which had been interrupted by psychosis. To varying degrees, they foresaw that they had to endure a transitory period, when they would 'get back on their feet again', but these informants thought that they would have to make no, or only minor, changes to their previous life styles. It was thus characteristic that they used expressions such as 'put behind', 'get over', and 'get through', to describe how the psychotic experiences constituted an 'annoying' interruption in their lives, but, in time, would no longer have any significance. They were going to take up their former life projects.

Irene thought that after one year, she would be 'well-functioning' in every sense, both at work and at home with her husband and child. She hoped that at that time, she would be able to say to herself that she had experienced two single episodes of psychosis. She explained that even if in this way she wanted to put the experiences behind her and not let them dominate her life in the future she would become wiser and learn that she should not get involved in too many things. Therefore, she had also decided that she would work 33 hours a week, instead of the normal 37 hours. Per, too, wanted to resume his previous vocation. He said that when he felt better and had been discharged from the hospital he wanted to get a job where he could use his training as a toolmaker. He expected that, in the first year, he might need an economic supplement to support him in the workplace, but after two years, he would work in a normal job, without a supplement. Per was, however, afraid that things might turn out differently. He told me that he especially feared that he would become a loner (*enegænger*). But, even so, he kept his positive outlook.

It could be a happy ending, surely. For real, I mean, function like other normal people. It is possible, it is.

Eva, too, said that she needed a period during which she could recover. She thought of starting in a school where she could practise playing the flute. But within a year, she expected to be back studying again, and she would like to study abroad for a period. In a longer-term perspective, she hoped to get a job in a ministry, or possibly do research. She would also like to get a boyfriend and, in time, get married and establish a nuclear family with two children. When asked about how he saw himself in the future, Anders said that he expected to have got over 'the illness hustle' (*sygdomsræs*). Like Eva, he was on sick leave from his studies and hoped to be able to start again, studying in a proper way. Anders was surprised when he was told about the long-term perspective for his recovery.

The psychiatrist I left at [the hospital], she said that maybe I had to be on medication for about a year. And that was a much longer time than I had expected. I thought: 'In a year, then I must have put this behind me'. That's how I thought: 'It will be that fast'. But of course I still feel that it is difficult to read, it is difficult to keep the concentration. And I don't know how long it will take before it is back again. But... it is definitely annoying, this. But I don't know anything about distant future or near future.

The psychosis and hospitalisation had interrupted Namira's training to become a shop assistant, but she was starting again the day after I interviewed her. Her training comprised two days a week in school and three days working as a trainee in the retail store. Namira expected to have completed the training in about one and a half years, and, thereafter, to get a job, possibly in the same retail store where she was under training. She thought that, at that time, she would have no illness.

Of all fifteen informants, Frank, at the time of the first interview, was least worried about the consequences of his psychotic experiences. He wanted to put it behind him. At the time, he was working part-time in a supermarket, with additional financial support from the municipality. He used most of his free time to practise break dancing and perform together with a dance group with which he was associated. Frank had thought about maybe using his office training (*HG eksamen*), or maybe working in a kindergarten. His dream was that he would be able to live from the professional 'show

dance', which would possibly mean that he should move to England, Germany, or Sweden, where demand and pay would be higher. At the time, he had no clear idea what he would be doing in two years time.

Encountering community intervention

As they were included in OPUS, the informants participated in screening interviews, where their symptoms were assessed and a psychiatric diagnosis established. Some informants were happy to have the opportunity to describe their experiences, sensations, and problems in detail. It gave them an overview of what they had experienced, and they could relive difficult emotions. Other informants said that they found the detailed interrogation tiring and unpleasant; some felt distressed about having to relive the psychotic experiences; one said that the arduous quantification of the sensations was alienating and he lied about his experiences to seem 'less crazy'. The informants generally thought that the process of randomisation for the medical trial was strange, like a lottery, but they were happy to have 'pulled the right number' and been included in OPUS.

At the time of the first interview, within a few months of their inclusion, the informants generally felt apathetic, bored, lazy, and tired. Many found it difficult to structure the day: to sleep at normal hours and to fill the day with activities. Some complained that the antipsychotic medication flattened their sensations and moods, and that they became asocial.

Those who had not been admitted to a psychiatric ward were primarily concerned about whether or not they needed to participate in OPUS, whether there was really something wrong with them, and they were reluctant to tell people in their close social network about their involvement in OPUS. Informants who were admitted to a psychiatric ward felt uncertain about the time perspective of their hospitalisation, especially one who was still at a secure ward. Generally, they were concerned about the prospects of feeling better, and found it difficult to talk about future perspectives. Some described how the stay in the hospital was personally humiliating and degrading due to their inferior social status compared to the staff, to being kept in a small space and in an environment with low requirements for social functioning, and to being identified with the other mentally disturbed in-patients – what Goffman called the 'mirroring effect'

(1961: 139). Informants who had been discharged from a psychiatric ward were engaged in re-establishing their lives and resuming their individual life projects.

The informants were positive about their involvement in OPUS. Generally, they found support from their case managers. When they were in hospital, the case manager helped them to develop individual plans and carry through their requests, and acted as a personal support for the informants in their relations with hospital staff and relatives. Once the informants had been discharged from hospital, the case manager helped them to arrange their living conditions and re-establish their lives. Some informants, however, requested therapeutic conversations with a psychologist and found the case manager incapable of taking on this role. Others felt that meeting OPUS staff in the physical environment of psychiatric institutions was stigmatising. But even critical informants had a generally positive wait-and-see outlook.

At this time, shortly after inclusion in the project, some informants found it difficult to have any expectations of their future lives; they were too subjugated by their mental problems. Others expected that they had to adjust the lives they used to live, in order to prevent a relapse. Some of these saw their participation in OPUS as a positive opportunity to establish a better life situation and develop new life projects. In some cases, the hope for a bright future was darkened by a fear that things might turn out differently. Other informants expected to resume the lives they used to live, and wanted to regain them as soon as possible – to put their experiences of psychosis behind them. The next two chapters describe their experiences of the various interventions in OPUS as my informants became familiar with them throughout the two years of inclusion in the project.

Chapter Six

Individual treatment: Personal support and illness control

The OPUS project aimed to provide individually-adjusted services in all central areas of the participants' lives, enabling them to live independently in society and experience continuous improvement in their mental conditions. A central component of this 'community approach' was individual support arranged and provided by case managers, who each had specialised professional expertise and consulted the multidisciplinary team to provide extra specialised services when needed. Also crucial in OPUS was the use of medication. During their inclusion in the project, medication was provided free to participants, continuously supervised by the case manager, assisted by the team psychiatrist.

Informants' understandings of this individualised treatment and support will be described, with particular attention to how it affected their perceptions of themselves. First, the role of the participants in OPUS will be examined, in a discussion of their preferences for being described as 'patients' or 'participants'.

'Patient' or 'participant': The meanings of categorisation

From the start of OPUS, there was uncertainty about what to call recipients of the project's services. When I was employed in April 1998, together with the majority of the other staff, there was an existing agreement, between the psychiatrist and the two nurses who had been employed some months previously to start up the project, to call them 'patients' (*patienter*). This term was used in the written project material and by the medical researchers. One and a half months after I started, I first reflected in my diary on the use of the concept. During a meeting of some of the staff, where we discussed therapeutic interventions to be used in the project, some colleagues suggested that the term 'patient' presented the person as passive, as an object. The term emphasised the biomedical and diagnostic perspective, and the power to categorise held by the representatives of the psychiatric profession (cf. Foucault 1980; Jenkins 1996: 80-89,

2000). As an alternative, I proposed 'participant' (*deltager*), to connote an active and responsible involvement (cf. Barham and Hayward 1995: 4).

In the following months, discussions about the appropriate term often occurred in staff meetings. Staff with a background in social work, alternatively, suggested 'client' (*klient*) or 'user' (*bruger*), which in Denmark are commonly used in that professional field. Two of the three nurses and the two psychiatrists were, however, persistent that 'patient' was the only correct term. As one psychiatrist stated, attempting to cut through what she saw as a nonsensical discussion: 'But they *are* patients!'. Their claim was supported by the, largely English-language, treatment protocols, manuals and other documents with which we had been provided, where they were always described as 'patients'. Particular categorisations carry significant cultural meanings (Jenkins 1996, 2000), but in scientific discussions of psychiatric illness these often remain unexamined (Barrett 1996: 40). In the day-to-day context of the OPUS project, however, these cultural meanings were addressed frequently, and by various actors.

The symbolic importance of categorisations was, for example, apparent during visits to different institutions offering social services which were potentially available to recipients of the OPUS intervention. One afternoon, we, the staff in OPUS, visited *Fountain House*³² in Copenhagen, an institution providing work and social activities for people with a record of mental illness living in the community, all of whom were called 'members'. After seeing the facilities, we had coffee with a group of Fountain House members, and one of our psychiatrists described the services provided in OPUS. When she had finished, one of the members asked, 'Do you really call them patients?', explaining that many found this term stigmatising and humiliating. It clearly challenged the otherwise sympathetic image of OPUS in the eyes of these members. Some of the OPUS staff – who had internally criticised the use of the term – explained that they only called them 'patients' when they were admitted to a hospital, and that they preferred 'user' or 'client'. This 'half truth' warded off the criticism latent in the question, and the friendly exchange over coffee continued.

Throughout my contact with OPUS, the issue continued to be unsettled. It is my impression that 'patient' remained the term most used by staff, especially when only professionals were present. However, during this period I observed that some staff,

especially those employed in the social section, increasingly used the term 'participant'. My persistent use of this term, in daily interaction and in my evaluation reports, may have had an influence. By the last year of fieldwork, 2000, some staff members had developed an innovative language use by adopting the term 'participant' to replace the customary use of 'patient' in the professionally dominant discourse of hospital-trained staff. For example, they might say 'my participant' when discussing a person for whom they were case manager. Another linguistic alternative to avoid the use of 'patient' occurred when staff used the term for the case manager, *kontaktperson*, which literally means 'contact person'. It led to some confusion as to who was the recipient, when the staff called a participant 'my contact person' (*min kontaktperson*). At the end of 2000, I participated in some meetings in therapeutic multiple-family groups and noticed that nobody used the term 'patient'; even a psychiatrist who, at the project's beginning, had insisted on the use of 'patient', on several occasions said 'participant' (Larsen 2001a: 131). Hence, staff expressed a widespread tacit appreciation of symbolic meaning in avoiding the term 'patient'.

I asked recipients of the OPUS services about these different categorisations during the second round of interviews, more than six months after they started in the project. Nine of the thirteen informants who talked about this said that they definitely preferred to be called, and perceived as, participants. As participants they saw themselves as active, whereas the notion of patient evoked ideas of being ill and passive, as in the following:

Anders: I would say that participant is better.

JAL: Yes. Why?

Anders: Well, because... it might be that you are still so weak that you could call them patients, but you should preferably get back on your feet and become a participant again, you see, a partner, kind of. So that not everything has to be done for you.

Julie: You are a participant in the project, you see. You are not just some ill person.

³² Fountain House was originally introduced in the USA as a meeting place and an institution of social support, work and rehabilitation for people with a history of mental illness living in the community.

Per emphasised that 'participant', more precisely than 'patient', reflected the more equal and personal relationship he had developed with his case manager, due to their frequent meetings. Other informants mentioned the relational aspect, observing that the notion of being a patient was related to the role they had when they were in the hospital. A recent study of the therapeutic transition undergone by patients in a contemporary psychiatric ward supports this view, observing that at the time of discharge, the patient has, ideally, reached or regained a level of individual integrity and competence which is informally rewarded by being evaluated morally as an equal and 'anyone' (Barrett 1996: 280). Hence, having been discharged from hospital, my informants no longer saw themselves as patients, and they felt that how they were addressed in OPUS should reflect and support this change:

Kristina: Patient, we are not that any longer, since we are not admitted [to the hospital] any longer, you see. So you definitely need to be addressed as participant... afterwards. Because you need to get out of that patient role you have occupied. That is what OPUS is all about, to get out of this patient role.

Eva and Namira, however, said that they did not mind whether staff called them 'patient' or 'participant'. As her immediate response, Birgit wondered why I had asked the question, since she obviously was a patient. I explained that there were different views among staff in OPUS, and that some of my other informants preferred to be called participants. Birgit reflected that maybe they did not see themselves as ill, and that it would therefore be more appropriate for them to be called participants. She said that if she had thought like that from the beginning, maybe she would have perceived of her participation in OPUS differently, as less problematic. But then again, she decided, being a participant sounded a bit like being a guinea pig, as if the service she was receiving could be easily influenced and uncertain.

Irene most clearly asserted her preference to be called a patient:

In relation to OPUS, I regard myself as a patient, and not a participant. You see, I mean, I am there because I am ill, right? If I was well, then I would never have heard about OPUS and entered anything. So I am a patient.

When I interviewed Irene again, however, about six months later, she spontaneously referred to her own position in OPUS as 'patient or client'. She explained that, recently,

she had come to question her role, whether she was a patient or a client. As she saw it, a patient is closer to and subdued by the treatment staff, whereas as a client you were more at distance, and more free. This change in her conception of her role in relation to OPUS also related to the way she perceived of herself and her illness:

I am about to reach a point in my life where I have accepted that I have this illness, I take my pills, it goes well, so it is rather good that... it is, kind of, a new orientation in my life, you see.

She had perceived 'being a patient' as a temporary state, related to the illness she was expecting to overcome. However, she now expected that this would be a more persistent part of her future life. Accepting this new orientation, she increasingly struggled with the notion of herself as a patient. This finding resonates with Parsons' (1951) notion of the 'sick role' as a temporary state. The notion of 'patient' represented a transitory sickness status, which became difficult to retain as Irene perceived of her state as more permanent. Being a 'client' offered more stability and created a distance from the treatment staff which allowed her personal space. Her choice is further illuminated by Luhrmann's (2000: 266-93) observation that the medical model of mental illness relieves the patient of guilt, but the long-term personally unacceptable logical consequence of the model is that if 'the illness never goes away and the illness lies in the way they [patients of psychiatric treatment] think, feel, and act, they can see themselves and be seen as never fully human' (*ibid.*: 278). Irene's changed perception of her role, and 'illness status', was an expression of her wish again to be able to perceive of herself as a responsible person – therefore, she had to reject the notion of herself as 'patient'.

Different concepts influenced how informants saw themselves, their relation to the staff, and the role they assumed in OPUS. For some informants, the concept 'patient' fixed them in the roles they held when they were in the hospital. Changing the categorisation, on the other hand, symbolised and encouraged the assumption of a more active and independent role on being discharged.

Individual support from OPUS

The case manager was at the centre of the treatment and support that participants received from OPUS, arranging the provision of medication, monitoring illness development, assessing the needs of each participant, and helping them to arrange housing and manage money by assisting their communication with private organisations and public institutions. The case manager also provided personal support and guidance by assisting participants if there were problems with relatives, and generally facilitating their plans and wishes.

On average, each member of staff was the case manager for eight participants (Larsen 2001a: 63), with just under an hour of individual contact with each participant per week (*ibid.*: 66). This, typically, involved meeting participants individually, once a week or a fortnight, depending on individual needs and requests, and their own work pressures. While some informants preferred to meet in the OPUS office, others were happy for the case manager to visit them in their homes; occasionally, they might meet on the 'neutral ground' of a café – as formulated by one participant. Apart from these individual meetings, staff also saw participants in various therapeutic group contexts. Time-budget data show that of the third of their time which OPUS staff spent on individual case management, 50 per cent was for one-to-one sessions (Larsen 2001a: 52). Faced with this data, some staff were surprised that they did not use more time on individual contact as case managers. However, focus group discussions revealed that they perceived case management as more time-consuming because they discussed issues concerning participants throughout their working day, both formally at case conferences and informally (*ibid.*: 53). Ethnographic research in a psychiatric hospital in Australia has demonstrated the crucial role of this kind of 'moral talk' among staff in the recovery of patients, by re-establishing them as responsible and capable persons (Barrett 1996: Chapter 6).

During 2000, I observed individual meetings between eight participants and their case managers (Larsen 2001a: 69-74). I chose to observe meetings with participants I did not know in advance, since I did not want to jeopardise my relationships with my informants by appearing in the role as observer of their personal conversations. The participants agreed beforehand that I could be present; after introducing myself, I remained quiet and sat at a distance, taking notes. The meetings

generally lasted one hour, but varied between 25 and 75 minutes. In focus group interviews during 2000 and 2001, discussing my descriptions of the meetings in evaluation reports, the staff said that these meetings were representative of their work as case persons with the more 'well-functioning' participants who could engage in conversations. They also had meetings with participants where very little was said, or they went for walks (*ibid.*: 70).

During the observed meetings, the positive control or monitoring mentioned by informants in Chapter Five was obvious. Case managers systematically asked the participants to report on difficulties or problems they had experienced since the last meeting. They asked direct questions about symptoms of psychosis, such as hearing voices, and required participants to give detailed reports about whether they, for example, were experiencing side-effects from medication. In one situation, a participant had experienced ticks in his legs and head as a side-effect. His case manager asked him about their severity and frequency, and asked him how he felt about them and whether they bothered him; whether he felt self-conscious because of the involuntary movements, and whether this prevented him from being among other people, for example when he went shopping. For the staff, these questions were important in order to assess the severity of the side-effects, physiologically, psychologically and socially.

Case managers asked participants to report individual 'warning signs', such as being unable to sleep, which for some participants indicated that a psychotic relapse could be underway (Birchwood *et al.* 2000b). In such cases, the medication would have to be reconsidered. Participants were also asked to report whether they had drunk alcohol, smoked cannabis, or used other drugs (if the person had previously used these). In one case, a young man reported that he had been drinking with some of his friends at the weekend; the case manager asked him how much he had drunk, and reminded him that it was risky for him to drink since it could provoke a new psychotic episode. During the focus group interview in 1999, staff previously inexperienced in working with psychiatric patients described how demanding they found it to monitor symptoms and side-effects and ensure that medication was prescribed appropriately (Larsen 2001a: 86-90).

Along with monitoring, an important aspect of the case manager's work was teaching participants about the dangers of relapse and what they could do to attempt to

prevent this by avoiding 'risky behaviour' and monitoring their individual 'warning signs' themselves. The teaching of the aetiology, the course, and the treatment of mental illness is called 'psychoeducation' in psychiatric practice, and it is considered especially valuable in the psychotherapeutic approach to patients who have experienced first episode psychosis (McGorry 1995).

In his first interview, Anders described the benefits of his weekly meetings with the case manager:

Anders: Then we are trained in how we can see it [the psychosis] come back.

JAL: Yes, is that something that helps you?

Anders: Yes. You keep an eye on your own symptoms. Before I couldn't really recognise them.

JAL: No. But, how does it help you that you can recognise the symptoms?

Anders: Well, I haven't experienced it yet, you see. I haven't had any relapse or anything.

JAL: No, but you feel anyway that it helps you that you talk about...?

Anders: Yes, and talk about the illness, and what it was I experienced, you see.

JAL: Yes. What does it help? I mean, when you talk about the illness, what...?

Anders: It helps me to understand what it was I experienced...It was a strange experience.

In later interviews, Anders mentioned again that it was helpful to him to talk to his case manager about the experiences he had when he was psychotic and when he was in the psychiatric ward. In the fourth interview, two years after he had been included in OPUS, he described conversations with his case manager as important in providing him with information about his illness, allowing him to relate to it more naturally, and making him 'come down to earth' a bit (*falde lidt ned til jorden*). Per, too, said that it was helpful that he could ask his case manager questions about his psychotic experiences, since, at the time, he was totally confused.

While the psychotic experience was a dominant theme in the first period of their contact with OPUS, informants explained that, as these became more distant, practical and everyday issues increasingly dominated the conversations. They generally talked about how they felt, what had happened since they last met, and their medication. A British study of psychiatric patients' views on different forms of treatment documented the crucial importance of their experience of 'being listened to as individuals, the fulfilment of the need for comfort and reassurance and concern in times

of difficulties' (Rogers and Pilgrim 1993: 624). It has been suggested that in the case of severe mental illness, supportive contact encourages the individual course of improvement (Davidson and Strauss 1992) and that the genuinely concerned 'normalising' talk keeps a negative, 'chronic' development at bay (Estroff *et al.* 1991: 363). Based on self-reports on individual processes of recovery from severe mental illness, Davidson and Strauss (1992: 136) observed that a 'significant other' who 'believed in them' played a crucial role in supporting the individuals by giving them a sense of hope. In OPUS, the ideal for the case manager was to adopt such a role as a professional 'significant other'.

Informants, generally, assessed their case managers positively: Julie said that it was nice and cosy to meet her case manager once a week and have tea together in her flat; Anders said that it helped him to pull himself together, that his case manager kept him focused on the things he had to do and the arrangements he had to make: for example, to start his studies again. Data from surveys of participants in 1999 and 2000 support these statements. On a five-point scale from 'not at all' to 'very much' 43 of the 62 respondents, or 69 per cent, indicated one of the two most positive evaluations of how much it had helped them to have a case manager; none replied 'not at all' (Larsen 2001a: 170; Larsen and Feldman 1999: 16). However, the static survey data disguise the changes over time revealed in the longitudinal interviews with my informants.

Martin, for example, felt that in the beginning it was often difficult for him to get to talk about the things that troubled him most; he thought that the case manager was dominating, that she decided what they talked about. After one and a half years, his case manager proposed that he should write down a list of issues beforehand that he wanted to discuss when they met. Sometimes, he wrote a little explanation under each point. Martin found that this technique had been very helpful. While he was participating in a social skills training group, he often used some of the time with his case manager to practise techniques he had learnt in the conversation training. Already, in my second interview with him, he thought that it was very helpful to talk with his case manager about his problems:

It has helped me that I have had somebody to talk to about my problems. Before I kept them to myself, and things like that, and then they grew. So it definitely helped to have somebody to talk to about the problems. And then we

have worked on concrete things, such as becoming better in being in the kitchen [of the student flat]. Before I didn't use the kitchen at all, but now I go out there to eat my breakfast and prepare my dinner, a few times a week. So concrete things like that it has also improved.

Informants, generally, said that they were happy to have the opportunity to talk to their case managers about personal problems that they normally would never tell other people. Martin told me that he found it relatively easy to talk to the OPUS staff about his problems. He would be very ashamed to talk to his parents about his problems, but talking to his case manager was 'more professional', i.e. less personally demanding. Namira and Dennis both described how they initially felt a bit strange talking openly to their case managers; they felt a bit shy, tense, and reserved. During the first interview, Hans told me that he was not sure at all whether it was a good idea for him to talk about his difficult thoughts.

Hans: I think that it is a bit embarrassing to sit and [LAUGHTER]... if I met those people [interviewers and staff in OPUS] some other place, then I would never have said those things, or opened up... talked with them in that way. It is a bit strange. I don't think that you should, I have a feeling that you should not be that open, or things like that.

JAL: You think that because you meet them here in the project then you talk to them in a different way?

Hans: Yes, you become more kind of sincere in some way, I don't think that it is always good, not always.

JAL: Why don't you think that?

Hans: Because... well, what can I say? I think that you will never be in such a way that you don't have any problems at all, I think that you will never feel like that.

JAL: No, no, it is human to have problems.

Hans: I think that you have it inside yourself. You have always got it, in some way or the other. Then you have to try and work with it. I don't know, maybe it is a load of bullshit to say that, in fact it is quite good...

While Hans eventually chose to leave the project, other informants said that they got used to it as they got to know their case managers better; they felt at ease and thought that it was helpful to have somebody to tell their problems to. Claus described how his understanding of the case manager changed over the first couple of months:

Claus: I remember in the beginning... I don't know how to explain it... I felt a bit like 'What the hell am I going to talk to her [the case manager] about?', you see.

JAL: What happened then?

Claus: Then it developed, and I, kind of, was forced to talk. And then I saw a value of it, I could discuss my problems, and things like that, you see, and I found out that she in fact was very constructive.

When, during a team conference, a staff member discussed one participant's problems with side-effects of medication, I discovered how private these issues could be. He had told her that he was troubled by impotence caused by the medication; the case manager explained, empathetically, that he was particularly sad about this, 'since he used to enjoy to masturbate daily.' The revelation of personal secrets, particularly of a sexual character, is common in psychiatric patients' communications with clinicians (Barrett 1996: 45ff.). Psychiatrist and anthropologist Robert Barrett has described how, even when patients are reluctant to reveal them, secrets are systematically uncovered in the process of documentation, using information from the case record and information provided by family members (1996: 126).

During her fourth interview, Eva mentioned that the meetings with her case manager helped in trying to sort out concrete problems in everyday life, and in achieving an overview of her situation:

Eva: This case manager function is quite good, because it helps you a lot to keep the overview. You see, the overview is easily lost when you have so many things to think about. ...//...

JAL: When you say overview, is it then...?

Eva: It is, kind of, the overview of your emotions, so you don't get excited about it and think, for example think: 'Oh! I have no energy to go down to the eating room' [of the student hall of residence]. When, in reality, it is because you don't feel comfortable to sit and small-talk with the others, if that would be the case. You can very easily be in a situation, if it is sensitive, then you focus on everything else than what it is about, you see, and in these situations it can be quite good to have somebody you can talk to about your emotions, so that you, kind of, can talk your way through it.

In the previous interview, she had described how useful it was to call her case manager and ask for his advice. They had decided that she should commence her studies at the university earlier than originally planned, but then she started to worry about what she was going to say to students from her original year, if she met them and they asked her

why she had been away. With her case manager she decided that she would prefer not to tell them the whole truth. During their next meetings they discussed which unpleasant and challenging questions she could be asked and what she could reply; they then rehearsed these questions and answers in role plays. Besides from immediately making her less anxious about beginning to study again, the rehearsed answers proved to be very useful when Eva actually met her fellow students; she didn't feel uncomfortable and just answered the questions automatically.

Not all informants prepared for difficult social situations with their case managers. Claus described how he became totally paralysed by anxiety when a fellow student on the course he had just started asked him, at an 'intro party', why he did not drink alcohol. Claus answered that it was because he was schizophrenic and took medication. Claus saw that she was shocked by his reply; she disappeared very fast. Claus felt that it had been inappropriate to tell her about it and for the rest of the party he felt self-conscious, anxious and introverted. The following days he refused to attend the school, and even though OPUS staff and his parents persuaded him to give it another try, he did not feel comfortable and he felt that the studies were too demanding. Soon he quit.

Even if Martin appreciated the constructive help from his case manager, he was annoyed that he could not sometimes just be allowed to be unhappy:

Martin: I think often if I come and tell that I feel bad, then she [my case manager] tries to dig out some positive things. It would be nice if I sometimes would be allowed just to be sad.

JAL: I don't know, maybe you could... I think that it is an interesting point. You have experienced that you sometimes have been there and felt sad, and then...?

Martin: Yes, but then it is almost as if they [OPUS staff] do everything to try to dig out some good things and some positive dimensions. Sometimes it is a bit too much.

JAL: Does it annoy you?

Martin: Yes, sometimes it can be annoying.

JAL: Why?

Martin: Sometimes you are just in a bad mood, then it is as if I block out all these... this great enthusiasm, or you have to overcome these... try to see the bright side, it can be quite difficult if you feel really bad.

JAL: Would it be a help for you, do you think, if they could talk about the problems at hand? To be allowed to be sad?

Martin: Yes, be allowed to be sad, and then just talk about how you feel.

There were individual variations in the ways case managers worked, reflecting not only how busy they were, but also their professional expertise, personality and ‘treatment ideology’ (cf. Schied 1994). In therapeutic groups, some informants met other participants, and in their chat outside the groups they compared the services that they received. After more than eighteen months in OPUS, Per was not entirely satisfied:

Per: It has appeared that my case manager is always quite busy. So I have missed, a bit, to have a real case manager. It has been a bit more loose.

JAL: What is it you have missed?

Per: Well, for example that she came to visit me, or I came up to her, once or twice a week. Well, we have met, but then only for about half an hour where I briefly tell her how I am. She could have gone a bit more into it.

JAL: Yes, so you would have liked to have more time?

Per: Yes, she could help me better to deal with the illness, if that is possible, I don’t know if it is.

Per explained that his case manager usually asked him how he was doing with his family and his mother, and that they always discussed medication. He, however, wished to talk about body language and communication, for example, or other things he had been introduced to in his social skills training group. Per told me that, unfortunately, they had not started talking about the difficulties he had following his father’s suicide, either. He was still being tormented by the experience; sometimes, for example, he had visions of his father before falling to sleep. He had recently talked to his case manager about the possibility of getting therapy, but she had told him that she did not have time to go into it. He then suggested that she find a psychologist to whom he could talk, but the case manager had refused this, saying that she would take care of it. If nothing happened soon, Per was considering going to his GP to ask for a referral. I asked him what he expected to achieve from consulting a psychologist:

To deal with this experience [my father’s suicide]. I have talked to a psychotherapist in OPUS [the therapeutically trained nurse], and told her about the things I experience daily, and she said that it was a sign that I had something I needed to deal with. Now I have carried it around so many years, you see, so now I would like to have it over and done with, so that I can move on. You see, so that I don’t have to carry it around.

As described in Chapter Five, six informants early on wished to receive conversational therapy, and of these four requested to receive consultations with a psychologist, since they were not content with the opportunity they had to talk to their case managers. Apart from Anders, who was the only of the informants who had a psychologist as case manager, the others, in later interviews, repeatedly complained that they did not have access to a psychologist, to talk in detail about difficult experiences and emotions.

In the first interview, Irene told me that she requested to meet with a psychologist. She had discussed the matter in OPUS and decided to take her case manager's advice to wait for at least a year, since it was believed that the emotional disturbance which could be created or awoken in psycho-dynamic therapy could trigger a psychotic relapse. Irene told me that in contrast to taking antipsychotic medication, she did not see consultation with a psychologist as an indication of her illness:

I would see it [consultation with a psychologist] as a way of working with the things happening. And when you deal with things in your emotions then... it is not necessarily because you are ill, but just because you want to gain a better insight into how you work.

At the same time, Irene stressed the important support she received from her case manager:

[My case manager] helps me through all the things I am struggling with: Why did I become ill, why exactly me, what was it really that happened in me? In this way she is an immense support.

Kristina, too, chose to supplement the support and treatment she received from OPUS with psychological consultation. I asked her to describe the difference compared to the contact she had with her case manager:

Kristina: I feel that the psychologist he, kind of, says that he definitely understands that I miss having a life, an inner life, or something. Whereas it seems as if [my case manager] not really... you see, she thinks that it is only about everyday issues, and then move on. And then realise that 'Well, you are fine now,' it's like she works in this way, you see. Whereas the psychologist can assure me that there is another dimension which is missing. But, you see, [my case manager] of course also says that the psychosis has weakened some

areas in me. But she has, kind of, this rather technical take on it, in some way. She very much sees everything from the perspective of illness, you see. My psychologist could say that he didn't understand why I didn't start doing Tai Chi again, 'That it is so healthy.' [My case manager] would never say that.

JAL: Because she sees everything from the perspective of illness?

Kristina: Yes.

JAL: What does it else mean to your conversation and contact that she sees everything from the perspective of illness?

Kristina: I don't feel that I am being met. I feel that I am understood in a 'square' way.

For Kristina and Irene, seeing a psychologist provided them with an alternative perspective on their life situations and the difficulties they encountered, one where illness was not in the centre. Both informants were in possession of knowledge and the personal strength to seek alternative treatment and support by requesting their GPs to prescribe consultations with a clinical psychologist, to supplement the services offered in OPUS. Other informants were less resourceful. In all my interviews with Lotte, she presented her wish to see a psychologist, but even if she had tried to talk to her case manager about it, Lotte was never offered this opportunity.

For both OPUS staff and participants there was, from the start, some confusion in distinguishing between the intervention provided by the case manager and the psychological therapy. The theme was discussed at several staff meetings in 1998, and during focus group interviews in 1999. The two trained psychologists argued from the beginning that a proper cognitive psychological therapeutic arrangement should be set up as part of the intervention in OPUS. This, however, found resistance among some other staff members; the three nurses were reluctant to hand over this therapeutic intervention as a particular responsibility and competence restricted to the psychologists. The three nurses had several years of experience of working with psychiatric patients and one had privately completed therapeutic training.

In the months after our employment in 1998, I conducted individual interviews with all staff members about their motivations for taking the job, and their expectations of the intervention in OPUS. From the interviews, I learned that most members of staff expected to have the opportunity to work close and therapeutically with the patients. In particular, the nurses expressed this ambition and saw it as an improvement over the restricted patient-work they had experienced previously. Ethnographic research has suggested that nurses in psychiatric hospitals are discouraged from engaging in 'too

deep' individual counselling (Barrett 1996: 52, 58). Having taken positions as case managers the nurses in OPUS left the traditional professional role within the psychiatric institutions for a higher position in the status hierarchy, as professionals responsible for 'the case' (cf. Barrett 1996: 51). Responsibility for some psychological counselling of 'the case' signified a further consolidation of this higher status and was, therefore, resolutely defended.

The psychologists' suggestion to set up a separate therapeutic intervention for the participants in OPUS was seen as a threat to the professional ambitions of some other members of staff. At a staff meeting, a nurse reminded one of the psychologists that knowledge of psychology, and therapeutic competence, was not restricted to staff with an academic degree in psychology. More than one and a half years elapsed between when the two psychologists presented the first ideas and written proposal regarding the introduction of a formalised therapeutic intervention, and when such an intervention was agreed upon by the leaders of OPUS. In October 2000, it was decided formally in OPUS Bispebjerg that all participants who required therapeutic meetings with a psychologist should be allowed a meeting with the team psychologist to elucidate the individual need and relevance. Thereafter, it would be a team decision whether or not a session of twelve cognitive therapeutic sessions would be initiated (Larsen 2001a: 145ff.). To Lotte, this decision, unfortunately, came too late for her to take any advantage of it. Just before Per's time as a participant in OPUS elapsed, he started a series of consultations with the team psychologist. At the time of the fourth interview, he had had six meetings, and Per told me that the conversations had convinced him that his problems were due to his illness and not due to the trauma of finding his father dead. The psychologist had told him that sometimes it is better not to talk about traumatic experiences, and they agreed that in his case, this would be the best solution.

At the beginning of 2000, another addition to the services offered in OPUS was introduced. A person was employed to work as an occupational consultant, assisting with finding appropriate work or education for the participants. Originally, this function had been allotted to the case managers, assisted by the social workers in the two teams. But the staff found that this job was very demanding, and that it often was under-prioritised in their daily work, when monitoring symptoms and assisting participants to function in their lives, and finding appropriate housing and ensuring financial support

took most of their time and attention. When an opportunity arose to seek additional funding from the Ministry of Social Affairs, it was decided that this specialised operation could be a helpful addition.

Originally, it was intended that the occupational consultant's main function would be to establish contacts with potential work places, but experience showed that the role primarily would be to identify, and assist participants in applying for, the programmes of financial support which were appropriate to individual situations. This is because the Danish welfare system is based on various programmes to aid people back in the work force, for example by providing training in sheltered workshops or by providing financial support to employers who employ people with disabilities (see Chapter Seven). The occupational consultant participated in weekly 'treatment conferences' in both OPUS teams, and had individual meetings with participants to discuss their vocational plans and opportunities.

A professional friend: The relationship with the case manager

The case manager constituted the core of the intervention in OPUS. By assertively establishing and maintaining a personal connection throughout the period, the case manager kept the participants as recipients of the support and treatment offered by the project. Hence the case manager constituted an important technique of treatment. In community treatment – without the physical restraints and enforcement of the earlier 'incarceration' in psychiatric hospitals, and the clearly demarcated social roles within the institution – the personal relationship established through frequent contact was the most persistent *social manifestation* of the individual's status in the intervention programme. Without physical institutions and formalised roles ascribed to the various actors, social identities were established on the basis of cultural meanings applied in social negotiations between individuals in personal meetings.

The informants described their relationship with their individual case managers, and thereby, indirectly examined their own role in this relationship. This section presents my informants' perspectives, and therefore does not take account of the various approaches adopted by individual members of staff in their roles as case

managers (cf. Scheid 1994).³³ In the first period in OPUS, informants did not see their case managers as the central person in their process of their treatment and recovery. As Claus explained in my third interview with him:

I didn't really need [my case manager] at the hospital. Because I had all the treatment staff there, and things like that, so... I don't even remember what we talked about, probably it has just been to get to know each other a bit better.

At the time, he felt that he *had* to talk to the case manager, because he had agreed to participate in OPUS. But when he was discharged the case manager became the primary professional person in supporting him and continuing the treatment.

In a focus group interview, the staff in OPUS discussed their role as case managers, and the notion of caring (*omsorg*) came up (Larsen 2001a: 80). Some of the nurses mentioned this as a special quality of the support they gave to the participants. One member of staff found this concept problematic, and – jokingly – requested to know exactly how you provide caring and how you determine when the participant needs caring, and how much. The discussion reflected the staff's difficulties when talking about this service, especially in the formal, technical, and quantifiable way which was generally applied and positively evaluated in this professional setting. In my observations of meetings between case managers and participants, it was, however, evident that caring was often an integrated and central part of the communicative exchange and the support given by the case manager to the participant (*ibid.*: 69-74). This was manifest in various ways, both by the frequent praise and the generally empathic attitude of the case manager, seeking to make the participant talk about how he or she felt and what had happened to them since the previous meeting, but also by expressions of concern for how it was going and attempts to help find solutions to the problems presented by the participant. When one, for example, said that he had problems getting up in the morning, the case manager offered to call every morning at a certain time to give a 'wake-up-call'. When another related that the previous weekend

³³ In her study of *treatment ideologies* held by mental health care providers in the USA, Scheid (1994) identified four ideal types: 'care-taking', 'reparenting', 'normalisation', and 'empowerment'. They differed with regard to treatment goal as either adjustment or autonomy, and role of the provider as either supportive or facilitative.

he had been drinking with some of his friends, the case manager expressed personal concern by saying that she did not want him to experience a relapse.

My informants' statements confirmed the presence of 'caring' in the relationship, even if they did not use this word. This is, however, not surprising since the word 'caring' describes the action taken by the staff in their function as case managers. Experienced from the other side of the relationship, this practice was described by the informants as giving them a sense of warm personal feelings and a feeling of safety (*tryghed*). In our third meeting, Anders explained that this characteristic of the relationship was directly related to how he felt just after the psychosis, and that it would have been different if he had met his case manager when he felt better.

[My case manager] was very gentle with me. I think that it is partly because she saw me in the beginning where I was, kind of, very poorly. You see, I had... well, I was totally on my knees, you see, self-confidence... and I was completely without... defence, yes. Whereas if I had met her today, then it probably would have been, kind of, in another way.

When I asked informants to compare their relationships with their case managers to the relationships they had with their friends and family, or with colleagues or teachers, some informants said the relationship with the case manager was familial (*familiært*), since they felt that the case manager cared for them and that they could have a nice time together. It is generally observed that treatment staff assume a parental relationship towards the patient (Helman 2000: 138; McCourt Perring 1994: 176ff.).

Namira: I feel that [my case manager] is part of my family.

JAL: In which way?

Namira: She understands me. ...//... I can't compare her to my mother, I can't, but she is almost like my family, she is.

JAL: Yes, because you can tell her things and she understands you?

Namira: I also think that she likes me, I like her too.

When I talked to Frank at the hospital, after he had experienced a psychotic relapse, he told me that his case manager often had talked to him about the danger of taking drugs, but, even so, Frank had continued to smoke cannabis and occasionally he had taken hallucinogenic mushrooms. Frank explained to me that he did not tell the case

manager about these instances, since he did not want to *disappoint* him. He felt a moral obligation, indicating the case manager had a role similar to that of a parent. This perception of the relationship seems directly related to the central elements of monitoring, teaching, and giving guidance in the functions of case managers in OPUS, as described previously. Staff in OPUS largely saw themselves as *role models* for the participants, setting an example of how to handle situations (Larsen 2001a: 82-84). Even so, Frank described his case manager as a friend:

He is most similar to a friend. You see, I regard him very much as a friend, and I don't think so much about OPUS when he is here, I think more that... that he comes and talks about you. He would also come outside normal working hours, if it was necessary. Because he is nice and friendly, [he] supports you, and things like that, that's what he does.

The 'slip of the tongue' when Frank said 'talks *about*' instead of 'talks with' revealed the focus of attention in their conversations and signified the unequal character of the relationship. However, of the fifteen informants, ten compared the relationship with their case manager as most similar to a friendship. I asked Irene what it meant to her that the relationship with her case manager was 'friend-like'.

It means that... for me it is, I won't say that it is imperative, but it is quite important that it has a personal dimension, because then I more want to open myself up. I don't necessarily want to open myself up to just anybody. And when you meet somebody once a week and tell them how everything is going, then... it is necessary that you, kind of, say: 'Here I am, and now I will sit down and tell you how I am,' you see.

Even if several informants thought that the case manager could be compared to a friend, on further investigation, all noted that there were some important differences. Anders said that an important aspect of the relationship he had with his case manager was that, when talking about difficult subjects such as, how he felt, she could direct the conversation and pinpoint the important issues. I asked him if this type of relationship made certain things possible.

In any case it is something I don't think that I have anywhere else. What is possible? You see, it is that you can talk, kind of, objectively about the illness and all the things you experienced, and talk to somebody who knows about it

and has seen it before with others, and then can show you how seriously you should take it, how much you should speculate about it. Plus, somebody who knows all these facts about risk of relapse, and all that stuff.

Like Anders, other informants emphasised the fact that the case managers were professionals, who had a special knowledge and authority, and that their relationships were established by the fact that the case managers were employed to help them. Lorencz has described this type of relationship as 'expert authoritarianism', characterised by obedience to experts (Lorencz 1992: 303-8). Informants explained that their relationships were unequal in that the case managers did not tell the informants about their personal problems. Irene said that this, in fact, was the strength of the relationship.

The good thing is that I can keep on seeing [my case manager] as 'the professional', whereas I have lots of friends who are happy to tell me about their problems, and I am happy to engage in these. But it is exactly where [my case manager] can be of use, to be professional, but in a personal way. You see, that is what I say: it is similar to a friendship, but we will never be friends, and we are not supposed to.

While some informants, like Irene, appreciated the professional distance, others said that they would like the relationship to be less unequal and that they also would like to know some personal things about the case manager. This was rarely possible during the usual meetings, which almost exclusively were, as Eva described it, 'one-way communication', in the sense that only the informants told the case managers about what they had experienced and how they felt. Martin said that he was happy that he sometimes had had the opportunity to ask his case manager some personal questions as part of the 'conversation training' they had sometimes practised. The arranged therapeutic context of 'a normal conversation' allowed him to engage in an equal and personal exchange, which was not possible during their usual professional meetings. Claus, too, told of how he was careful to respect the private life of his case manager. I asked him if he had ever asked her personal questions.

It rarely happens. I do it sometimes, but then I really have to think about how I am going to formulate it, and find the right time to ask about it, and things like

that. Because I don't want to barge in and... I don't know. I think that it maybe is quite a good idea to have this 'professional clinician'.

Eva said that the only time she had asked her case manager a question concerning his private life was when his child was in hospital, and she asked how it was going. In some situations the difference in authority challenged the notion of the relationship as similar to a friendship. I asked Julie to compare it to her relationships with family and friends.

It is difficult. [My case manager] has always insisted that I should take my medication, and things like that. I have tried to avoid taking it, for a short while, but she insists that I have to take the medication all the time. This is where she draws the line: 'No, you have to take your medication!', you see, 'We can't have you being admitted again!', and things like that.

In situations as these, it was apparent that the positive relational bond between the case managers and the informants was used by the case managers to persuade the informants to do things they did not want to. This is an important aspect of the strength of the individual case manager as a method of treatment which I often heard the staff in OPUS comment upon. Because of the personal bond, and the feelings of trust and sympathy, the participants in OPUS felt more safe to follow the treatment plan and it was possible for the staff to convince, or gently pressure, the participants to do so. The case manager assumed the role of a personal support to the participant, while authoritative techniques of force were presented as *external*. As in the above quotation, where the case manager presented the case that she helped Julie to avoid *somebody else* admitting her to a psychiatric ward.

In this way *caring*, and not force, remained a key aspect of the relationship and this type of intervention technique. The significance of a good relationship between clinician and patient to secure compliance with treatment is echoed in a British study of psychiatric patients' views of different types of treatment; Rogers and Pilgrim (1993: 619, 626) found that patients preferred interventions which were accompanied by a positive personal relationship.

Staff in OPUS agreed that a personal bond developed with the participants they saw regularly, and that the contact was influenced by personal sympathies and antipathies – the 'chemistry' of the relationship (Larsen 2001a: 80-82). Staff made it

clear, however, that they were not participants' friends. This was explicitly stated during a focus group interview and in personal accounts of their work as case managers (*ibid.*: 81). It was also expressed indirectly when, for example, a staff member during the informal talk one morning said that it was long time since she had seen any people, apart from her 'patients', that was. The staff saw the relationship they had with participants as professional, even if they might have personal sympathies or antipathies. Research among psychiatric staff has suggested that too close a relationship with patients is not only perceived of as degrading to professional status, but also potentially 'contaminating' (Barrett 1996: 54ff.). Staff in OPUS suggested that the fact that participants were first-time psychotic, and relatively 'well-functioning' compared to patients in psychiatric wards, made the work particularly psychologically demanding, since it was easier to identify with them. This suggests that the 'mirroring effect' (Goffman 1961: 139) works not only between in-patients in psychiatric wards, but also between patients and staff in community mental health services.

Eva was one of the four informants who explicitly stated that the relationship she had with her case manager was not that of a friendship. She thought that the fact that her case manager was a man might have made it easier to keep the roles straight, so that he could not be confused with a same-gender friend. Eva gave this explanation when I asked her what constitutes a good case manager:

I guess that it is important that they [the case managers] have some intuitive understanding of people, that is probably what makes it possible to somehow relate to them. That they understand what you say, and that they can give some good advice. I think that it is imperative that they say something which is useful to you. And it is also important that they, kind of, take this doctor-like role upon them, that they also can draw the line for you. For example, the thing about the university [referring to earlier talk about this issue], if [my case manager] had considered it unrealistic that I could start there, then I think that it would have been very important that he told me. You see, they should take some of this responsibility, I think, for the decisions you take in the process of becoming well. Then they should say it clearly, so that you have something to be guided by. Because it is difficult to be your own doctor, and assess 'Am I well enough for this, or...?'

Whereas most informants described how they felt that there was a good relationship (*god kemi*) with their case managers, some were not entirely satisfied. Kristina stood out in her request for a radically more personal and engaged contact with

her case manager. In our second meeting, half a year after she had started in OPUS, she told me that she had been disappointed that her case manager had refused to give her a hug when she felt she needed it. For Kristina the relationship was too distant and superficial. The case manager had listened to her critique, but nothing had changed, and Kristina, therefore, had lowered her expectations, and they had decided to meet less frequently as Kristina had become busy with the school she attended. In the following interview, Kristina explained that she had accepted the way their relationship was and that she was reasonably content with what it gave her, but she did not feel that she got any valuable advice or 'psychological guidance' from her. She felt that the case manager was trying to convince her that a normal life was alright.

In the first interview, Lotte expressed positive expectations of her case manager. But in the following interviews, she said that the case manager was not interested in talking with her. In the first months after the psychosis, Lotte felt 'completely brain dead.' But one time she started to talk to her case manager about painful experiences of having been abused as a child, but she had the feeling that the case manager was not interested. And in one situation, the case manager had told her that she was not her friend. Lotte was very angry about this:

What the hell can you use somebody for, who can say something like that! As if I would consider her my friend! If that had been the case, then things probably would have looked differently. I don't know if she [my case manager] has this kind of friendships with ill people, and she comes and gives them medication, and things like that. I don't have such friendships, I never have had!

When I asked her to compare the relationship she had with her case manager with other relationships, for example with her family, she replied that the relationship was as bad as the one she had with her parents.

In the first interview, Hans worried about his feeling that the staff in OPUS wanted to enter his private life. His case manager had told him that he would like to come and visit him in his flat.

If you mess around in peoples private lives, then I think that you would find many who had something, or you would say 'It is strange that...', and I am a bit afraid of that.

Hans was also concerned what the neighbours might think when they noticed that he had regular visits from his case manager. Hans did not like the role he was assigned as recipient of the intervention in OPUS, and that was a main reason why he decided early on to leave the project. He thought that it was embarrassing that he needed to get help, since he was a grown person himself. When I interviewed Hans again, about a year after he had stopped having regular contact with OPUS, he said that the case manager maybe could have been a bit more patient with him and listened more. Once, when he felt depressed and started to talk about his feelings and thoughts, the case manager had been quick to send him to the team psychiatrist. The psychiatrist advised him to take some pills, and when Hans refused, she threatened him that she would commit him to a psychiatric ward. After this experience, Hans wanted out.

When I was about to arrange the second interviews with the informants, I learned that Ole had been readmitted to a psychiatric ward. I called Ole on the patient phone, and we had a short conversation. Ole was very upset and angry with OPUS and his case manager, who he said had participated in forcing him to be admitted to the secure ward. He did not want to have anything more to do with OPUS, and he implied that the case manager was working under a false identity, which indicated that the case manager had become part of his florid psychotic delusions. Later, Ole formally left the project. In accordance with the 'assertive' ideology of OPUS, however, participants' requests to leave the project were first formally accepted after several repeated attempts from the staff to re-establish contact.

Martin experienced a different difficulty in the relationship with his case manager; he fell in love with her. Martin explained to me that he had not been used to a woman being interested in him and asking him what he was doing and how he felt. For a while, it had been a problem for him that he had these feelings, but eventually he had found courage to tell her about it. Martin was happy that she responded in a nice way; she said that she could not reciprocate his feelings. He had then talked about it with the team psychiatrist, and she had told him that it was good that he had found out that he was capable of having these emotions. Martin was happy that he could keep the case manager. He had been afraid that he might have been assigned a different member of the team.

Meanings and functions of medication

Medication was part of the everyday life of the OPUS project. Apart from constantly being one of the treatment options when assessing the situation of 'patients' (which the participants were when medication was discussed), the familiarisation with medication was encouraged through its representation on advertising items presented by pharmaceutical companies. I got used to drinking my tea and coffee from mugs on which 'Risperdal', or another popular brand of drugs, was printed in large letters, often accompanied by a cute drawing of, for example, a flower in bright colours. Such ceramic mugs were used in addition to the disposable plastic cups which were commonly used by staff in hospital settings (cf. Luhrmann 2000: 55).

The significance of the advertising items can possibly be overstated, but, on the other hand, companies do not incur these expenses without benefiting from a well calculated interest. The items associate positive feelings towards the drugs and the pharmaceutical companies. Getting used to drinking from a mug which bears the logo of a particular pharmaceutical drug and company makes you associate the drug with the positive and non-toxic qualities of the coffee and tea you are drinking. Further, the layout and illustrations accompanying the logos are colourful, often naïvely childlike, and therefore appear 'innocent'. In most cases, the direct influence is minor, and not consciously apprehended; for example, I changed from first having hesitated to see the name of a drug on the mug, to drinking from the mug without noticing it. Another aspect is the mere visibility of the logos of drugs and pharmaceutical companies. Being present on mugs, pens, bags, posters, and little note stickers, they are manifested as part of the physical environment, and integrated into the culture of treatment.

Advertising by pharmaceutical companies can have a significant effect on the general 'medicalisation', or 'normalisation of drugs', by which problems in life are increasingly dealt with by the use of medicine (Helman 2000: 141). The danger of medicalisation is that it can mean an overemphasis on the drug treatment of symptoms, instead of finding ways to improve life conditions of the patients, which might have a role to play in tackling the cause of any particular disease (*ibid.*: 152ff.). The direct target group of the advertising by pharmaceutical companies in OPUS was the treatment staff and not the consumers. This was a reflection of the power-knowledge relations

between staff and patient, in which it was the staff, and principally the doctors, who were in charge of the drug treatment and chose which medication to prescribe. It can be assumed that the parental-type authority role typically occupied by treatment staff or 'healers' (*ibid.*: 138) strengthens patients' learning of values (*ibid.*: 141), also when it comes to attitudes towards medication.

Staff in OPUS expressed some concern that medication might take on a too dominant role in the treatment (Larsen 2001a: 86-89). During a focus group interview in 1999, they said that medication was often the first treatment option that was considered if a participant felt worse. Staff, however, agreed that they were careful to prescribe medication in the lowest possible doses and to re-evaluate continually the possibility of lowering the dose. They stressed that they took care to bring in various perspectives on options of treatment and support during the team meetings that they had several times per week. Staff explained that there was a noticeable difference between the comprehensive consideration of the overall situation of participants in OPUS, and how staff at psychiatric wards almost exclusively focused on observations of patients' behaviour and medication when they discussed treatment options at conferences (*ibid.*: 88).

But even if 'the whole person' was considered in the multidisciplinary OPUS teams, the psychiatric biomedical approach occupied a prominent position. This was not only due to a recognition within the team of the psychiatrist's superior knowledge about psychiatric conditions and insights to 'the core of the illness', and the natural authority and hegemony of the psychiatric perspective that came with this (cf. Barrett 1996: Chapter 4), it was also for safety reasons and due to the potency of medication to control symptoms of illness. The staff explained that the danger of psychotic relapse made them particular focused on keeping symptoms down. One explained that when a participant experienced problems she would often first consider consulting the team psychiatrist regarding the adjustment of medication, since her next meeting with the participant would be in a week's time, and prescribing the medication was a way to execute immediate action to alleviate the problems experienced by the participant (Larsen 2001a: 87).

Notions of risk of illness and the necessity of safety were also crucial to the participants' attitudes to medication. My informants expressed ambivalent feelings

towards the medication they took, but they took it anyway, because they considered it necessary. Together with Hans, Julie was an exception to this general picture. She did not express any positive expectations or attitudes towards medication, and she only took it because she was either forced, or persuaded, to do so. As described earlier, she felt pressure from her case manager and other OPUS staff. Julie explained that she only agreed to keep on taking the medication because she did not feel any effect from it – it did not bother her. When I asked her what she thought about the way medication was dealt with in OPUS, she said that she was content, since the staff listened to her, and, for example, had recently reduced her dose when she requested them to. Julie's attitude to medication was directly related to her notion that she was not, and had not been, mentally ill. Informants shared the belief that medication and illness were directly related: *they took medication because they were ill, and when they took medication it was an indication of their illness.*

All informants said that in the beginning it had been difficult for them to accept medication; they had reservations regarding possible side-effects and influences on their personality. As time went by, most, however, felt more at ease about taking the medication. Several emphasised that the medication had helped them to avoid or reduce symptoms. Dennis and Frank, for example, explained that they, as a matter of principle, were against taking medication, but they thought that it was necessary for them, and they believed that they would feel worse if they stopped taking it. Per, too, said that medication kept him going. At the time of the first interview, Birgit expected that it could help her in many areas:

I think that I have quite big expectations of this medication, I think so. I have started to have it, but in the beginning I wouldn't touch any medication. I have always been that kind of person who was totally abstinent, for many years, you see. But I think that the medication will do so that... I believe what they [staff in OPUS] say, that it works, so we'll see. Well, maybe I should be a bit more realistic, but, if I could get out, in any case, among some other people and do something, and such, then it would be quite good. And then, if I could learn to think a bit positive, and be a bit happy about life, you see.

Birgit saw medication primarily as a means to feel better psychologically and to be able to engage in social activities. The medication became a symbol of hope (cf. Van Dongen 1998: 172).

Some informants expressed a view on medication similar to a formulation which came up in a focus group meeting with participants in 1999, where a young woman said that taking the psychoactive medication was like taking vitamin pills. Patients' notions of psychoactive medication as vitamins have been reported in other studies (Estroff *et al.* 1991: 345). As Per said in the fourth interview: 'The pills sustain the chemistry in my brain.' The idea that medicine correct a biochemical imbalance has not only been widely documented among psychiatric patients (e.g. Estroff 1981: 108); the view also reflects a more general idea of *chemical coping* in the Western industrialised societies and elsewhere. Regular use of medications – including 'chemical comforters' such as alcohol, coffee, and tobacco – are seen as necessary in order to 'improve one's emotional state and social relationships and help one to conform to societal norms' (Helman 2000: 141).

In OPUS, however, there was a strict separation between *acceptable* and *non-acceptable* drugs for chemical coping. During a meeting in a multiple-family group in 2000, one of the participants said that she, on some occasions, became very nervous, and it was discussed what to do about it. Another participant, who was receiving antabuse³⁴ treatment due to his drinking problem, suggested that she could take a little drink to calm her down. The suggestion resulted in laughter in the group, but one of the participating fathers asked if, maybe, it was a good idea. The team psychiatrist, who was one of the two group therapists, said that it might be a help, but that he 'as a psychiatrist' would recommend her to take some calming medication, to achieve a similar effect. The situation illustrates the difference between acceptable and non-acceptable medication prevailing in the professional culture of treatment staff. It is, however, also important to consider the therapeutic context of the professional advice: it might have been unwise in the group to recommend a (chemical) coping strategy, to deal with a problem of one participant, which at the same time constituted a significant problem for one of the other participants. This could possibly have been interpreted by him as a legitimization of his problematic 'self-medicating'³⁵ use of alcohol as a solution

³⁴ Antabuse treatment is a Danish medical invention which works by a chemical reaction in the body between alcohol and the antabuse drug which creates a poisonous substance making the person feel ill. The treatment is widely used in Denmark even if a high intake of alcohol, in combination with the antabuse drug, can lead to death.

³⁵ In psychiatry the notion of self-medication is used widely to identify mental patients' use of street drugs to reduce their psychological problems or 'symptoms'. Thoits (1985: 240ff.) has suggested a useful

to his general anxiety, and thereby counteracted the therapeutic attempt to help him overcome his drinking problem.

Other chemical comforters were *not recognised* as drugs in OPUS, especially coffee, tea, and tobacco. The discussion of whether to consider coffee as a drug came up early in the establishment of OPUS when staff met to rehearse the treatment manual for the therapeutic intervention in the psychoeducational multiple-family groups (McFarlane *et al.* 1991). In the American manual, it was recommended that only caffeine-free coffee should be served, to avoid the exaltation of emotions, which is a well known effect of caffeine. In the discussion among OPUS staff, it was, however, decided that this recommendation was specific to puritanist values in American culture. In Denmark, where 'everybody is galvanised inside from caffeine and nicotine,' as one member of staff expressed it, it would not go down well to serve caffeine-free coffee. It would be considered inhospitable, and even rude by suggesting a paternalistic attitude of the staff towards the participants and their relatives. It was commented by a psychiatric nurse that the habituation to these stimulants was particularly true of those who had been patients in a psychiatric ward, where the social activities were organised around coffee and cigarettes. This analysis was confirmed when one of the participants in a multiple-family group meeting explained that he had taken up smoking in order to socialise more easily in the social club for young people with mental health problems, by sharing the activity of smoking. The vices of smoking were then discussed: the smell it caused, the danger to health it posed, and the bad effects it had on personal finances. However, the mental effects of the intake of nicotine were not mentioned, even although its calming effects might make it easier to socialise.

Informants' attitudes towards taking prescribed psychoactive medication were not only directly related to their views on whether they were ill or not, but also to whether they expected to get well in the near future. Those who perceived their problems as permanent, and saw themselves as suffering from a mental illness, described medication as a necessary substance to correct the chemical imbalance in their brains and prevent them from getting ill by experiencing a relapse. The medication facilitated a sense of control, which increased their general well-being (cf. Lorencz 1992: 295). In this way they accepted *essentially* 'being ill', due to a chemical

sociological conceptualisation of this behaviour as overuse or misuse of one of several types of emotion

imbalance, but the medication could prevent them from 'getting ill' in an *experiential* sense by keeping symptoms away and preventing outbreaks of psychosis. As Per explained during our first interview, when I asked him if he was satisfied with the medicine he received:

Per: Yes, I cannot do without my medicine. It is probably something I have to take the rest of my life. And that's... that is just the way it is.

JAL: How do you feel about that?

Per: You see, there is nothing to do about it, as long as I get well again. I can live with it. From what I can understand, then it is going to be two pills in the evening before I go to bed. I should not worry about it. In fact, I don't dare to stop it.

In contrast, those who believed that their problems resulted from an isolated incidence of acute psychosis which they would soon get over, saw the medication as an unwelcome, but temporary and necessary intrusion into their normal states. They wanted, as soon as possible, to stop taking the medication because it would also be a sign that they were no longer ill. Kristina, thus, described the medication she took as a 'maintenance dose' (*vedligeholdelsesdosis*) to prevent her from experiencing a relapse. As Irene explained during the first interview, when we discussed the help she was receiving from her case manager:

I feel very confident about her [my case manager]. Sometimes I try to pressure her a bit to let me take a smaller dose [of the prescribed type of medication], but I only do that because I prefer to be 'not-ill', and the pills are also saying that as long as I take pills, then I am still ill.

When I interviewed Irene the second time, more than half a year later, she had recently experienced a relapse, as she became manic two weeks after having stopped taking medication. With the relapse, her diagnosis had been changed from 'acute psychosis' to 'bipolar disorder', or manic depression (as known in previous diagnostic systems). At first, the prospect had been that she should take medication for about a year; after the relapse, it had been decided that she should keep on taking the medication for two years. Irene started to change her perception of taking medication. When I confronted her with what she had said in the first interview, she responded:

management techniques.

Maybe I am contradicting myself a bit, but I... You see, I still think that you take medicine because you are ill. And that means that I am not well, in my own eyes, before I have finished with the medication. But I have been told through [receiving] the diagnosis manic depression that I can risk having to undergo medical treatment again. And now I say 'risk', and that is again because I feel bad about being 'abnormal', in reality. You see, I would like to be my normal *Myself* again.

In the fourth interview, two years after she started in OPUS in late 1998, she still would like to stop taking the medication, even if it possibly first would be by the end of 2002:

Irene: It is still my hope, even if it is a ridiculous hope. In the way that I keep on thinking 'As long I take these pills I am ill,' you see. That is what all the time gets in the way. And, in reality, if I... if I just could function as I do today, then it really does not matter whether I have to take pills for three, four, or five years.

JAL: We have talked about this before, but you think a bit differently about this today, that taking these pills does not necessary mean that you are ill?

Irene: No. But I would like to know whether I would be... I mean, how the pills really work on me. Compared to how I felt before I got ill, you see. But, yes, what came first? You see. ...//... I remember that I said [in previous interviews] that to me this about taking pills is connected to being ill. And I was very, very strongly determined that I had to get over that. Now I try to say to myself: 'Relax, take it easy, don't get too focused on that,' because, in fact, it is... the pills I take now, they should not be changing... you see, they are not dangerous, they don't damage any functions of the body. You see, I have heard about other pills which are really hard on the body, but these are not.

Irene gradually modified her view on taking medication. At the start, she simply saw medication as a sign of illness, and abnormality, and since she did not consider herself as such, she wanted, as soon as possible, to stop taking medication. After her relapse, and a new psychiatric diagnosis, she struggled to come to terms with a new self-understanding: that she *essentially* was 'abnormal' and needed medication. First of all, this meant that the time perspective changed. She still hoped that she would regain her 'normal *Myself*', but instead of expecting this to happen in the immediate future the perspective was now more indefinite, possibly several years. Another thing that happened was that she then emphasised the difference between various types of medication, and the symbolic meaning this had for her. By classifying some medication as 'not dangerous', compared to 'dangerous', concerning the effect they had on body

organs, it became more acceptable to her to take the first type of medication, even if it would have to be for several years. By emphasising the way medication helped her 'to function', rather than emphasising the symbolic meaning of taking medication, Irene changed her overall perspective. As with other informants, she came to acknowledge her need to take medication in order to be normal, in the *experiential* sense of 'not getting ill'.

Informants were generally happy to let staff in OPUS take the responsibility for determining the type and dose of the medication. At the time of the second interview, Eva was, therefore, dissatisfied when she had to wait for over a month to get to see the team psychiatrist to discuss the possibility of adjusting the medication. In this situation, she felt that the responsibility of OPUS was not fully met.

You accept that you need to take this medicine, and things like that. But then it is important that there is control over things, and that the development is followed.

The psychiatrist in one of the teams, however, intended that the participants in OPUS, throughout their contact, should familiarise themselves with medication and, to a certain extent, 'become their own doctors.' The psychiatrist was Per's case manager and in the fourth interview, he told me that he, to a large extent, was regulating his medication himself. If he felt particularly anxious, he could take a higher dose of a certain type of medication, and when things were going well, he could try gradually to reduce the dose. Regularly, he consulted these manoeuvres with his case manager, who warned him if he, for example, was approaching a dangerously high dose of a certain medicine.

Of all the informants it was only Per who described such a level of freedom and competence in regulating his medication. Informants could also actively influence their medication by activities outside OPUS. In the fourth interview, Birgit stressed the positive influences of the homeopathic treatment she had received privately. In the fifth interview with Per, when he had left OPUS and was receiving treatment from the community mental health centre, he told me that regrettably he was no longer allowed to regulate the medication himself; his new psychiatrist did not agree with this level of freedom.

Drug effects and engagement in life

The primary effects of the medication, when any were reported, were weakened or diminished sensations, feelings, and thoughts. My informants said that the medication took their hallucinations away and that they felt apathetic, unmotivated, and tired, and several said that they ‘became brain dead’ and ‘felt like a vegetable.’ Frank described the effect of the medication when he first was admitted to the psychiatric ward:

When I started to get medication, I, kind of, became... it was almost as if I got a blow to my head, I could hardly say anything.

As described in Chapter Five, many informants reported similar experiences when they started to take medication. To many it was also an indication that the right dose, or type, of medication had not yet been found for them. Some informants experienced the process of finding the right medication rather uncomplicated, and they were satisfied with the regular adjustments. For others, the process was complicated and long-winded. In his account for the book project, Per described how, in the seven months he spent in the psychiatric ward, the psychiatrists changed the type of medication five or six times, but none of them had the requested effect. It took one and a half years before a combination of drugs was found to help Per more or less satisfactorily. In the third interview, I asked my informants if they thought that medication was a help:

Eva: Yes, that makes all the difference, because then you are not psychotic. You can receive treatment, you can be together with your friends, you can read, and things like that. It makes it possible for you to have a life, at all, in the most fundamental sense.

Per: Yes, if you consider how I felt [before], and compare to how I feel now, then it helps in many areas. All the areas where you are normal... or normal, it sounds so extreme, where you function.

JAL: You feel that you become more normal by taking the medicine?

Per: Yes, definitely. You see, when I watch television I don't think that the television is talking to me, and when I talk to people then I don't think that it is some message they say to do me evil, or talk [badly] about me.

Birgit, Claus, Dennis, Namira, and Per stressed that the medicine reduced their angst when together with other people. Dennis said that he used to be very nervous and

bite his nails all the time, but that he was now more open socially and that it was not so difficult to get in contact with other people. Like Per, he thought that he, without medication, would isolate himself. For them, psychological well-being and ability to function socially was interrelated. This finding challenges Lorencz's (1992: 275ff.) observation that for psychiatric patients 'becoming ordinary' merely meant functional normalcy and not psychological well-being. The difference might, however, be due to Per's and Dennis' more progressed states of recovery, compared to Lorencz's informants, who were described as 'chronic schizophrenics' (1992: 260).

Some informants stressed that the medication made them have a brighter outlook on life, compared to the feelings of depression they suffered from preceding their psychosis and inclusion in OPUS. The negative side was that good feelings were also weakened:

Martin: It is, kind of, a problem that it [the medicine] cuts a bit of the top and the bottom of your emotions. I don't really know, of cause I don't get sad, but neither am I really in a good mood. It is a bit of a problem.

Per agreed that the medication diminished his 'healthy thoughts', and he felt that, in general, he had become more slow in his thinking. Eva, too, said that her thinking was affected and that she, for example, had forgotten many words in English, which she used to speak fluently, so that it now took her much longer to read English language texts for her studies. Even so, my informants generally thought that it was necessary for them to take the medicine.

Per: It [the medicine] helps me to feel better, you see. And think and experience as normal people.

Some participants in OPUS found it difficult to assess the effect of the medication. This became clear in surveys I conducted among the participants in 1999 and 2000. They were asked to assess the degree to which the medication had helped them on a five point scale from 'not at all' to 'very much'. In the questionnaires some respondents commented that they were not able to give a reply to the question, since they did not know whether the absence of psychotic symptoms was a result of the

medicine (Larsen 2001a: 175ff.; Larsen and Feldman 1999: 17). Some of my informants expressed similar views. I asked Eva if the medicine affected her:

I don't think so. But it does anyway, because when I recently had the dose reduced, then I suddenly had a lot of emotions. Whereas I [used to] have an even sensation, you see. So, in fact, it does affect your personality, I think that this is to affect your personality. If you suddenly get a lot of negative thoughts and emotions you never used to have, and it is because of the medication you didn't use to have them. So I think you can say that it does affect you to take the medication.

Similarly, Kristina said, in the third interview, that she had only experienced the effect of the medicine indirectly, when she recently had her dose of medication reduced. She started feeling 'indefinably bad', but after her case manager had seen to increasing the dose, this feeling disappeared. Frank said, in the third interview, that the medicine made him 'more myself', and most other informants reported that the medicine 'did not affect them,' in other words, when taking the medicine they felt 'normal' and 'themselves'.

Anders found it difficult to assess whether or not the medicine affected him, not because he did not know how he would feel without the medication, but because he did not know what to compare it to. For a long period before his contact with OPUS he felt emotionally unstable and he had been smoking cannabis daily, so he was not sure what was normal for him. Claus expressed a variant of this understanding when, in the third interview, I asked him whether he felt that the medicine made him feel and experience things differently. He told me that he did not know what to compare it to, since he could not imagine how he would feel without the medication. For him, 'chemical coping' had come to encompass his whole sense of self, not just restricted to isolated situations such as the morning coffee 'in order to wake up,' alcohol 'to have a good time,' tobacco to relax, the occasional sleeping pill or pain killer, or Ecstasy when clubbing. Claus had developed a new sense of *medication-sustained normality*. The rapid changes in the informants' notions of the meaning of their use of medicine shows just how flexible their notions of 'normality' were in this respect. Recent research in social pharmacology indicates that this is a more widespread phenomenon. In Denmark, and other Western societies, drugs are increasingly used to achieve a desired level of competence and enhance normal performances (Møldrup 2000; Møldrup *et al.* in press).

While Claus and others felt that medication helped them to achieve 'normality', some informants were concerned that the medication might affect their 'non-medicated normality'. Irene explained, in the third interview, that she used to be afraid that the medicine would change her personality:

Irene: I think that it is connected to a basic fear of medicine, and this tendency to make you ill (*sygelliggørelse*) that you experience when you are being told that you have to take some medicine in order not to become crazy in your head. Therefore, all along [I thought that] the only right thing for me was to become free of medicine, because else I would not be myself. And now I really try to work on myself with this.

JAL: You mean, to change this perception?

Irene: Yes, precisely. Because I can see, whether it is a placebo or not, I can see that 'Yes, but I can easily function.' And I can think my thoughts, and I can, almost, do what the hell I want to, with this new medicine, you see. I am far more myself, I am far more free, I am far more... Yes, myself, really. ...//... I used to think about the medicine that it could change my personality and now I realise that, in fact, it does not change my personality. And that gives a freedom, I know that it does not sound straightforward logical, but it gives a freedom suddenly to experience that it not as bad as I used to think.

Even so, in the following interview, Irene said that she was not completely assured about the effect of the medication on her, and she speculated what had caused the changes she had experienced in herself:

Irene: I have this problem with taking the pills: 'Will they anyway affect my personality?'. You see, I think that I somehow... that I am different compared to how I was before, two years ago.

JAL: That the pills make you different, or what?

Irene: That is exactly what I don't really know, I don't know which unknown factor is at play. If it is me... is it really me who has changed that radically, or is it the pills, or is it... yes, what could it else be? Or is it simply the illness. Is it?...

When the right type and dose of medication was found, informants experienced that they got more energy, both because, due to the individual adjustment, they no longer suffered from the side-effects of medication, making them apathetic and tired, and feeling emotionally numbed, but also because the medication removed or decreased psychotic symptoms of hallucinations and delusions. In this way, informants generally

expressed the notion of medication-sustained normality, whether it was directly or indirectly.

In the fourth interview, Birgit explained how the medication had reduced her delusions which used to 'take a lot of energy' in her head. It had also helped her to sleep, and both these effects meant that she had more energy to do things during the day. She said that she now felt quite restless and that she no longer could stand doing nothing for long. She felt that this was positive, since it motivated her to be more active and go out and meet people. Lotte, too, explained how she felt empty and restless when her inner voices disappeared. In the beginning, she was happy that the medication, finally, had given her peace in her head, but after some months she felt that it was 'totally empty'. Instead of using the feelings of emptiness and restlessness constructively to engage in social activities, Lotte increasingly felt lonely, and she began to miss the companionship of the voices.

In the last interviews, several informants stressed the importance of having been able to fill in the time and expend their increased levels of energy on meaningful activities during this phase of recovery. Whether it was a successful holiday, getting back together with friends, a good start in the studying, achievements at work, or a better relationship with relatives, informants stressed that the medicine did not do it all alone. Lotte did not have such activities, or positive achievements; neither had she had the opportunity to talk to a psychologist about the problems in her personal history that she, in the same period, had started to speculate about.

It has already been mentioned that informants reported having experienced psychological side-effects such as apathy and tiredness, and many felt 'dead' or 'stoned'. In his account for the book project, Per described that, during his time at the psychiatric ward, he suffered from various somatic side-effects such as blurred vision, and involuntary movements of his legs and mouth. With continuous medical treatment, side-effects can become permanent. Per did not notice these himself, since he, at the time, was preoccupied by his psychotic delusions. But, fortunately, a nurse at the ward noticed it and the medication was adjusted. In the fourth interview, Per told me that he was taking a combination of very strong medications which could be dangerous, especially in combination with alcohol, and that he had to go for medical checks regularly. Dennis described how one drug had the very unpleasant side-effect of making

him salivate, and that it had been so bad that his pillow was completely wet in the morning. After having changed to a new drug, it stopped, but he then experienced restlessness in his legs. This side-effect faded over time, but once, it was so bad that he could not fall asleep at night and had to walk around.

Several informants experienced an increase in weight as a side-effect. Frank told me that in the beginning, it disturbed him a lot that he became fat, but that he learned later that this was because the medicine took away the feeling of being full, so he would keep on eating. Frank learned to keep his weight down by paying attention to the amount he ate, and not relying on the sensation of being full, which used to guide him.

It has also been mentioned that some male participants in OPUS experienced impotence as a side-effect. Similarly, Kristina was particularly annoyed that the medication influenced her menstruation cycle, and her sexuality. Lotte felt amputated by having lost her sex drive.

Lotte: In the year I took Risperdal I didn't want to have sex, at all. And I think that that is very weird, totally weird. Therefore I stopped.

JAL: Yes, simply to experience this dimension?

Lotte: Yes, God damn it, I don't want to feel completely weird. One thing is that I have become weird, another is that it becomes more and more. First the head, then a leg, then an arm. You see. Then it is not worth it.

She already felt weird by hearing voices, and then amputated when they disappeared. When the medicine also took away her sexuality, she lost more of herself and decided that she would be better off by stopping taking the medication. Because of his increase in weight, Frank had also stopped taking the medication, and he first started taking it again when he was readmitted to a psychiatric ward after he had experienced a relapse. Lotte told me, in the third interview, that she had decided to try to take a new medication, which staff in OPUS had said would possibly make her voices disappear without taking away her sexuality.

As Eva explained in the fourth interview, the question of effects and side-effects of medication not only concerns the primary or, derived, secondary mental and somatic effects (i.e. feeling restless or getting fat), but the quality of life in general.

The thing about weighing side-effect and effect up against each other, is very important, I think. You can expand the notion a bit, you see, so you not only say that a side-effect is tiredness. But, also, that a side-effect is that your quality of life is reduced, because you are not able to go so much out, because you have to sleep a lot. Somehow that is also a side-effect, you see. And an effect [of the medicine] is not only that you wake up, [or] that you are not psychotic, an effect is also that you can read [because of that].

With effects and side-effects, the medication can both limit and facilitate things you are able to do in your life. Eva stressed that it was imperative for her to keep on taking the lower dose of medication, even if the team psychiatrist recently had recommended that she should increase it. Eva knew, from experience, that the higher dose affected her memory and her ability to concentrate, and the increased dose would mean that she would go back to only being able to read three pages per hour compared to the six or seven she was able to manage now. And this would have the result that she could not keep up with the reading for her courses, and eventually would drop out of her studies.

Getting back to being well and engaging in ‘normal life’ was thus crucially influenced by medication. In most cases, informants reported that the medicine helped them to control the illness by keeping psychotic symptoms down or totally away, while many also found comfort in the assurance that a ‘maintenance dose’ could help preventing a relapse. At the same time, the informants described how the management of medication should aim not only to prevent certain unwanted mental experiences, but also to facilitate thought activity and the energy to engage in activities. For most informants, the medicine had these desired effects, and they were supported by other initiatives in OPUS as well in their social environment, to take up former or new engagements. In Lotte’s case, the medication took away her psychotic experiences, but at the same time she felt amputated because of the side-effect of losing her sexuality and she was not provided with either psychological or social engagements which could stimulate and fulfil her satisfactorily. In this situation, the psychotic experiences provided an alluring refuge to return to. In his account for the book project Anders also described how it was tempting to return to rich and full sensations during the psychosis – especially in the period when he was strongly sedated by the antipsychotic medication.

The individual's role in treatment

In OPUS, the participant, as individual, was the focus of the intervention. This was a consequence of the overall approach, stressing treatment in the community, that is to say, individually adjusted support and treatment to each participant in the context of their personal environments, by considering their needs and requirements.

The role of the individual as a recipient of this intervention was varyingly identified as 'patient' or 'participant'. Generally, the informants for this study preferred to be called and perceived of as participants, since for them this indicated a distance from the position as in-patient in a hospital, and a positive development in the direction of an independent status where they were considered as equal with anyone else. The word 'patient', on the other hand, invoked in informants notions of being in an unstable and transitory situation, subordinated to and controlled by the treatment staff.

The individual case managers provided regular contact and facilitated treatment and support for the participants living in the community. Participants found security in the frequent meetings, and the monitoring of the progress in their recovery. Apart from helping to sort out practical and concrete matters in everyday life, the case manager, furthermore, gave education in mental illness and helped the participants to a better understanding of their individual symptoms and 'warning signs' of psychotic relapse. Some informants were satisfied with the opportunity to talk to their case manager about experiences that troubled them, for example experiences they had when they were psychotic or when they were in the psychiatric ward. Others were not satisfied with the counselling thus provided, especially when issues concerned unpleasant experiences in their childhood or youth. They requested to see a psychologist.

Unlike the situation in psychiatric wards, the participant's role in OPUS was not determined and formally regulated within a spatially restrained institutional context. Therefore the contact with the case manager constituted the most influential and visible social manifestation of the social role of participants. Informants and staff alike generally perceived of the relationship as a professional friendship: personal in character, but based on a contractual relationship and with a purposeful interaction agreed upon. As such, the relationship was basically unequal and 'one-way': the participants talked about their personal problems and private secrets, while the case

manager provided support and guidance based on empathy and professional advice. Initially, participants had to get accustomed to sharing their private life with the professional. To some, this constituted an unsurpassable barrier, while, for others, it became a genuine support to be able to share their difficult emotions and thoughts.

Medication was considered crucial for the individual support and treatment provided in OPUS, and it was integrated into the social and cultural organisation of the project. First of all, it was seen to prevent psychotic relapse and to ensure a continuous progress, during which the participant, increasingly, would be able to take control of an autonomous life, without, or with a minimum of, the hindrance created by symptoms of mental illness. Participants were ambivalent regarding the effects and consequences of taking medication, but they generally took it because they considered it necessary. Medicine was seen to control the illness, but it also symbolically represented the illness. Some participants were eager to stop taking the medication, as soon as possible, since it represented an abnormal state of their being. Others accepted that they had to take medication because, essentially, they accepted being mentally ill and had adjusted their sense of medically sustained normality: they thought that they needed the medicine to maintain the biochemical balance in their brains.

The antipsychotic medication could create a feeling of emptiness and lifelessness, which, for some, became a motivation to be more active and find new directions in life. For a few, the same feeling took a more depressive shape, and, encouraged by unpleasant side-effects such as the eradication of sexual sensations, it made some informants consider giving up the pills and return to the lively state of mind experienced during the psychosis. Their craving for a fuller life experience was partly met in OPUS by the efforts made for them to engage in activities and social relations, to be described in the next chapter.

Chapter Seven

The social and cultural context of recovery

This chapter examines processes of recovery for the participants in OPUS in their social and cultural contexts. Treating ‘the whole person’ not only meant providing supervision of the illness and medication, offering personal, practical and therapeutic support, and helping participants to engage in activities in society, as outlined in the previous chapter, it also meant the inclusion of the social network as support for each individual and it meant therapeutic intervention to help participants develop social competencies.

The interventions of OPUS in this field are discussed as part of the life situation of the individual, and perceived within an analytic framework of practices of symbolic healing. Further, there is a wider social and cultural context to be accounted for: features of the Danish welfare policy are presented and discussed as crucial structural facilitators of this type of community intervention. But first, I will introduce the relevance of the social and cultural perspectives by discussing symbolic aspects of the transition process for the individual from being ill towards getting well.

Recovery and symbolic healing

Recovery is a ‘buzzword’ in contemporary therapeutic literature on mental illness. A review of the literature proves a lack of clarity of the term (Mountain 1998: 13ff.), but generally it describes a state of the former, or present, psychiatric patient which is characterised by a *well-functioning social life* (Topor *et al.* 1998: 3). Sometimes, the distinction is made between ‘total recovery’, defined as a total absence of any symptoms of mental illness, and ‘social recovery’, defined as the occasional presence of positive symptoms, such as hearing voices and paranoid delusions (Topor *et al.* 1998; Warner 1985). The concept of recovery carries significant symbolic meaning by explicating that it is possible to live a good life with a diagnosis of schizophrenia, thus contradicting the common sense, culturally-infused notion which constitutes the historical origin of the diagnosis (Barrett 1996: Chapter 7), as discussed in Chapter One.

The focus on recovery repudiates the historical models depicting individuals with schizophrenia as passive and helpless victims of an incurable and deteriorating disease by, alternatively, presenting the individual as an active and responsible agent (Mountain 1998: 18). This perspective finds support in empirical evidence. Topor and colleagues (1998: 1) mention results from several independent longitudinal studies, which demonstrated that between 46 per cent and 68 per cent of all patients diagnosed with schizophrenia achieved either total or social recovery. Harding found that: 'In fact, these studies and others have shown that the course of severe psychotic disorder is a complex, dynamic, and heterogeneous process which is non-linear in its patterns moving towards significant improvement over time and helped along by an active, developing person in interaction with his or her environment' (Harding 1986: 199, cited in Mountain 1998: 14). Based on in-depth interviews with people with a history of schizophrenic illness, Mountain (1998) recently developed a theoretical model of recovery, presenting it as a process of personal *transformation*. The model describes how the individuals went through four main phases: 1) battling or coming to terms with the symptoms, 2) connecting to and engaging in supportive social relationships, 3) being personally determined to recover, and 4) committing to a continuous, life-long recovery work (*ibid.*: 75-102).

This and similar theoretical conceptualisations of the process of recovery (Davidson and Strauss 1992; Topor *et al.* 1998) are characterised by a *psychological focus*. While explaining individual sensations and motivations, the approach does not adequately, if at all, account for the cultural context and social positioning of the individual, thus making no specific reference to the influence of directed attempts to intervene from the surrounding society. One consequence of this is that the recovery process is depicted wrongly as an isolated individual struggle, paraphrasing cultural values in the West of the autonomous and self-motivated individual (cf. Barrett 1996: Chapter 7; Corin 1990: 183).

As an alternative, I present an anthropological perspective on recovery by highlighting individual experiences in the specific social and cultural context of the therapeutic process in OPUS. The perspective supports the notion of personal transformation, and it reflects the standpoint that health is not only achieved due to the physiological effects of biomedical or surgical interventions. The individual process of

regaining health is also conditioned by the way a person *feels* and *thinks* about his or her illness, as well as by the specific cultural understandings and social situations which influence these feelings and thoughts. The significance of these psychological processes is evident from the *placebo* effect, which can account for an average of one third of the improvement in patients' illness conditions following drug therapy (Helman 2000: 139; Kleinman 1988a: 112). The anthropologists Arthur Kleinman (1988a: 112) and Cecil Helman (2000: 137-9) argue that instead of viewing placebo as an unwanted disturbance of 'real effects', as the medical perspective widely suggests, it should be embraced in an effort to cure patients by being acknowledged as part of the 'total effect' of the therapeutic intervention. The biomedical understanding of healing is limited by its perception and treatment of the body as a passive 'terrain of medical practice' (Lyon and Barbalet 1994: 52-3). In this light, Kleinman has suggested a reconfiguration of placebo as 'the activation through the process of interpersonal communication of a powerful endogenous therapeutic system that is part of the psychophysiology of all individuals and the sociophysiology of relationships' (1988a: 112).

This definition describes the placebo effect as it works for the individual, on a psychological and physical level, but through social encounters and communication. The concept of *symbolic healing* designates the general concern within anthropology to illuminate the way social aspects of interpersonal interaction and cultural aspects of meaning and understanding act together to influence processes of recovery from illness. Helman defines symbolic healing as: 'healing that does not rely on any physical or pharmacological treatments for its efficacy, but rather on language, ritual and the manipulation of powerful cultural symbols' (2000: 191). With this concept, anthropologists have attempted to synthesise basic themes and structures in the process of these types of healing in diverse cultural settings, whether based on traditional religious healing or 'talk therapy' common in the West (e.g. Dow 1986; Helman 2000: 191-6; Kleinman 1988a: 108-41). Following Helman (2000: 191ff.), symbolic healing includes six elements:

1. The healer has a coherent system of explanation, or frame of reference, for the origin and nature of the problem, and how it can be dealt with. It can, for

example, be a mythical world of a religious cosmology, a folk tradition, a theory of personality, or a scientific model of the body.

2. This system of explanation provides the suffering individual (the 'patient') with an understanding of his or her own situation and its resolution in terms of imagery and symbols which are part of the system. Kleinman (1988a: 131ff.) calls this a symbolic bridge between personal experience, social relations, and cultural meanings. The symbols thus evoked are generally deeply rooted in the cultural experience and the way individuals orient themselves in the social and supernatural world.
3. The healer activates this symbolic bridge by convincing the suffering individual that his or her problems can be understood within the particular system of explanation. In order to convince the individual that the suffering can thus be 'renamed', the healer may use many different theatrical or rhetorical techniques.
4. When this consensus is reached, the healer needs to get the suffering individual emotionally and intellectually attached to the symbols, by experiencing them as relating personally to his or her situation, for example, by persuading them that the suffering is caused by possession by an angry evil spirit. In this way, the individual is also linked to the wider social, cultural, and cosmological concerns to which the symbols are connected.
5. The process of therapeutic change is then led by the healer, by manipulating the symbols of the system of explanation to achieve a transformation of experience. The suffering individual learns to re-evaluate or 'reframe' past and present experiences. A successful transformation not only affects the emotional state of the individual, but also their physiology, their relationships with other people and their relationship to the culture at large.
6. The 'healed' individual acquires a new way of conceptualising his or her experiences in symbolic terms, and a new way of functioning. The process produces a new individual narrative of the personal past and present, and the likely future. The narrative summarises what happened to the individual, and how the healer was able to restore him or her to happiness and health.

These universal features of symbolic healing have been outlined within the last couple of decades, but their general properties can be found also in earlier anthropological discussions of ritual healing.

In his paper on 'The Effectiveness of Symbols', the French anthropologist Claude Lévi-Strauss (1963: 186-205) described the healing properties of a South American shamanistic cure to facilitate difficult childbirth, and in the analysis he compared it with the therapeutic efficacy of psychoanalysis as it is practiced in the Western world. Lévi-Strauss showed that psychoanalysis could be seen as a form of 'shamanistic cure' – or symbolic healing. They shared similar structural properties, but one difference in content was that 'in one case [psychoanalysis], the patient constructs an individual myth with elements drawn from his past; in the other case [shamanistic cure], the patient receives from the outside a social myth which does not correspond to a former personal state' (1963: 199). He argued that psychoanalysis developed its special characteristics 'from the fact that in industrial civilisation there is no longer any room for mythical time, except within man himself' (*ibid.*: 204).

Both the universal features of symbolic healing and the themes and analytic perspectives presented in Lévi-Strauss' discussion prove useful when describing and seeking to understand the symbolic efficacy of the therapeutic interventions in OPUS. In 1988 Arthur Kleinman discussed the development of psychiatry in North America, where the use of psychotherapy as an alternative or supplement to drug treatment traditionally is a considerably more established component of psychiatric care, compared to Europe and non-Western societies (Kleinman 1988a: 110). He described the transformation of the psychiatric profession, towards becoming 'a version of high-technology medicine' (*ibid.*: 140). Kleinman criticised the increasing focus on clinical diagnosis and pathology and the narrow use of biological techniques. Instead, he pleaded for a developing awareness of the powers of techniques of symbolic healing, and a focus on the biography of the individual patient and the social context of the illness experience (*ibid.*: 139-41; 1988b). He observed that '[b]iomedicine is the major system of healing in the West. Yet it has little to do with what is most central to most healing systems, symbolic healing' (1988a: 140). However, a few sentences below he continues: 'Whatever the doctor thinks she is doing (being scientific or providing the most up-to-date technology), she is nonetheless involved in a powerful set of

psychological transactions with her patient. Her only choice is whether to recognise and maximise her 'psychotherapy' or be inattentive to it' (*ibid.*).

Kleinman observed that the dimension of symbolic healing was not a *recognised* part of the healing process for doctors using a strictly biomedical approach to treatment, even if, in fact, it was unavoidably present. To maximise the potency and constructive use of the symbolic aspects, he argued that the medical profession should direct attention to it and be trained to apply it. If not, he feared that 'over the next century in North America, [symbolic healing] will wither away in the profession of medicine, to be practiced only in the folk and popular arenas of health care' (*ibid.*: 140-41). Even though Kleinman recognised the symbolic aspects of biomedical treatment, his attention remained focused on the qualities of symbolic healing when employed through psychotherapeutic approaches. He did not fully anticipate the way in which biomedical reasoning and theory would come to constitute a shared and accepted set of symbols and systems of in their own right – a cultural language, or social myth, which can be referred to and manipulated in the process of symbolic healing. Interestingly, Lévi-Strauss noted that this had, however, been anticipated several decades earlier by Freud, who, on two different occasions, suggested 'that the description in psychological terms of the structure of psychoses and neuroses must one day be replaced by physiological, or even biochemical, concepts' (Lévi-Strauss 1963: 201).

In the OPUS project it seems that the social myth has returned to civilisation. Biomedical explanations and theories enjoy widespread currency in Danish society, represented as 'science' and 'objective truth'. As such, they function as a social myth in the process of symbolic healing: they provide a narrative which can explain phenomena and advice people how to deal with difficult life circumstances. By treating biomedical explanations and theories as a social myth I do not intend to imply that these explanations are not true: I am simply emphasising their *symbolic qualities* and demonstrating that, *as such*, they have therapeutic value within OPUS.

It has recently been argued (Csordas 1994a; Hollan 2001: 60ff.) that in order to understand the effects and the workings of symbolic healing, it is not sufficient to examine the ritual events and the activities of the healer. Instead, focus has to be directed towards the experiences of the individual undertaking the healing process. Kleinman (1980: 226-7) has supported this view by pointing out that it cannot be taken

for granted that individuals participating in healing rituals share the meanings of the symbols. The specific cultural symbols' therapeutic significance to the individual have therefore to be demonstrated – '*effective* meaning in healing rituals needs to be strictly distinguished from *potential* meaning' (*ibid.*: 226, italics in original).

Further, it is not enough to focus attention on the spatial and temporal context of the ritual. The symbolic transformation 'is not usually instantaneous, global, and definitive in nature, but rather gradual, partial, and incremental, and cannot be understood apart from the patient's or supplicant's life experience that both proceeds and then overflows the event or ritual of healing itself' (Hollan 2001: 61). Therefore, the process of healing has to be understood from the perspective of the individual in his or her daily life, to examine how the imaginative and self-transformative processes remain active in the mind and in the experience of the individual after the healing event is concluded (Csordas 1994a).

In accordance with this recommendation, and in line with the person-centred ethnographic approach of this study, I will therefore present the experiences of the participants at a time when they were part of a wider social and cultural context and engaged in therapeutic work in OPUS. The perspective of symbolic healing remains a recurrent theme in the presentation.

Family groups: Support from the social network

In the first interviews, I asked informants how people in their social network had reacted to their inclusion in OPUS. As described in Chapter Five, those who had not been admitted to a psychiatric hospital were very concerned about whether or not to tell anyone anything about their problems, while this was not an option for the others. But still, to many it cost a great deal of effort to let anyone know in more detail about their problems. Many said that they were ashamed of their problems, and that they had, over some time prior to OPUS, gone to great lengths to try to avoid anyone discovering that they had problems. Claus described how, in the beginning, he did not want his parents to know in detail about his difficult thoughts and feelings, but eventually he made an agreement with a doctor at the psychiatric ward that she could tell them about some of it. By using the doctor as an intermediary, and by making a kind of contract with her, defining what she could and could not tell his parents, Claus found that his parents came

to understand him better. They became acquainted with the inner world he had been living in. Similarly, Martin related that it had been a relief for him to say that he was having problems and was seeking help in OPUS to overcome them. Previously, he had constantly been 'on guard' when he was together with his family, careful not to reveal that he had problems. Now he could relax and be himself when they were together.

Most informants said that they had support from their social network, often close relatives. Frank said that his parents were happy and supportive that he was participating in OPUS, but he had not talked in detail with any of his relatives about his psychotic experiences. Frank felt that he had been 'spared' his relatives asking him questions, and he preferred not to think about the experiences since it made him feel bad. Among the informants, Lotte stood out as having a particularly weak social network. She did not talk very much at all with any of her relatives, and during the time when she was psychotic, she had virtually lost all her friends, as described in Chapter Four. The meetings with her case manager provided her only opportunity to share her thoughts with another person. I asked her if she felt that anyone supported her:

Lotte: How should... how can people support me? What do you expect... how would you support me, if it was you?

JAL: No, I don't know. The question is whether you...

Lotte: No, exactly! Your yourself... you have the answer yourself: You don't know! The same answer as everybody else.

JAL: Eh... so you can't really say whether they have supported you, or, you can't really...?

Lotte: N...

JAL: No. But you feel that you are very alone with the problem, or...?

Lotte: Yes, I guess I do... yes. I guess I do.

Birgit was also very isolated. She said that she could not tell her relatives about her problems and her participation in OPUS, since they would not believe that she had any serious problems. Birgit explained that in her family they did not talk about such things as psychological problems; it was considered taboo, and it was embarrassing to have problems such as these. Hence Birgit argued that if she was convinced that her psychotic experiences were not true, that is, that she really did not have them, then it would not be acceptable for her to receive treatment. The paradox arose from the fact that she was not certain about her experiences, and, more generally, that she felt ontologically insecure, as discussed in Chapter Five.

Per also mentioned the problem of lacking acceptance of his psychological problems in his social network. He said that in his social environment it was not allowed to show signs of weakness, and that, for some of his friends, it was unacceptable that he had these problems. I asked him what consequences this had for him:

Well, I have to find some new friends. I have to... I have told myself that I have to start afresh. With some of my old [friends] and find some new, and then rely a bit on the family also, in the beginning.

In OPUS, group therapeutic interventions were set up to support the participants in their social networks and to help the individuals in the social network to engage in supporting the participant. In the original design of the treatment in OPUS, two types of therapeutic groups supplemented the medical treatment and the individual support provided by the case manager: multiple-family groups and social skills training groups. Both interventions were based on principles of 'psychoeducation' and 'cognitive therapy', which, in international studies, have demonstrated effectiveness in improving the prognosis of persons with schizophrenic illnesses (for a review see Jeppesen 2001: 24-50). Apart from these formal therapeutic interventions, during the third year of the project another type of group was informally introduced into one of the two teams, under the name 'Friday Get-Together' (*fredagshygge*).

Not all participants took part in the groups. Three years after OPUS was started, in April 2001, when about a hundred people were active as participants, six multiple-family groups were active in OPUS and, apart from relatives, they consisted of thirty-two participants altogether (Larsen 2001a: 115). At the same time two social skills training groups, with eleven participants, were active (*ibid.*: 100). At any time it was usual that about six family groups and four social skills training groups were active in OPUS, divided between the two teams. This number could, however, vary depending on the times of start and finish of the individual groups. The multiple-family groups each lasted one and a half years and the social skills training groups lasted one year. On average, each participant stayed 27.5 months in OPUS (*ibid.*: 213). In accordance with these conditions of 'flow', the one-year follow-up medical research demonstrated that

57 per cent of the recipients participated in a multiple family group and 40 per cent participated in a social skills training group (Jeppesen 2001: 101).

Staff in OPUS worked to motivate the participants and their relatives, primarily the parents, for participation in a family group. But some participants, like Hans and Birgit, were determined that their relatives should not be involved in OPUS at all. Irene and Frank felt that they already had good support from their families, and, in the first interview, Irene said that she was not attracted by the idea of sitting together with other participants in OPUS and their families, to be part of a group feeling of mutual support. Others, like Lotte, had had a rather loose contact with, and poor support from, their parents, and the staff did not succeed in motivating either to enter a group. For Namira it was a problem that her mother did not speak Danish, and she said that her brother was too busy with his work (see Appendix A for an overview of my informants' participation).

Each OPUS team arranged regularly Saturday seminars, to which relatives of new participants were invited to come and hear about mental illnesses and the treatment and support offered in OPUS. The content was primarily *psychoeducational*: in a pedagogic way, staff presented biochemical explanations of psychosis with a focus on the 'dopamine hypothesis' (cf. Barrett 1996: 226-37) and statistics on prognosis and the distribution of schizophrenic illness in the population, supporting the view that vulnerability to schizophrenia is inherited. Originally, the one-day seminar was planned as an introduction to the 'psychoeducational multiple-family groups' (McFarlane *et al.* 1991; 1995), but it was soon decided that the seminar should be offered to all the relatives of participants in OPUS, whether they later decided to participate in a group or not. In some situations, close friends of participants participated together with the parents, siblings, and partners of participants. The staff explained that the reason participants themselves were not invited to the seminars was to make it possible for the relatives to talk more freely about their experiences and anxieties, and to be able to describe the illness in more detail (most participants had impaired cognitive functions when they started in OPUS: they found it difficult to concentrate and remember, either because of delusions and thought disturbances or as side-effects of antipsychotic medication). Later, it was, however, decided to regularly present a reduced version of

the information on aetiology, the course and the treatment of mental illness, in special seminars for all new participants too.

After each seminar for relatives, staff organised one or more multiple-family groups consisting of four to six 'families' (that is: a participant and the relative or relatives who were to accompany them in the group). Each group would run over eighteen months with meetings every fortnight, lasting for one and a half hours. The group meeting started at 5.30 p.m. so that it was possible to participate after normal working hours. General patterns emerged from the five meetings, of two different groups, one in each team, in which I participated. Both groups had five participants; some were there only with one relative, either a mother or a brother; others brought both their parents, or a parent and a sibling, and on one occasion a participant brought four relatives: mother, father, step-father, and step-brother. While parents or siblings were most commonly seen, one participant also once brought his grandmother, and in other groups sometimes friends had taken part as 'relatives'. In general, it was the same relative, or relatives, who each time accompanied the participant in the group.

Surveys among relatives in 1999 and 2000 revealed that they thought that OPUS generally had been a support and help for them in their relationship with the participant. On a five-point scale from 'not at all' to 'very much', 68 per cent of the 31 relatives who answered the questionnaires indicated one of the two most positive estimations in response (Larsen 2000a: 195). The surveys also showed that the relatives, generally, were happy to have the opportunity to participate in family groups in OPUS (*ibid.*: 205-7). Research has emphasised the positive importance of families' involvement in the treatment of persons with schizophrenia, both as a support for the person, but also as a way of avoiding negative psychological effects for the relatives themselves (Spencer *et al.* 2001: 138; Milliken 1998, cited in Mountain 1998: 32ff.).

Meetings in the family groups in OPUS were, in both teams, held in the physical space of the community mental health centres, where the medical half of the teams' staff had their offices. Suitable spaces were found in a general activity room and a conference room, respectively. Arriving at the meeting, everybody engaged in small talk, each participant keeping together with his or her relatives. In the general activity room, used by the Bispebjerg Team, there was an area with comfortable sofas, where the participants and their relatives waited, while having a cup of coffee or tea and some

snacks prepared by the two team members who were group leaders. At 5.30 p.m., or shortly after, once everybody had arrived, one of the group leaders would indicate that it was time to start. Participants and relatives were seated in an open circle of chairs. Some brought an extra cup of coffee which they kept on their lap or placed next to the chair. Participants and relatives were seated next to each other and, on one occasion, when one of the group leaders was seated so that the last 'family' to arrive would have had to be separated, the group leader moved her chair so that they could remain together.

In the Vesterbro Team, multiple-family groups were accommodated either in the large common office of the OPUS staff or in the conference room. Neither had a comfortable sitting area like the one used by the family groups in the Bispebjerg Team. During the meetings I took part in, in the conference room, the participants and their families sat around the large conference table, which could be adjusted in size by the group leaders 'to avoid sitting too far apart.' An open 'therapeutic circle' of chairs, as applied in the Bispebjerg Team and recommended in the manual (McFarlane *et al.* 1995), was not practiced in the Vesterbro Team, where coffee, tea, and snacks were put on the table and consumed whenever people wanted throughout the meeting. On one occasion, a group leader was seated so that a family who arrived late had to be spatially separated. The group leader commented on this but did not change chair, so the participant and his brother ended up sitting on either side of her.

Following the manual, the meeting was divided into a sequence of elements: 15 minutes for socialising; 20 minutes for 'the round', when participants and their relatives talked about what had happened since the last meeting: whether the participants had had, or caused, any problems; 5 minutes for the group leaders to choose a problem; 45 minutes for 'problem solving', when the chosen problem was further scrutinised by a group leader and ideas for its solution were put forward in collaboration and discussed; and 5 minutes for socialising before breaking up. This structure was followed in the groups in OPUS, while the time estimates were taken as guidelines.

In OPUS it became a general practice to describe the informal talk which should start the meeting as 'socialisation' (*socialisering*). This was due to an initial mistake in the translation of the American manual, which used the American-English word 'socializing'. But even though I commented on the error the mistake was not

corrected and the word continued to be used in the groups. It is tempting to attach a symbolic meaning to this error of translation, and the persistence with which it remained in the vocabulary of the staff. The concept reflected the *psycho-educational* content of the meetings, as staff were teaching participants and users to perceive the participants' problems as an indication of illness and, furthermore, by presenting a model of therapeutic talking, *socialise* them into a different way of social interaction and conflict solving. As part of the therapeutic process in the symbolic healing, the participants and their relatives were persuaded to re-conceptualise and re-evaluate their experiences and problems to develop an *explanatory model* which was in accordance with the information on mental illness provided in OPUS. The explanatory model draws on general cultural beliefs – or systems of explanation – about sickness and health, but is formulated in response to a *particular* illness episode (Kleinman 1980: 104-118).³⁶

The group leaders had roles as teachers and role models, but there were some differences in the techniques and intensity of the corrective moralising they exercised. In the Bispebjerg group³⁷, the group leaders made great efforts to express caring compassion for the difficulties of both participants and relatives. Mental illness was repeatedly presented as the reason for the suffering: in the participants' case as an alien force within them and in the parents' case as a force which was in danger of corrupting their lives by affecting their relationship with, and aspirations for, their ill relative. The socialisation focused on letting both parties come to terms with the illness and the limitations for life prospects it had as a consequence. They were directed towards developing a new understanding of the present and future life of the participants – a new narrative. Further, by sharing problems, and engaging in helping others to deal with them, a model was presented of how to talk to each other and find solutions to problems without creating a conflict in the relationship. The sharing meant that participants and relatives developed a notion of other families experiencing similar problems, and of not being isolated.

During the meetings I observed in the Vesterbro group, however, the group leaders were directly moralising towards the relatives. They challenged and corrected

³⁶ Elsewhere Kleinman (1988a: 155-157; 1988b: 239-244) has described how clinical practitioners can engage with patients to negotiate an agreement on an explanatory model which can support the treatment.

³⁷ By using the word 'group' I refer to the meetings I observed in a specific therapeutic group, and I am not generally referring to practices in the team as a whole.

the relatives' actions towards the participants, rather than expressing sympathy for their difficulties. This created a more confrontational atmosphere in the Vesterbro group, and on a few occasions it seemed as if one group leader was questioning the parental competencies of one relative. The group leaders were, however, careful to avoid allowing unpleasant feelings to surface and find expression. When a relative, on one occasion, made the sharp remark 'That is not how we do things in our family,' to fend off an encouragement by the group leader to show more affection towards each other, the leader skilfully used the technique of 'positive reformulation' to encompass the remark into another suggestion as to how to deal with the problem: 'Do as we usually do.' This manipulation of discourse underlined the power and authority of the group leaders within the group. The group leaders obviously held the balance of power: controlling the sequence of events and the form of the conversation. The participants and relatives, nevertheless, always had the option to resist this dominance, for example by refusing to do homework suggested in the group, or simply by not coming to the meetings.

In the period I observed the two groups, the participants were generally passive in the group and it was the parental relationship with, and support of, the participants which was the focus. Problems of the participants were dealt with in a pragmatic fashion, as recommended in the cognitive therapeutic approach. For example: 'How to prepare for an operation,' 'How to prepare moving to a new place,' and 'How to make sure to eat healthily.' And the solutions often involved the relatives and staff in OPUS: what they could do to help. This was directly reflected in the formulation of one of the problems to be solved: 'How can we recognise signs that [the participant] could be experiencing a psychotic relapse? And what can we do to prevent it from happening?'. The participants tended to 'carry the problems,' as a psychologist in OPUS once critically remarked, and relatives were presented as integral to the solutions, which created a balance of activity in favour of the relatives (cf. Feldman 1999). This was also obvious during the meetings, when the relatives were by far the most talkative (together with the group leaders), and the participants often had to be directly encouraged by a group leader to share their opinions with the group.

The multiple-family groups constructed and confirmed a notion of 'illness' as an explanatory entity in the lives of the participants and in the relationship between

participants and relatives. Further, the groups created a 'we'-notion, both of the participants as belonging to the group of 'mentally ill', or of 'schizophrenics', and of 'families affected by mental illness'. These generalised and reified concepts and group identities possibly helped to comfort and reduce the development of guilt feelings, as the constructive and emotionally controlled style of communication could be used to avoid conflicts and instead find solutions to problems. But the conceptualisations and forms of the interaction undoubtedly also encouraged social roles in which the participant was perceived of as an innocent, passive, and 'childlike' individual. While the group leaders took the parental roles of empathic and directive authority figures, the relatives were directed towards assuming the roles of supporting care-takers (cf. Scheid 1994: 679-681).

Eight of my fifteen informants participated with their relatives in a multiple-family group. Martin said that he, originally, was very reluctant to participate, but his case manager and the team psychiatrist convinced him to give it a try. In the first months, he only agreed to let his sister participate, since he anticipated that intimate problems would be revealed, and he would feel embarrassed in front of his parents. As he learned that the problems discussed in the group were of a more everyday character, and after further pressure from OPUS staff, he agreed that his parents could participate. Towards the end of the one-and-a-half-year period of fortnightly meetings, Martin had grown to become quite happy about the group.

The good thing about the family group has been that I have drawn in my family, my elder sister and my mum and dad. It has been quite nice that they, in this way, have been included in the treatment. But I think that the problems that mean something for me are more rather intimate problems, which are difficult to present in a family group, because so many people are present. In this way I haven't got that much out of it.

Informants were generally happy that their families were included in the treatment; they felt that their relatives got to know them and their problems better. Most emphasised that they here had an opportunity to meet others who experienced similar problems, and they could get concrete ideas how to deal with difficult situations which arose. Like Martin, Claus complained that it was not possible to present intimate problems in the group. In the second interview, some months after he started in the

group, he said that he felt a bit restrained in the family group, since he had to be considerate to his parents; for example, he would not make them sad by saying that, once in a while, he still used street drugs at the weekend.

In the second interview, Eva told me that the existence of the group could help putting the everyday problems into perspective, since you could consider whether a problem was serious enough to present at the meeting. But she explained that she would like the group to be able to deal with problems in the relationship with parents. In the following interview, we talked about this issue again:

JAL: Last time you said that you in the family group had not discussed problems about the relations within the family?

Eva: No, we still haven't done that. I don't know if we are supposed to. Because the problem solving is general, you formulate a problem and deal with this, and you don't go deeper into the individual situation. It is the problem you find solutions to, you see. In a more abstract sense, in some way. They still don't do that [go deeper into the individual situation], but sometimes they should.

Eva also said that she would prefer it if the group leaders would sometimes be more authoritative towards the parents in the group. For example, Eva had recently felt that her mother interfered too much in her life and had been too open-mouthed about Eva's problems, and a father of another participant in the group often created a bad feeling in the group. Eva thought that the group leaders could act more firmly and sometimes tell the relatives off when they were wrong. Eva's critique reflected the different degree to which the group leaders were 'moralising', as observed in the two different groups. Kristina, too, was disappointed with the group in this respect. Originally, she had thought that the family therapy would make them set things right in her family, but she found that they did not make any difference. In the following interview, she said that she had kept on coming to the meetings anyway, since it was nice to meet other people in similar circumstances.

On the other hand, in the fourth interview after the family group had ended, Eva explained, that she had been surprised how the simple, pragmatic solutions had been a help to her.

I think that one thing I have benefited from [in OPUS] ...//... has been the fact that you can make a quite down-to-earth treatment which has an effect, especially in the family group. It is very down-to-earth, in fact, it is just a structured conversation. A bit more focused, a few more people, but the things people say, the solutions people propose, are normal peoples solutions on more or less usual or unusual problems. And it works pretty well when you have a problem yourself. You see, I think that it is pretty cool that you don't have to go in psychotherapy for ten years because your bicycle has a flat tyre. ...//... We have also dealt with pretty complex things, such as how you handle criticism, I think that that was great. It has been really good. So I think that it has been really good, also about OPUS, that even if you think that it is a bit confusing and a bit huge, and a serious problem, then it is maybe not certain that it is as impossible as you think.

Informants generally stressed the value that the group had by giving their relatives, often parents, a better understanding of their problems, and that it became more easy to talk to them about problems. Seen in the perspective of symbolic healing, the group evoked and reinforced a common system of explanation and approach to dealing with problems. The resulting shared understanding of the problems caused less conflict in the relationships. Further, the perspective applied in the group defined and strengthened the care-taking, parental role of the relatives, and the role of the participants as 'children', resulting in fewer role conflicts arising in the relationships. Julie explained that the family group was a help to her and to her parents because they met others who had similar problems.

Julie: In this group there are also others who have been admitted [to a psychiatric ward], and things like that, who also can tell some stories, and their parents too. So my parents can see that they are in the same boat.

JAL: Yes, you have something in common?

Julie: Yes, they have something in common, they have also got some children [sic] who are ill.

Informants related how the regular meetings not only meant that it became easier for the parents to understand them, and that issues presented at the meetings later could be discussed outside the group, but that the meeting provided opportunities to meet socially. Some participants used to go home to eat with their parents after the group had finished, and there they could talk about what had happened in the group. Informants explained that they had become much closer to their families during the time in OPUS, and that they had begun to visit their families more regularly. Claus and

Dennis regularly stayed with relatives at weekends; and Frank, Eva and Anders had, for a period after being discharged from hospital, moved in to live with them. Every morning, both Per's mother and his aunt gave him a ring to help him get out of bed, as arranged in the family group.

While the general view was that OPUS supported the participant in his or her social network, Kristina made clear that the support also could go in the other direction. In the second interview, she told me that she had been disappointed with OPUS and several times considered whether she should leave the project. But when she had talked it over with her relatives, they argued that she should appreciate the help she got, and eventually they convinced her to stay.

Anders explained that the focus on problems in the family group was sometimes too much. He sometimes felt that the group leaders were a bit too keen to keep on asking questions and analysing the problems. In the fourth interview, he told me that even if he had benefited from the group, he was happy that it had ended. He was happy that he no longer had to be constantly reminded of the illness, and have to bother his parents by asking them to spend an evening on this every fortnight. Sometimes, Anders had also felt bad hearing about the problems of other participants, and he felt guilty that he did not have similar problems.

There was a period where I thought that it was a bit depressing to go to those family group meetings, because some of them [the other participants] felt so bad. And I felt like... I felt a bit guilty that I thought that I was fine, and things like that, you see. That annoyed me a bit. Just to talk to the psychologists [the group leaders], they had this way of talking, and they [the group leaders] were girls, all the time they kept on asking the same things, and things like that, you see.

In the previous interview, Anders explained how he thought that the psychological and analytical way of talking was a special female characteristic, and that it generally did not appeal that much to men. This reflected my own observations, especially in the Bispebjerg group, where there was a focus on expressions of concern and caring towards the participants – which, in a Danish context, would generally be perceived as 'motherly feelings'.

Dennis was sad when the family group ended after the scheduled one-and-a-half-year period. Even if, in the beginning, he felt very shy in the group, and the group

leaders had to work hard to get him to talk, he grew fond of it. He was happy to meet the other participants and their families in a cosy and relaxed atmosphere, and to hear how everybody was getting along. Not all groups ended when the staff in OPUS stopped arranging them and attending as group leaders. The group Claus, Martin and Per participated in continued to meet regularly in a rented room in a community centre after the group leaders from OPUS had left it.

Training for social skills: Competence as 'a well-functioning individual'

The notion of 'the well-functioning individual' was often presented in various situations in OPUS, and it was a central concept in the 'moral talk', whereby the participants were evaluating their own situation and were being discursively reconstituted as capable and responsible persons. Robert Barrett (1996: Chapter 6) introduced the notion of the positive therapeutic qualities of the informal moral talk among psychiatric staff which previously in the sociological literature (e.g. Goffman 1961: 117-55) had been considered as improper and as evidence of 'institutional pathology' (Barrett 1996: 144). Likewise, among psychiatric staff, this type of personal evaluating talk about patients is, generally, regarded as unprofessional, and considered embarrassing when overheard by somebody who is not a recognised member of staff (*ibid.*: 147). This study demonstrates that not only staff, but also the participants, used moral evaluations, and, for example, a normative measurement such as 'the well-functioning individual', when they talked about the hopes and expectations they had for their own recovery or when they assessed which people it would be appropriate for them to befriend. Similarly, Lorencz (1992) has observed that among persons with a history of mental illness, it was the accomplishment of functional normalcy, and not psychological well-being, which was considered an indication of 'becoming ordinary'.

In the context of Danish society being 'a well-functioning individual' was considered the normal state of the person – the unnoticed 'anyone', to use Barrett's expression (1996: 280). This both taken-for-granted and ideal state of the person was characterised by self-control, independence, and successful integration in the society. When nothing indicates otherwise, these qualities were silently and unquestioned assumed to be possessed by the individual. But if an individual was socially defined as being mentally ill, the assumed normal status was revoked, and these basic qualities

were questioned. The status as mentally ill *per se* meant that you were not ‘a well-functioning individual’. The concepts were each other’s opposites.

When the status of a person as a well-functioning individual was questioned, a transformation happened, whereby what used to be perceived of as a personal quality was split up into a set of particular *competencies* – or in-competencies. What used to be seen as part of the identity was objectified as things or abilities external to the person – to be possessed, lost, learned, and regained. This process revealed the intrinsic quality ascribed to competencies, whereby they are seen as *axiomatic*, suggesting that ‘the competence of most individuals is not in doubt until it *is* in doubt: in the absence of evidence to the contrary, competence can be presumed, by self and others’ (Jenkins 1998: 1, italics in original).

In OPUS, impairment of social competencies was seen as a consequence of, and a further negative development of, mental illness. This is consistent with the diagnostic classification of ‘negative symptoms’, e.g. social withdrawal and lack of ability to carry out interpersonal communication, as part of the diagnosis. It has been documented that people who have experienced long-term treatment for schizophrenia regarded their lack of social skills as a consequence of ‘what they did not learn while they were incapacitated by the illness’ (Mountain 1998: 125). Others have argued that ‘negative symptoms’ represent strategies of coping with an environment which is experienced as overly stressful by the individual (Sayre 2000: 81), and that they represent a ‘self-protective regulatory mechanism’ (Strauss 1989: 184ff.). Corin (1990) has demonstrated that ‘positive withdrawal’, also, can be an efficient way for people with persistent symptoms of serious mental illness to avoid readmission by keeping at a distance from social life. And she suggested that withdrawal, in a caricature and distorted form, mirrors cultural values of self-reliance and autonomy generally celebrated in the West (*ibid.*: 183).

In OPUS the aims of treatment and support was not only to help the participant to minimise ‘positive’ psychotic symptoms and avoid relapse, but also to direct special attention towards bringing the individual to the point when he or she, as far as possible, would be able to function independently in the society – become a well-functioning individual. Towards this end, a special treatment programme was introduced to improve the social competencies of those participants who were considered to need it. Using a

formal procedure (the WHO 'Psychiatric Disability Assessment'), there was an assessment of the social skills of participants who staff considered needy. If they 'scored' sufficiently poorly on the scales, they were invited to join a *social skills training group*.

Social skills training was first introduced in Denmark by the psychologist Irene Oestrich, who in Britain in the early 1980s was introduced to a very behaviourist version of the approach and then developed her own group model (Irene Oestrich, personal communication). Following a Canadian model, it has been introduced in some Danish prisons in the 1990s, to help young, violent offenders learn to avoid aggressive reactions when faced with difficult social situations (*Weekendavisen* 17.08.2001). Social skills training groups were implemented in OPUS based on a manual targeted at people with schizophrenic illnesses by the Swedish psychologist Per Borell (1996), who used guidelines developed by the American Robert Lieberman. There is growing international attention towards providing social skills training for people with schizophrenia (Bellack *et al.* 1997). In OPUS, each group consisted of two members of staff who functioned as therapists and a maximum of six participants. The group ran over an one-year period; the first three months with sessions twice a week and, during the rest of the time, once a week. Each session lasted one and a half hours, and took place during the day, which, in some cases, unfortunately meant that participants had to leave the group when they started on education or work. The group went through five modules, focusing on medication self-management, coping with symptoms, conversational skills, problem-solving skills, and conflict-solving skills.

During two months in 2000, I participated in 13 sessions altogether in two groups, one in each team. As participants in the Bispebjerg group started arriving a little before the scheduled start of the session, they were let in by the staff and either waited in the meeting room or had a cigarette outside the door of the ground floor offices. Meanwhile, the two trainers finished their preparation for the session (generally they met an hour or half an hour beforehand). At the time of the start of the session, the trainers came to the room with coffee and tea, and sat down around the conference table to chat with the participants. Sometimes not everybody had arrived by then and the trainers would wait for about ten minutes before beginning. In the Vesterbro group, the meeting took place in the large common office of the hospital section of OPUS in the

community psychiatry centre. When participants came early for the session, the staff waited with them around the table, making small talk.

As in the meetings in the family groups, the sessions were scheduled to start and end with informal socialising, but while this was a natural or extended part of the chat in the Bispebjerg group, it was formalised as an issue on the agenda written on the whiteboard in the Vesterbro group. This 'formalised informality' had been developed to fit the structure of 'the round', as it was practiced in the family group. The group trainers, a psychiatrist and a vocational trainer, started the 'informal talk' by asking the participants successively, 'How are you?'. The interaction in the group revealed a clear demarcation in role and status between trainers and participants, but the trainers made an effort to create a relaxed, friendly and supportive atmosphere during the sessions.

On one occasion, a trainer attempted to stress the equal status of trainers and participants by starting 'the round' asking the other trainer: 'How are you?', the other trainer replied 'Thanks, I'm fine, how are you?', and the first trainer said 'I am also fine.' This exchange created some giggling in the group since it seemed artificial and peculiar. The trainer, however, continued and asked the participant sitting next to the other trainer 'And how are you?', the participant answered 'I am also fine.' The trainer then said with a smile 'Well, it appears to be the short version today' and then chose another way to question the next participant about whether she had experienced any difficult situations in the past week and if she had done the homework from the previous time. This example illustrates that there was a clear difference between the roles occupied by the participants and the trainers. It reflected the difference between the participants and the case managers described in detail in Chapter Six: the participants were expected to reveal private issues and problems, while the trainers could be friendly and personal but they maintained professional authority and distance.

In the Bispebjerg group, the informal talk was not set up as individual questioning but developed naturally from the chat around the table. Prompted by the trainers, participants talked about their interesting or exciting experiences during the week, with special attention to problematic experiences such as feeling uncomfortable together with friends or having a row with a person on the street. Sometimes, the trainers asked a participant about a particular social situation discussed in a previous session, planned as 'homework'. In both groups, the day's programme started when a

trainer asked the participants to take out their individual folders and find a certain page. The trainer then introduced the theme, which could be how to recognise symptoms or 'warning signs', which are early symptoms indicating that a relapse can be underway, or it could be about the danger of taking drugs and drinking alcohol.

In the presentation of the theme, the participants were frequently asked to repeat information and to read from the text provided. This pedagogic technique emphasised the staff's roles as trainers or teachers and the participants' roles as pupils in the group. On one occasion, in the Vesterbro group, a young man rebelled against this format. When a trainer asked him to read aloud from the text, he refused, claiming that it was 'school-like' and that it suggested he was not able to read. He found the format humiliating and patronising. During an interview Eva, too, criticised one of the trainers for being too dominating and patronising. Eva experienced that the trainer had an unpleasant way of phrasing questions which made her feel stupid. After the first months, it had, however, become better.

In the two observed groups, I noticed some stylistic difference in the trainers' presentation of information: in the Vesterbro group the trainers had an *absolutist* style, presenting the information as 'unquestionable facts', not to be negotiated, while the general attitude in the Bispebjerg group was *relativistic*. On one occasion, in the latter group, a young man, who had recently entered the group, said that he did not think that they were right to say that he had been ill, since he was convinced that his psychotic experiences had been influenced by God. The trainer explained that in the group they were not specialists in religion, but they knew a lot about mental illnesses and how to help people to avoid having the experience of psychosis again. Thus reassured that his notion of the religious qualities of his experiences would not be challenged directly in the group, he agreed to stay there and he conceded that they used the concept of illness, in the expectation that it might help him to get better.

On most occasions, the participants accepted the pedagogic format of the group. In particular, participants who had considerable cognitive difficulties after the psychosis – symptoms which in many cases were enforced by the antipsychotic medication – appreciated the slow and repetitive approach. Originally, the training had been arranged to suit people with severe and 'chronic' mental illnesses, and this caused some problems when applied to the target group in OPUS (cf. Feldman 1999).

Participants without (major) cognitive difficulties sometimes found the form patronising, especially when the trainers did not vary the approach to fit individuals. In the Bispebjerg group, the trainers seemed to be more aware of the need to make these adjustments, which, apart from the relativistic and non-absolutist approach, was possibly strengthened by the fact that several times only two participants showed up to the sessions, allowing for more time in this group, and more focus on each participant.

The 'school-like' and supportive pedagogic attitude was, in both groups, particularly visible through the trainers' perpetual praise when participants answered a question correctly or if they had completed their homework. In most situations, the praise appeared as a constructive reinforcement of the work by participants in the group. Trainers could sometimes unwittingly overdo this praising, but often the participants were ready to react to this in the situation with a remark as 'Yea, yea!', indicating that the trainer had gone a bit too far. In the groups there was, generally, a sensation that even if the trainers were in a recognised authoritative position in relation to the participants, then it was acceptable for the participants to protest and 'correct' the trainers. This is possibly a reflection of the pedagogic approach generally practiced in the Danish school system, enforcing the pupils' ability to critique and raise self-awareness.

After the presentation of the theme of the day, the participants were asked to relate the theme to their individual experiences or habits. They took turns to talk about their symptoms, what they felt like and how frequently they occurred, and, in the session on drugs, they described which drugs they had tried, and whether they still used drugs or drank alcohol. Their individual folders contained pre-printed forms where they, guided by the trainers, filled in the individual information. The trainers asked which problems each participant had concerning the particular issue, and it was discussed in the group how individual solutions could be found to these. Claus told me, in one interview, that he was happy that he could talk about his experiences and problems in the group, and that it was possible to say more about personal details, compared to the family group where he had to consider his parents' feelings if he knew they would disapprove of his actions. Per also thought that it was interesting to learn about the illness, and that it was nice to meet the other participants in the group.

It is almost purely social, you see. We are sitting and chatting, and then we talk about our problems. And I think that all of us see it as a kind of eh, 'chat club'... chat club, where you can air your thoughts and problems, and things like that.

Per said that sometimes they arranged the session at a café, so that they could practise getting out among people. There was a nice feeling among the participants in the group he was in and they had continued to meet socially after the group had ended. This was, however, the only group in OPUS I heard of where this was the case. Per thought that it was also the intention of the trainers that they should go out together so that they could bond (*blive rystet sammen*).

Often a particular problem of one of the participants was chosen to be solved in the group. Sometimes, the problem arose from the day's theme, but on other occasions it was a problem a participant had presented during the informal talk. Using the 'problem-solving' technique meant that the problem would be formulated as a sentence and written on the top of a whiteboard. Personal difficulties and experiences were controlled by objectifying them in language (cf. Jackson 1994: 204-9). This transformation of private experience into the public domain of written discourse (cf. Barrett 1996: 259) demonstrated the general technique of explication, de-privatisation, and generalisation which was a core element in the cognitive therapeutic approach applied in OPUS. In the Bispebjerg group, it was, in all the observed sessions, one of the trainers who wrote on the whiteboard, but in the other group, it alternated between a trainer or the participant who was having his or her problem solved who wrote on the board. In one situation, a participant was sad and angry that another member of Klub Fontana had taken over his place as a drummer in the club band, especially since he would like to play at the coming party. The problem was formulated as: 'How can I play the drums again in the band?'

The trainers encouraged the participants to 'brain-storm' to find different solutions, which were written underneath the problem. All ideas were written, except for suggestions which contained violence, such as: 'Set fire to the other drummer.' When this jokingly was suggested by a participant it was censured by the trainer, who also disliked the idea of beating the rival up. Thereafter, a trainer took the participant through the suggestions one by one and in a dialogue he or she sought to bring out the good and bad aspects of each idea. If positive things could be found a plus was written

next to the idea, and if negative things could be found a minus was written. As the assessment took place in an open discussion in the group, a variety of judgements were presented, which meant that sometimes a suggestion got both a plus and a minus. In other situations, it was the trainer standing at the board, and thus in control of the situation (cf. Barrett 1996: 258-66), who in practice decided what to write. The problem-solving was thus an exercise in real life moral judgements, where the trainers were provided with authority to censor and correct unacceptable beliefs and actions. When all the ideas had been assessed, the participant was asked to choose between the suggestions marked with a plus.

Sometimes an idea, for example 'Suggest to the other drummer that you can take turns playing the drums,' was rehearsed in a role play. The role play seemed most successful when the participant directed the play in detail, to set up the scene convincingly. Some of the participants and trainers played actors, and the remainder were observers. In this particular situation, the participant played himself, and a trainer played the other drummer. As preparation for the role play, it was discussed in the group when and how the participant could approach the other drummer and what he should say. After the role play, the actors said how they felt during the play, and the trainer who played the other drummer explained how she felt when the participant asked if they should take turns. Then the observers were asked what they thought. Often the role play was repeated, adding improvements. After this particular role play, it was discussed how the participant could create an opportunity to make the suggestion to the other drummer, and as 'homework' it was planned that he should join the band's rehearsal session that coming Sunday. Apart from individual tasks, homework would often be general for all the participants, for example, writing down for every day of the week which symptoms they experienced and how severe they were. The following session the trainers would ask each about the homework. In the case of the drummer, it turned out that he had not gone for the Sunday training because his bicycle had a flat tyre. It was noted by some participants (cf. Feldman 1999) that homework was unpleasant since it reminded them of their illness, even outside the group. But during the sessions, I observed that the trainers were not strict in demanding participants to do the homework, but, on the other hand, they praised them when they had done it.

In the Bispebjerg group, problem-solving and subsequent role plays were used frequently and sometimes less formally as an immediate response to a problem presented by a participant. One day, a participant came to the session and said during the informal talk that he was a bit upset because a guy had blocked his way on the pavement with a bicycle. The participant had told him 'Clear off! Or do you want to get smacked!'. This was a real threat coming from the more than 1.9 metre tall participant with a record of violence. In this situation, the trainers immediately did a problem-solving exercise to find other ways of dealing with the situation, which the participant had experienced as offensive. In a role play, he rehearsed how he could have avoided the confrontation. The participants formulated individual goals for their participation in the group. For this participant, it was to learn to react to difficult situations in other ways than with violence.

During the third interview, Martin told me that they did not formulate personal goals in the group he participated in, but he would have liked to have done that, and focus more on becoming better at socialising in the kitchen with his flat mates. Due to the time period of their inclusion in the project my key informants participated in some of the first groups in OPUS, when the staff still did not have much experience with the technique.

As the participants in the groups became more accustomed with role play, video recording was frequently used, so that the participants could see themselves afterwards. Dennis said that he at first was very embarrassed about being filmed, but after getting used to it, he found it was useful and 'funny'. Eva, however, said that she preferred the 'problem-solving' in the family group.

Role play [in the social skills training group] is more demanding, you are in the spotlight, and it is a bit more peculiar, in some way. And peculiar because we are not professional actors, you see. And when we have to analyse these 'yes'- and 'no'-signals, I think that is very difficult. You realise that things are working in many dimensions, and we are not professionals. We can't simply radiate just one emotion, we radiate both what we feel and what we have been told to radiate, you see. In any case I think that it is difficult... the other thing [problem-solving in the family group] seems more natural for me. Because it might be good even if it is difficult. I just feel that it [problem-solving in the family group] is more natural, and I would also say that it has been a greater help.

During the period of observation, role play was not used in the Vesterbro group, and it seemed that on a few occasions, one of the trainers' professional background as a psychiatrist encouraged the frequent medical solutions alternatively proposed by the group. One participant complained that he sometimes felt very anxious when he was doing the part-time job he had recently started. The trainers asked him to make a note every day about the frequency, duration, and intensity of this feeling. The following week he reported that he had the feeling almost exactly at the same time every day some time after the lunch break in connection with his colleagues going for a break, while he preferred to stay at his desk. The psychiatrist trainer suggested that he should take some calming medicine an hour before this time of the day. The following week he reported that he now did not have these strong feelings of anxiety any longer. The medical approach to solve the participant's problem was in stark contrast to the social and cognitive therapeutic practice I observed in the other group which had a psychologist and a nurse as trainers.

Dimensions of symbolic healing were clearly present throughout the work in the social skills training groups, whether the techniques and solutions presented were socially interactive, cognitive, or medical. It has been ethnographically documented (Barrett 1996: 255-71) that an Australian education programme for in-patients diagnosed with schizophrenia provided a similar process of transformation. The trainers in OPUS were experts in a system of explanation which they presented to the participants. Through an intensive procedure of explanation, illustration, rehearsal, and repetition, aspects of this system of causal beliefs about the character and causes of the symptoms of mental illness were taught to the participants. Further, the participants were requested to relate these systems of explanation to their personal experiences, describing their past actions, present situation, and future intentions using these categories of meaning. Through role play, the categories were related intellectually and emotionally to the participants, teaching them how to perceive of, and react to, situations and circumstances in a new way. The process was intensified by requesting the participants to repeat the 'ritual enactment' of the role play in real life situations outside the therapeutic environment of the group.

Interviews with my informants revealed that they were selective in what they took in from the teaching in the group – as Birgit said: 'Many of the things were of no

use for me, but some of them were relevant.’ Per and Dennis said that the information they had been given about how to read body language had been very interesting, and that it would be useful to know more about how to interpret gestures. Julie empathised that it was nice (*rart*) to have explained how the medicine is working, and Namira was happy that she had learned ‘what is it our illness is, what it is that makes you ill.’ Martin, however, was not satisfied with the level of information he had been provided with and he requested that they be given a more thorough book on the subject. Informants mentioned the value of the information they had been provided with and the usefulness of this knowledge in their daily lives.

Per: What I have learned from [social skills training] is that I can handle my symptoms quite well. If I, for example, find it difficult that someone is talking badly about me behind my back, or things like that, then I can stop, it is difficult, but I can stop and say to myself: ‘Oops, this is a sign of illness,’ and ‘It will pass,’ and ‘I will feel better.’ It varies in periods, you see. So I have learned a lot about illness.

It has been argued elsewhere (Mountain 1998: 86-8) that information about illness and medication is positively evaluated by psychiatric patients, and helps them to become more involved and committed to treatment. However, though Eva thought that she had benefited from participating in the group, she told me that the focus on illness and scrutinising yourself to detect symptoms and ‘warning signs’ of psychotic relapse became too much for her. So she panicked in the period just before Christmas when there was a lot of stress.

Well, it became very much too much. And, in fact, it had a quite bad effect on me, because in the end I went out to the reception [of the psychiatric ward] at Bispebjerg [Hospital] because I got myself all wound up. I was sure that I had 117 warning signs and that I had to increase the dose of medicine.

During a session in one of the groups, another situation likewise demonstrated the potential problem of self-diagnosis when teaching the participants to interpret their own feelings and actions as possible symptoms of mental illness. A trainer described the difference between positive and negative symptoms and said that people diagnosed with a schizotypal disorder only had the negative symptoms, whereas people with schizophrenia also had positive symptoms. One of the participants asked what it then

meant if he could recognise some positive symptoms, but he was diagnosed with a schizotypal disorder. The trainer explained that it could be expected that his diagnosis should be changed, since this was the development many went through. Even though the trainer stressed that it would be for the psychiatrists to assess whether the diagnosis should be changed, the situation, along with Eva's account, clearly illustrates the risk that although participants can use the newly gained knowledge to be able to better control and react to their feelings and problems, such knowledge can also create anxiety and expectations of development of the illness.

Claus talked about a similar problem of identification with symptoms of mental illness. He told me that he did not remember having had any social anxiety before he started in the social skills training group, but, after he had met other participants in the group who had this problem and he had been taught about how to notice it and prevent it from worsening, he frequently experienced problems of social anxiety. I asked Eva if it was possible to get too much of the illness perspective:

Yes, but in the longer perspective you can't. You see, you have to learn... it is not because we are talking too much about it [in the social skills training group], it is just the subject in itself, you see, it is very sensitive.

Of the eight of my informants who participated in social skills training, it was only Kristina who said that what she had been taught had been completely useless. After some months, she left the group as she started to attend a school. She thought that the social skills training was 'square' and that the issue should have been dealt with in a completely different way.

Kristina: Everything was placed in tables 'that I had all kinds of spiritual visions' and things like that. And that was just labelled 'spiritual openness', box one. You see, 'open', that was my warning sign. So now I had to be aware when I was 'spiritually open', and be careful of that. Well, it is okay, but it was so... it lacked feeling. There was no life and energy in it. It was just, you see.

JAL: Have I understood you right that it was because they did not take account of your experience of what happened?

Kristina: Yes, but also... you see, it was put in tables and things like that. And it was talked about in such a... well, they almost completely avoided talking about any thing at all, you see. And then it was also very childish. It was on a quite low level, and many [of the participants] thought that.

In the spring of 2000, the psychiatrist in the Vesterbro Team initiated a new group intervention. It originated from a conflation of incidences as the psychiatrist arranged for the participants to come on Friday afternoons to collect the week's supply of medication and sometimes to have individual case manager meetings. As several people were assembled, the psychiatrist suggested that everybody should sit down and have a chat and a cup of coffee. And it developed to become a recurring social event. Among staff it was initially referred to as 'medicine delivery' and 'doctor consultation', but gradually it became known as the 'Friday Get-Together' (*fredagshygge*). The name connoted the informal and social quality of the meeting.

When I participated in the meetings in November and December 2000, between six and nine participants turned up each time to the meeting, which started at noon and lasted for two or two and a half hours. The meeting took place at the community mental health centre, in the common office of the hospital section of the Vesterbro Team. Participants were free to come whenever they wanted, and they stayed for either the whole period or only for a short while. Some participants followed the psychiatrist's encouragement to bring fruit or home-made cakes to supplement the snacks provided by the team. In contrast to the formal and structured forms of the family group and the social skills training group, the social interaction was free, and role and status differences between staff and participants were not strongly demarcated. Apart for the team psychiatrist, who was present all the time, other staff members sometimes came by and joined the group around the table for a while. The psychiatrist told me that some of her colleagues in the team initially found it difficult to take an appropriately laid-back role in the group – not being too dominating and controlling towards the participants. The therapeutic strategy was to let the participants talk to each other and gain confidence and personal strength from the exchange and interaction.

The psychiatrist took her a role as catalyst of the interaction between the informants by asking questions and by drawing quiet participants into the conversation by asking about their experiences or opinions on a particular subject. The psychiatrist also mediated interaction between participants. Per told me how, one Friday, he had met a participant trained as an electrical engineer who could help him to repair his television. The participants exchanged knowledge, ideas, and personal information during the meetings.

The general knowledge game *Trivial Pursuit* was an established part of each meeting. During the meetings when I participated, two teams were formed on a gender basis: 'boys against girls'. It was played in an amicable atmosphere of mutual joking, and it proved that the staff did not always possess superior knowledge to the participants. The rules of social interaction and the social structure of the game indicated an equal status between staff and participants. Further, the game gave an opportunity for participants who otherwise were quiet in the social interaction around the table to talk, and be addressed by the others, when they, as part of a team, had to find the right answer to a difficult question. The group responded to a request which participants had presented from the start of the project, to meet other participants on an informal social basis (Larsen 1998a, 2000a; Larsen and Feldman 1999).

Strategies of social contact

The therapeutic groups in OPUS only presented a narrow spectrum of opportunities for social interaction open to the participants. Living 'in the community', they had all the options available to anyone else, which meant social affiliations related to work, study, interests, religion, sport, and health – and any other organisation or grouping which is present in a European capital city. For example, Anders socialised at the golf club, and Birgit, twice a week, went to meetings of the Jehovah's Witnesses.

Towards the end of their period in OPUS, several informants told me that they had experienced some change in friends from when they had started. Many said that it had been important for them to have friends who could understand their experiences and problems, and maybe had experienced psychiatric treatment themselves. Per described earlier that some of his friends did not accept that he had psychological problems, and Claus mentioned that a problem with old friends could be that they would not accept his illness. Some had told him that they did not believe that he 'was schizophrenic.' Claus was particularly annoyed that they, on some occasions, had told him that they recognised his problems of feeling apathetic and unmotivated: they also found it difficult to get out of the bed in the morning and go to work. Claus felt that he was misunderstood and 'mis-recognised' by these statements of apparent empathy, because for him the problem was much more severe and dominating his life. As a consequence, he stopped telling these friends about how he felt, he just said 'I'm fine' when they

asked, and with time he saw them less frequently – he did not feel that they had much in common any longer.

Kristina said that she had lost most of the group of friends she used to know from her interest in spiritual subjects. She found herself seeking to meet people who had similar experiences as herself so that they could ‘meet around that.’ Lotte, too, said that she would like to meet some people who were in a situation similar to herself following her ‘hash-psychosis’. But she did not want to befriend mentally ill people, as she did not think that they could give her anything. Instead, Lotte would like to meet ‘well-functioning’ people who were not just hanging around all day, having nothing to do.

Anders said that he had always been part of a big circle of acquaintances and that he had kept most of his friends; for example through playing golf and regularly attending training and tournaments. But in the family group he had befriended one of the other participants. I asked him if it meant anything that they had similar experiences.

Yes, because we have many things to talk about. We also talked about concrete experiences [during the psychosis] where he had the same [as I], surprisingly. And then we laughed a bit about that and talked about these imaginations we had, and things like that. And it was just when we sat together and talked a bit, suddenly there was a lot of things to talk about.

Dennis said that he did not really have any friends before OPUS, and when he was discharged from the hospital, he was happy that he soon could move into a collective for young people with mental problems. He was afraid to be lonely and become depressed, and he appreciated that he could chat with his neighbours in the collective, and five days a week they ate dinner together. Dennis explained, in the fourth interview, that it meant that he generally felt better.

Well, I feel that it has become better after I have moved to this collective. I live with three others who have similar problems, so they have a better understanding of how I feel. They better understand... well, you can have a bad day where you just need to be yourself, or sit and talk. I still think that explaining to an outsider how you feel, you see, he or she will find it difficult to really understand how you feel. It is not like talking to someone who tried to be completely depressed, or go black, or... ..//... My neighbour who lives just next to me, if there is anything, then I just knock on his door once in a while, [and ask] if he wants to sit and talk for a while, or take a cup of coffee, or things like that.

My informants' positive evaluations of being able to share their experiences with others who had similar experiences echo Jackson's (1994) finding that chronic pain sufferers 'can find themselves in a state of being that has almost no meaning for non-sufferers' (*ibid.*: 211) and that the *communitas* of fellow-sufferers provide an exclusive social forum of mutual understanding (*ibid.*: 211-22; see also Mountain 1998: 91). Jackson uses Schutz's (1971) notion of 'multiple realities' to conceptualise the preobjective bodily experience of chronic pain as constituting a distinctive 'pain-full world' which is different from the everyday world and, therefore, cannot be fully described in the 'everyday-world language' (Jackson 1994: 211-22). My informants' experiences with severe mental illness is likely to represent a similar distinctive experiential world. Likewise, this might explain why they felt misunderstood by their old friends, as Per and Claus did, and found comfort in the company of fellow sufferers.

Ten different organisations in Copenhagen, supported and organised either privately or by the municipality, provided an opportunity for social activities (*Familie- og Arbejdsmarkedsforvaltningen* 2000b: 29). Most had been established without the interference of central planning during the 1990s (*ibid.*: 31), as the need for social services for the mentally ill living in the community became increasingly apparent (see also Chapter Three). In an agreement between Copenhagen Municipality and Fountain House, Klub Fontana was established in 1995, as a special service for young people between 18 and 25 years with serious mental problems (Jöhncke 1998: 30ff.) and it was often introduced to the participants in OPUS. Eva had started coming to Klub Fontana before she was discharged from the psychiatric ward, and in the following period she went there three days a week.

Eva: When you have been mentally ill then you are in contact with some different sides of yourself than normally, and you need to talk about them. So there is not much talk about different things [in Klub Fontana], in some way. Not necessarily symptoms or things like that, but talk about problems and...

JAL: Which sides of yourself are those?

Eva: I suppose that it is that you have some weak sides, and you have some problems, you see. Maybe you have some fears, or many have had a hard childhood, or... You can also talk about whether you are supported or not, by your family.

In the next interview, about two years after she experienced the psychosis, Eva told me that after she started in the social skills training group, she had stopped coming regularly to Klub Fontana. I asked her if it was still important to meet people who had experienced mental illness.

I guess that the answer is both yes and no, because it can also drag you down. In fact it is a bit of a problem for me now that I have many friends who are mentally ill. It is not always I think that it is very encouraging to be together with them, and it is not always that I think that they do enough themselves. The thing is that the treatment generally is not as good as in OPUS, you see. Well, it is not, right! It can [therefore] be difficult [for them] to find something to do. I have a friend who somehow must be too ill to find something to do. She is not able to get out of the door to do anything, she is simply not able to get out of the door. And then she sits. And I kind of feel pity for her, and I think that she feels pity for herself, she even says that she has become lazy. I guess that you can call it that.

Eva explained that this was one of the reasons why she decided to move out from the collective for young people with a record of mental health problems where she lived for a while. She said that she had often tried to avoid talking about illness, but inevitably they ended up talking about it. In the long run it was too 'heavy' for Eva.

Yesterday Susanne came to visit me. She jumped out of a window and is both psychically and mentally handicapped. [In this situation it is difficult] to create the right atmosphere, you see. You can't be full of energy, can you! ...//... What you have in common is somehow something negative. We also have other things in common, but you just can't expect that people who feel like shit to be running around and having 100 hobbies. And focus on that, you see, you just can't expect that.

Eva suggested that new patients of psychiatry should be better prepared for the social challenges of meeting the other patients. In the beginning, she was often overwhelmed by the conversations she had both with in-patients at the psychiatric ward and with the discharged psychiatric outpatients she met in Klub Fontana. She was not used to talking to people about their problems and she was not acquainted with any conversational or therapeutic techniques which could help her to listen, give advice and back out of interactions which became too demanding for her. On top of that, she had her own

problems to confront. Eva suggested that social skills training should include training in how to deal with these difficult interactions.

How do you deal with this, you could say: 'Now you are in a phase where you are going to be put together with other ill people, and it has some advantages and some disadvantages,' and 'How do you get the best out of that, so that it does not break you down.' Because it has been a bit destructive for me, some times, in fact it has.

Eva felt that she had received good support from OPUS to move on with her life after the psychosis, but retrospectively she could see that she also had had her own *social strategy of recovery* to avoid being broken down and locked in a fixation with the illness. After staying at the collective for young people with a record of mental health problems, she moved to a normal student hall of residence. In this new environment, she was socially stimulated and encouraged to resume her studies.

It has not been automatic for me to start studying and go travelling, and things like that. I really considered it and thought about it, nobody asked me 'Do you want to start studying?'. But when I lived in the hall of residence then everybody ask me 'What are you doing?', you see. And after a while I am fed up of thinking 'Well, God knows what!', and then I start to say 'Well, I am writing my BA essay,' and then it dawns to me that I am writing the BA essay, and then I register [at the University] to do it. You see, then everything happens automatically. Some times things happen because you are in a certain environment where certain expectations pertain, and where you help each other and know each other. Then things happen a bit more automatically, you see.

For Eva it proved to be an important social competence to be able to manoeuvre to and from different social environments which supported her at different times and in varying situations. The strategy of social positioning supported her in pursuing her personal goals. As it happened, the 'strategy' was not a calculated plan, but more a chain of coincidences. But Eva differed from some of the other informants in her marked ability for social mobility and her firm pursuit of the life direction she had been pushed away from by her psychosis, even if the dream at times had seemed out of reach. This discussion will continue in Chapter Eight, after having introduced another crucial foundation of the recovery process.

Social integration and Danish welfare policy

The possibility of re-establishing a direction in the individual life course after the psychosis was, however, not solely dependent on individual strength, willpower, and personal relationships. An important aspect of the support in OPUS was help to plan social integration by facilitating access to, or use of, educational programmes, sheltered workshops, and individually adjusted financial arrangements to support rehabilitation. The prospects of individual recovery were dependent on the general system of social welfare policy in Denmark.

As presented in Chapter Three, during the last decade, Denmark has experienced a rapid development of social services targeted at people with a history of mental illness as part of a community neo-institutionalisation following the de-institutionalisation of psychiatry. Institutions with a focus on social aspects of mental health, allowing people to meet around activities or just have a cup of coffee, have existed in Copenhagen since the 1970s, but the majority of the places which exist today were first established in the 1990s (*Familie- og Arbejdsmarkedsforvaltningen* 2000b: 31). It is estimated that about 7000 people are potential users of these services in Copenhagen, but it is only slightly more than a third of that number who actually use them (*ibid.*: 32).

Options of specialised education or training have also increased. In 2000, eight such schools were listed in Copenhagen, and apart from these, the four major public education institutions operating in Copenhagen arranged various special education programmes (*ibid.*: 34). Through her case manager, Kristina got enrolled in one of these specialised schools, where she followed courses in gymnastics and personal development. Also, the social activities and cafés targeted for people with a history of mental illness offered some possibilities of employment, apart from the voluntary work done by the users of the places. And in the capital as a whole, around 300 ‘sheltered workplaces’ were available (*ibid.*: 35).

Throughout the 1990s, there was an intensified political focus in Denmark on the moral need for everybody to work. The moral pursuit was both to avoid the assumed moral decay of the unemployed, by being inactive, and to satisfy the moral indignation of the taxpayers. The political focus has resulted in an expanding public business of ‘activation’ of unemployed people and an increasing number of possible financial

support schemes for people with limited working abilities to take up employment. Further, there is the opportunity of being accepted in a rehabilitation programme (*revalidering*), where the individual is financially supported to gain vocational qualifications in an appropriate field, by undertaking education or training. In this way, the Danish social welfare policy has been formulated to encourage people to work and to prevent people from passively receiving financial support.

This policy had significant implications for the possibilities of social integration open to the participants in OPUS, and often they were combined in various complex ways to fit the individual situations in the course of the two-year period of their participation. There is no standard design of the financial arrangement presented to the participants, but some general patterns can be outlined. If the participant had a job before inclusion, he or she would go on sick pay from the time of the active psychosis. In some cases, the participant could, after a relatively short time, resume the job, possibly with reduced hours, and with additional financial support either through social benefits or a rehabilitation agreement with the municipality. In other cases, the participant would have to leave the job while continuing to receive sick pay for a maximum of two years. After this period, he or she would be subject to the rules concerning social benefit (*kontanthjælp*), or could apply for an early retirement pension (*førtidspension*). In Denmark, social benefits are granted depending on individual needs, i.e. if you cannot be maintained by your spouse or your personal savings. Early retirement pension is granted to people who are considered incapable of maintaining a self-supporting employment. In Britain, this kind of social support scheme is called 'Invalidity Benefit', but avoiding the implications of a permanent status as 'invalid', the terminology in Denmark emphasises the temporal notion of deserved support in the concept of 'early retirement'. If the participant before inclusion in OPUS was a student receiving a student scholarship (*Statens Uddannelsesstøtte*), he or she would typically not be entitled to sick pay, but would, instead, receive social benefits from the time of leaving their full-time studies. If the participant was unemployed before inclusion in OPUS, he or she either received unemployment benefits in a special 'sick pay' arrangement, if having paid unemployment insurance, or received social benefits. In a few cases, people were without any form of financial support at the time they were included in OPUS, in which case an arrangement of social benefits would be set up.

Apart from the possibility of taking up unpaid voluntary jobs, the participants could engage in a variety of paid employment, either as part of the 'activation plan' for unemployed, as part of an individual rehabilitation programme, or as a special job arrangement (*støttejob* or *flexjob*). For example, Kristina was studying as part of her unemployment 'activation plan' in the period before she was included in OPUS, and, in a revision of this plan, she could start her new training to become a teacher of gymnastics, while continuing to receive unemployment benefits. Since she, due to the time restriction, lost this entitlement for financial support one year before she was scheduled to finish her training, she made arrangements with the social authorities to receive financial support for the last period as part of an individual rehabilitation programme provided by the municipality. Irene's situation was different: not long after she was discharged from the psychiatric ward, and in this period receiving sick pay, she returned to work on reduced time. After having experienced a relapse while in OPUS, her employer suggested that she should find a way to reduce the stress in her job, and together with a vocational consultant she constructed a rehabilitation plan (*løn med refusion* or *virksomhedsrevalidering*), whereby the municipality compensated the workplace for her taking a less demanding position in the firm for a one year period.

Both Anders and Eva received social benefits for a period during and after the hospitalisation, but on resuming their studies, they were granted an individual rehabilitation plan to finish their studies, providing them with financial support superior to the normal state student scholarship universally granted in Denmark when undertaking recognised full-time studies. Having avoided admission at a hospital, Martin kept on with his studies financially supported by the state student scholarship, and having finished his education, he was employed in a firm on normal terms.

While rehabilitation was the prime concern for some informants, others were eager to request a form of financial support which could give them security and stability. Already at the time of the first interview, Ole expressed his hope that OPUS could help him to be accepted for an early retirement pension, as described in Chapter Five. For other informants, the decision to apply was less obvious and, in some cases, more troublesome. At the time of the first interview, Per hoped that a rehabilitation plan giving him some time and support to 'get back on his feet' would make it possible for him to start in an ordinary job within a two-year period, and this was the plan as he

started working in a sheltered workshop. But after he experienced a relapse, he realised that he had to revise his expectations and, after discussions with staff in OPUS, he decided that he would be better off with an early retirement pension. Important for Per's decision was the fact that he would be able to keep his job in the workshop by converting it from a rehabilitation position into a special job arrangement (*støttejob*). Furthermore, the fact that his situation and right to receive the pension would be revised after three years assured him that he would not be permanently put aside from the labour market and 'normal life'. He hoped that he, after a period of doing well in the workshop, could move on to another type of special job arrangement (*flexjob*) in an ordinary firm, and possibly, with time, be employed on normal conditions. His success in passing the tests to achieve a driving licence for car and motorbike had strengthened his beliefs in himself. He told me about his plans to get a job in a large factory producing hearing aid devices, since there he would be able to use his training as a toolmaker to the fullest, and learn new sophisticated techniques of manufacturing.

Claus and Julie, too, stressed that the possibility of working with reduced requirements was important for their decisions to apply for early retirement pensions. Julie told me that the staff at the hospital had encouraged her to apply so that she would not have to receive the smaller amount given as social benefit when she was no longer entitled to receive sick pay.

Julie: I have been a bit against it. You feel old already, in some way. Already having to receive pension, and things like that. As if you are finished on the labour market. But of course you are not. You can get a job, even if you receive a pension.

JAL: Yes, but you have anyway not been sure about it?

Julie: Yea, you feel totally old. Being pensioned, and such. It is a bit a negatively charged word, I think.

Dennis told me, in the fourth interview, that he had been accepted for early retirement pension. His case manager in OPUS had wanted him to apply more than a year previously, but at that time he had resisted. He was afraid of being labelled (*sat i bås*) and he had similar fears to Julie of being perceived of as old: 'not able to chew butter' and ready to 'pop my clogs' (*stille træskoene*). His attitude gradually changed as he got to know more about it, talking to some of his neighbours who were already receiving early retirement pension. He felt less labelled as he learned that he, in time,

could maybe get a special job arrangement; it then did not seem as permanent and stigmatising to him. Claus said that he decided to apply for the early retirement pension while he still was in OPUS so that the team could support him in getting it accepted. He suspected that it could be more difficult when he had left the project.

For Birgit, who already had an early retirement pension when she was included in OPUS, it was also important to have the opportunity to work. After about a year in OPUS, she started working some days a week in a café of a voluntary organisation, and even if she found it difficult and challenging to be together with the other workers, especially in the breaks when there was nothing to do but talk, she was happy to have this opportunity to meet other people. Other research has emphasised the positive influence on self-esteem of having a productive community role (Barham and Hayward 1995; Davidson and Strauss 1992; Lorencz 1992). Altogether, six of the fifteen informants were receiving early retirement pension two years after they started in OPUS. Registration numbers of people with severe mental illnesses in Copenhagen reveal a steady increase over the age groups in the proportion of those being financially supported by early retirement pensions. For those aged 18 to 29 it is about 15 per cent, a proportion which gradually increases to more than 95 per cent for those from 60 to 66 years old (*Familie- og Arbejdsmarkedsforvaltningen* 2000b: 35). At the age of 67, a retirement pension is universally granted to Danish citizens. Due to changes in the policy over the years, it is, however, difficult to describe the exact reasons for this seemingly linear development.

The informants' considerations in relation to applying for early retirement pensions show how detailed aspects of social welfare policy programmes affect the meanings they attach to these schemes and the final decisions they make. Except for Ole, who stressed the opportunity of being left in peace, the informants attached positive value to the fact that the early retirement pension did not mean taking a permanent position outside the labour market. The possibility of arranging various degrees of support and attachment to the labour market gave them the possibility of gradually resuming a normal employment, or, to stay in a less demanding position without it having economic consequences. This is in contrast to the situation in, for example, the USA, where economic security is not provided in a similar policy arrangement, and where people therefore have to balance the benefits of having an

active role in society through employment against the stress and insecurity of maybe not being able to manage in the job (Mountain 1998: 106-8, 121-4). Estroff, too, demonstrated how the Social Security Income in the USA of the 1970s paradoxically rewarded the continuation of inadequacy demonstrated by not working (1981: 164-173).

Social policy did not, however, do it all alone. The informants' personal resources, in the form of previously gained competencies and social roles, as well as the support they received in their social environment, affected the way they were able to make use of the various possibilities of social support. It was easier for those informants who, before their inclusion in OPUS, were already following a certain professional career or 'track of life' by being enrolled in a certain job or an education or training programme. They could seek support aimed at helping them back to these particular tracks. For example, Irene could resume her job after a period on sick leave, and after she experienced a relapse, her employer suggested that she found a way to rearrange her situation at work, which led to an agreement between the workplace and the municipality to set up an one-year rehabilitation programme. Anders, Eva and Namira went back to the studies and training they had already begun. And Per found a workshop where he could use his training as a toolmaker. That they all, in various ways, had established social positions before their psychotic breakdowns meant that it was easier both for themselves, but also for the professional support systems in OPUS and elsewhere, to focus interventions on bringing them back to these positions.

An important quality of the intervention in OPUS was that the close personal contact between participants and staff generally ensured that the staff were familiar with the former achievements, as well as the present dreams and expectations, of the participants. This facilitated a better co-ordination between the wishes and competencies of the participant, on the one side, and the available programmes of social support, on the other. Further, the multiple-disciplinary teams drew on the competencies of both the team social worker and the project's specialist vocational consultant (see Chapter Six) to give advice in this complex field of rights and duties in social welfare policy. The knowledge, competencies, and resources available to the staff are thus crucial in determining the type of support for social integration to be provided the participant (cf. Barham and Hayward 1998).

OPUS as an agent of change: The recovery process as symbolic healing

This and the preceding chapter have provided detailed accounts of various techniques of treatment and forms of social support which have either been provided directly in OPUS or facilitated from the wider society through the mediation of OPUS staff. Chapter Six presented the individual support from the case manager and the uses and effects of medication. This chapter has presented social and cultural aspects of the intervention by describing the therapeutic work in the family groups and the social skills training groups, and by outlining the individual strategies of participants towards engagement in social relationships as well as the financial support and vocational integration provided by the Danish welfare system. These various dimensions are interconnected in the lives of the participants in OPUS. For example, a good personal relationship with the case manager can motivate the individual to take medication which can reduce symptoms, allowing the person to be together with other people and get a job. On the other hand, social welfare facilities, the stability provided by a job, and a good social network can support the individual to engage in therapeutic groups while continuing to see the case manager and to take the medication.

The individual course of recovery in OPUS was therefore neither a straightforward nor an automatic process. While general structural aspects of the Danish welfare system have been presented above, the symbolic dimension of the healing process can now be outlined, referring to the six universal elements of symbolic healing:

1. The staff in OPUS had a coherent system of biochemical and cognitive psychological explanations for the origin and nature of mental illness, and how it could be dealt with.
2. This system of explanation provided the participant in OPUS with an understanding of his or her own situation and its resolution. Biochemical and psychological explanations are generally accepted in Danish society and both are used in various professional settings and by individuals themselves (e.g. when speculating about their biological, genetic dispositions and when doing 'personality tests' printed in popular magazines). As such, the explanations qualify as a 'social myth', generally accepted in society.

3. The staff in OPUS convinced the participant that his or her problems could be understood within the framework of the biochemical and cognitive psychological explanations. In order to convince the participant, the staff used various techniques: they supplied books and magazines illustrating the biological basis of mental illness in text and colourful images, presented posters and overheads with similar content, and manipulated the participant rhetorically by consistent repetition of the explanations when they met individually for case manager meetings or in the psychoeducational family group or for social skills training.
4. When this consensus was reached, or simultaneously with the process of convincing the participants, the staff in OPUS attached the participant emotionally and intellectually to these explanations. They attempted to influence the participant to accept that his or her problems were caused by a mental illness. The success of this work was then named by staff as a quality in the mind of the participant: 'insight in illness'.
5. The process of therapeutic change was then led by the staff in OPUS by using the concepts and explanations of mental illness to achieve a transformation of experience. Through therapeutic encounters the participant learned to re-evaluate or 'reframe' past and present experiences as indications of, or significant to, mental illness. The successful transformation made the participant feel more safe and relaxed since the suffering could be explained and controlled; and the participant stopped feeling guilt for having the problems since they could be explained as caused by the mental illness. The physiology was directly affected by the extent to which the participant took medicine (with the possible effects and side-effects that followed). Relationships with other people were affected directly by learning new ways of social interaction in social skills training and in the family group. The individual's relationship with society at large was influenced due to the achieved social status as 'mentally ill' which gave access to various forms of social and financial support. The new social status also affected the individual's relationship with society in a more subtle way by making the

individual engage in information management strategies, e.g. to avoid discrimination at work.

6. The 'healed' individual acquired a new way of conceptualising his or her experiences as influenced by mental illness, and a new way of functioning which had to take the 'mental vulnerability' and the danger of psychotic relapse into account. The process produced a new individual narrative of the personal past and present, and the likely future. The narrative summarised what happened to the individual, and how the psychiatric treatment and participation in OPUS was able to restore him or her to happiness and health.

This presentation helps us to see how the intervention facilitated the participants to go through a recovery process – it provides a cultural explanation of the function of OPUS as a social agent of change. The recipients of the intervention programme were provided with narratives to (re-)engage in individual life projects. Further, the practice of symbolic healing in the community intervention programme can be seen as an institutionalised ritual to mark the person's transformation back into health – an end stage in the *rite the passage* (van Gennep 1960 [1906]). This is a *ceremonial dimension* in mental health care which has been missing in psychiatric practice where the admission to a psychiatric hospital has generally not been followed by a 'passing out ceremony' (Barrett 1998: 478ff.). A British study, too, observed that former patients of psychiatric wards 'appeared to have received little or no guidance in tackling the meanings of schizophrenia and negotiating the cultural burden which the diagnosis inflicted on them' (Barham and Hayward 1995: 136). These testimonies indicate striking contrasts to the therapeutic work in the innovative OPUS project.

The mechanisms of symbolic healing do not account for the individuals' appropriation or rejection of the explanation presented in OPUS; nor do they account for how a transformation of self was brought about on the individual level. In the next chapter, I will turn to these issues as I examine individuals' attempts to make sense of their experiences with psychosis, or other serious mental problems, and how the experience in OPUS affected their self-understandings, or identities.

Chapter Eight

Understanding mental illness and identity

This chapter returns to examine the perspectives of the recipients of the intervention. As individual actors under special, and especially demanding, life circumstances, their situations raised existential questions concerning the meaning of their experiences and their individual identities.

The chapter describes how the individuals took active parts in making sense of their experiences. They were not mere objects of health and social policy providing them with support and treatment in community services. They defined themselves, given their individual predicaments, their biographies, and the particular social circumstances and the cultural repertoire accessible to them. The broader, anthropological perspective of this presentation and discussion is to demonstrate how institutionalised discursive hegemony is both reflected and challenged by individuals drawing on a range of cultural conceptualisations, and by engaging in innovative, meaning creating-activity. Towards the end, the chapter presents an overview of the informants' general situations after having ended their approximately two-year long involvement with OPUS.

Experience management and systems of explanation

Through techniques of symbolic healing, demonstrated in the previous chapter, the OPUS project promoted a particular system of explanation. Biochemical conceptual models and cognitive psychological approaches to problem-solving and interpersonal communication were taught to the recipients in social encounters with the case manager, in the family groups, and in the social skills training groups. These understandings and conceptual models were not intended to be used exclusively in these particular social settings. The intervention aimed to promote the idea that this 'knowledge', as it was presented, would be used by the individuals in their daily lives, during the periods when they were not in contact with the intervention programme and when they had terminated their involvement in the programme after the two-year period. Since the individuals are

members of a larger society and cultural tradition, the particular understanding promoted in institutions of mental health care were, however, not unchallenged. Users of mental health services apply various systems of explanation when describing their sensations and individual situations, often by using different explanations in different social situations (Harold-Steckley 1987; Lindow 1986).

This attention to how individuals access, and actually appropriate, systems of explanation is similar in some respects to the anthropological and sociological interest in extracting and analysing *illness narratives* (Becker 1997; Hydén 1997; Kleinman 1988b). It has, for example, been described how narratives are used by the chronically ill to reconstruct their lives and identities within a biographical context (Hydén 1997: 56ff.), and how cultural ideologies are reproduced in these (Becker 1997). However, taking illness narratives of suffering (cf. Kleinman 1988b) as a point of departure for the anthropological or sociological analysis of the life courses of individuals who have been diagnosed as mentally ill has the unfortunate consequence of reproducing and reinforcing the 'native' discourse of suffering that dominates psychiatric practice (Barrett 1996:262-66). It has been observed that the emphasis on 'suffering' and 'witness' in studies of illness narratives echoes powerfully-symbolised Christian themes as well as secular morality, and that individuals in pain and distress are at times portrayed in romantic, if not downright sentimental, terms (Bury 2001:277). In a similar vein, Van Dongen (1998) has demonstrated how the Protestant Christian notion of 'hope' is an important cultural symbol in Dutch psychiatric practice.

A further limitation of the analysis of illness narratives is a tendency to focus on the situatedness of the narrative event (Hydén 1997:52). Other studies elicit individual *explanatory models* (Kleinman 1980: 104-118; 1988a: 155-157), demonstrating how psychiatric patients' descriptions represent different understandings of the nature, cause and course of mental illness (Estroff *et al.* 1991; Sayre 2000). Approaches such as these emphasise the individual specifics of the narrative and make it difficult to clarify how specific social and cultural factors influence and motivate the person concerned. As a paradoxical result, individual agency and reflexivity may be underplayed in the analysis of the narrative.

As an alternative, I will argue that individuals take an active role, when applying understandings and meanings to their situations and experiences, in a constant

process of negotiation between various *systems of explanation*. This is in agreement with the observation that ‘plural healing systems can exist within an overarching cultural tradition’ (Csordas 2002:125). Thus I am not introducing a fundamental theoretical innovation here: the concept of ‘systems of explanation’ is simply my terminology for a broad notion that is elsewhere referred to in various other ways.³⁸ Systems of explanation are *generalised* explanatory frameworks, in contrast to ‘illness narratives’ or ‘explanatory models’ which are *specific* stories or discourses narrated by specific individuals placed in time and space. Systems of explanation exist in the cultural repertoire of the society and are available to individuals depending on their social positioning. For example, the biochemical and cognitive psychological systems of explanation became available to my informants as they encountered the intervention in OPUS and were subject to the influences described in Chapters Six and Seven. This chapter will explore why and how those individuals, viewed in the context of their personal circumstances and experiences, appropriated or rejected systems of explanation.

Csordas (2002) argues that the very differences in the ways in which different systems, such as psychiatry and religion, for example, explain phenomena may, paradoxically, contribute to the possibility of their coexistence in the experience and understanding of individuals. An individual might, for example, simultaneously seek help both from a religious healer and a psychotherapist: insofar as these represent ‘intersecting planes in the field of experience, they can be *complementary* rather than contradictory’ (*ibid.*:126, italics added). While Csordas is concerned primarily with explicating the embodied common ground of the various explanations, the following presentation directs attention to the ways in which my informants manoeuvre to appropriate, integrate, synthesis and negotiate the various explanations available to them, in their efforts to make sense of their experiences of mental illness.

During the first two rounds of interviews with my informants, I learned that the way they perceived their psychotic experiences and their personal situations was significantly influenced by their participation in OPUS. Several told me that during the time they had been in the project, they had come to a better understanding of their

³⁸ Various terms similar to ‘systems of explanation’ are, for example, deployed by the same author and in the same text; for example, Csordas (2002) talks about ‘sets of cultural knowledge’ (*ibid.*: 124), ‘healing systems’ (*ibid.*: 125) and ‘interpretive forms’ (*ibid.*: 136).

situations and difficulties. To find out if this was a more general feeling among the participants, I included a question on the subject in the survey I conducted among participants in 2000. On a five-point scale from 'not at all' to 'very much', 18 of the 38 respondents, almost half, replied with one of the two most positive indications; 13 replied with the median indication 'somewhat', 7 replied 'a bit', and none replied 'not at all' (Larsen 2001a: 161). While the initial interviews with informants indicated that, primarily, those who had participated in a social skills training group had benefited from a new, and better, understanding of their problems, the results from the survey proved that there was no such simple effect from this particular intervention technique. Of the eleven survey-respondents who indicated that OPUS 'very much' helped them to understand their situations and difficulties, only five had participated in a social skills training group (*ibid.*). The finding indicated that psychoeducation and the general practice of symbolic healing in OPUS was also effective through the case manager and the multiple-family group.

In the interviews that followed, I questioned the informants in detail about their perceptions of their psychotic experiences, their situation, and their difficulties: whether they had changed over time, whether their participation in OPUS had had any influence on them, and what the new understanding meant to them. My data supported the observation that, following first episode psychosis, it is imperative for the individual to find meaning in the experiences (McGorry 1995). As my informants were part of a society presenting a plurality of institutions and traditions of knowledge, they could draw on various social contexts, and various sources of cultural authority, to complement, substitute, and challenge meanings and understandings presented in the intervention programme. I was especially interested in exploring whether my informants had been influenced by any particular social relations or systems of explanation in making sense of their experiences. Further, I wanted to find out in what sense their understandings were private, thereby exploring the relationships between individual and collective meanings of psychosis.

Informants presented varying strategies in the management of their experiences, which differed in two important respects. The first pair of contrasting strategies have, elsewhere, been described as the principal contrasting recovery styles of 'sealing over' and 'integration' (McGlashan 1987, in Mountain 1998: 29ff.). The

informants could choose 'sealing over', by trying to encapsulate and forget about their experiences so that they could concentrate on their present and future lives and 'move on', or 'integration' by taking an active role in integrating an awareness of the experience as part of their self-understanding. The second pair of contrasting strategies clarified significant differences within the 'integration' strategy: either informants dogmatically endorsed an all-explanatory model, or they tried to connect and supplement various models in innovative theory-building work, which I, following Lévi-Strauss (1966: 16-33), will call a strategy of *bricolage* (see also Corin 1990: 179; Van Dongen 1998: 178).³⁹

Even if some informants in the period of research kept to one of the strategies of experience management, it was most common that they, in the course of the period following their first psychotic episodes, changed and modified their strategies several times, depending on their prevailing mental state and on the influences from their social network or therapeutic interventions. For example, in the first interview, Frank said that he did not want to concern himself with the psychotic experiences since they made him depressed, but when I interviewed him about two years later, he was very eager to tell me about his experiences and regretted that he had not had the opportunity to talk in depth about what had happened to him. On the other hand, Eva described how she initially firmly held the biomedical explanation of her experiences, whereas later she sought psychological explanations and was intrigued to learn that some artists had seen psychotic experiences as a source of creative inspiration. Two years after her psychosis, however, she told me that she had stopped speculating about how her experience might be explained, since she had learned that each explanation repeatedly became falsified by another theory. In this way, there were individual motivations behind the various strategies, and, for example, it was possible to distinguish between 'sealing over' strategies, which were either chosen for lack of any explanations, as in Frank's case, or those which were informed, as in Eva's.

³⁹ Corin uses the expression 'Their strategies of relating to the world and to themselves remain a mere "*bricolage*," always fragile and vulnerable' (1990: 184) to suggest that *bricolage* represents a somewhat inferior life strategy. I agree that the strategy is 'fragile', since it is characterised by constant (re-) negotiation. But it is my position that this is an attribute of human creativity in life, and a proof of individual analytic and theory-generating capabilities, as originally suggested by Lévi-Strauss (1966: 16-33).

My data further proved that the strategies were not mutually exclusive. In the single face-to-face meeting I had with Ole, just after he started in OPUS, he described to me his conscious strategy of sealing over, involving an effort to integrate his experiences. He told me that it was important for him to get an overview of what had happened to him during the psychosis, to ‘think the problems through.’ Then, he encapsulated (*indkapsle*) the chain of events (*forløb*) and created a mental space for them. Ole explained that his experiences had roots which went back to his childhood, and that it was not something he could talk to anybody about since they were his innermost thoughts, his secrets. Describing the psychosis he said: ‘It is your whole life which is being revised. It is the course of a human life (*menneskeligt forløb*) – it is my life.’ Since I did not have the opportunity to conduct a further in-depth interview with Ole, I do not know whether he later revised this strategy of combined integration and sealing over.

As described in Chapter Five, some informants were eager to get back to their former life course and put the experience of psychosis behind them. This did not, however, mean that they all immediately wanted to seal over the experience. Anders, for example, appreciated the opportunity to talk to his case manager about his strange experiences. Later, he was also happy to meet other participants in OPUS during the meetings of the editorial board of the book project, to read and talk about the similar experiences they had.

Anders: It has been exciting to hear the others’ thoughts about it [the psychotic experiences]. ...//... It seems to be similar, and that we have had similar experiences. There are some differences in the ways to describe it, but... of course, there are also many clear differences. But these strange experiences, I think that they are very similar, when I take a look at them.

JAL: What does it mean to you that you hear that they had similar experiences?
Anders: Well, first of all it has confirmed that I was ill. Or, that I had that experience, and that others experienced the same, you see, more or less. I suppose that it becomes less mysterious, or, less unique, you see. Because it felt very unique, but, in fact, it’s not.

Anders here addresses three important points regarding the subjective reflection on the psychotic experiences. First, it was confirmation that he had had the experiences. Secondly, the experiences felt unique and mysterious. And thirdly, finding similarities

in others' experiences confirmed that he had been ill. Other informants also emphasised each of these points.

During our first meeting, Brigit talked about the uncertainty she felt concerning the psychotic experiences. In Chapter Five, she described this as her 'identity problems', not being sure whether her experiences and beliefs were right or wrong, and if she had them at all.

Birgit: I feel that it is a bit imagination that I felt like that, that it wasn't really anything.

JAL: No, that you haven't really accepted, maybe, that, in some periods, that you felt bad?

Birgit: Yes, I find it hard, also, because time has passed, you see. And if I just could remember it as if it was yesterday, then it would be much easier to say: 'Well, that was how it was,' you see. Therefore, I really need to have it repeated all the time, so that I can see that it was... that there really is something... that I have become wiser, you see.

JAL: Yes.

Birgit: But I still, sometimes, find it difficult... then I just believe that it was imagination. I sometimes think that it was because I was ill, and that it probably was not that bad, and I could just try to relax and... [I tell myself:] 'it is probably just my own fault,' and so forth, you see. And if I just had not done some things then I wouldn't have all these problems, you see. And again taken the blame for it.

Birgit's statement that her hallucinations and delusions might have been her own imagination, compared to if they 'were real', has to be understood in the moral perspective of *personal responsibility*. In her perspective, if she was responsible for having the psychotic experiences, she would be to blame for them. They would be a product of her imagination and hence subject to her control. On the other hand, if they 'were real,' they happened to her without her having any control over them, she could not take responsibility, and would not be to blame for them. The latter perspective is contained within the notion of illness – a power not to be controlled by the individual subject to it.

Martin, too, addressed this issue of whether he was to blame for his problems when he, in Chapter Five, mentioned that the notion of illness relieved him from feeling that they were his own fault, because 'I am a bad person.' Apart from clarifying that, like Anders, informants retrospectively were in doubt about whether their experiences had been 'real', or just a product of their imagination, the issue concerns the notion of

the individual as a *morally responsible agent* (cf. Barrett 1996). By being classified as mentally ill, the person is regarded as not responsible for his or her sensations, feelings, thoughts, and actions. The reality of the experiences and actions are ascribed to the illness, and not to the person.

The experiences felt unique and mysterious to the informants. In some cases, this intensified the individual experience of religious or existential insight, as described by Anders and Kristina in Chapter Four. Frank, too, thought that his experiences were signs that he had been selected by God as ‘number one’, and that he was immortal. When he had an out-of-the-body experience, he compared this to religious descriptions of what happens when the soul leaves the body when dying. In other cases, my informants’ thoughts that their fears and problems were unique to them made them feel alone in their struggle, and the thoughts increased their feelings of guilt; they thought that they were the only ones who had these problems.

Realising that other people also suffered from the problems or experiences both confirmed that they were not that unique and mysterious, and that they ‘were real’ since they could be categorised as an illness. Eva explained, in the fourth interview, that the strength of the biological explanation of illness was that you could find similar structures and patterns in the psychotic experiences, across individual biographical and socio-cultural background.

Because, anything which is not that [the biological explanation of mental illness], is in some way very specific. The environments you have been in, the way you lived, and your personality, it is specific, but, in fact, the psychotic symptoms are general. You see, they are both general... they are also general across cultures, I mean, the experience of what is up and what is down, you see. And to believe that when you read the newspaper then it is about yourself, you see, then all different people, who have been in all kinds of different situations, they got exactly the same symptoms. And therefore there cannot be some direct causal link between the environment which surrounds you and the psychotic symptoms, there has to be something else too.

Apart from confirming that the experiences had been ‘real’ – i.e. that they had been experienced by the individual as a passively receptive subject, and not created by the individual as an active and responsible agent – the integrative approach involved making sense of them by finding structural similarities and recognition in other people’s experiences and becoming acquainted with systems of explanation.

Understanding mental illness

I will now turn to a description of my informants' attempts to understand mental illness, either by dogmatically embracing a particular explanation or engaging in creative work by adopting and adjusting various systems of explanation.

Some informants described how seeking explanations for their experiences or problems could have similarities with their delusions. Irene told me that after she had been admitted to the psychiatric ward, and the medication had 'slowed down' her psychosis, she thought that her experiences, maybe, were caused by clairvoyant abilities.

[The idea that I had been clairvoyant] came just after I... I won't say that I had become well, but just after the pills started to work. Then I started to explain to myself what happened to me, what I had just gone through. You could say 'Well, the pills apparently did not work that well that I had completely regained my sense of reality.' But I started to generate explanations for what I had gone through.

Irene said that the idea that she had been clairvoyant probably came to her because she was trying hard to understand her experiences and explain to herself why she was in this situation.

Similarly, Claus said that he got the idea that a microchip had been implanted in his head to explain the chaos of thoughts and feelings he endured when he was psychotic. I asked him what it meant to him to have learnt concepts and explanations of these sensations:

Claus: You can put your thoughts and emotions into words. You can categorise them and say that 'This is this, and this is this,' and then that's it, you see.

JAL: So, words as 'racing thoughts' (*tankemylder*) make you sure about what it is. It becomes understandable, or what happens if you don't have these words?

Claus: Then you start having paranoid thoughts that something is implanted in your brain, or something, you see.

JAL: Yes, because you don't have the words to understand what you are experiencing?

Claus: You see, if you talk about schizophrenia, then it is split personality, right. And I never thought that schizophrenia had anything to do with things as racing thoughts. I did not know what racing thoughts was, I just knew that at

night, when I was in my bed and was about to fall asleep, and then everything just turned around, it was just unpleasant, you see.

JAL: But because you have got these words then you are more able to relate to it, and say 'This is racing thoughts,' so that you can control the experiences and thoughts?

Claus: Yes, and try to relax a bit again.

The language provided a means of objectification by which he could control his disturbing sensations and experiences (cf. Jackson 1994: 204-9).

Irene and Claus talked about how they created delusion-like explanations for their psychotic perceptions in the absence of a biochemical, cognitive psychological, or any other suitable explanation. Martin told me about a similar mechanism when he sought explanations for his social problems by telling himself that he was too ugly for other people to be able to like him. Delusions can thus, partly, be understood as the individual's attempts to make sense of disturbing perceptions and problems. This interpretation is supported by other studies: Thoits (1985: 240ff.) found that psychiatric patients' seemingly 'irrational' explanations and beliefs had a psychological function by giving meaning to experiences and emotions which otherwise were difficult to grasp for the individual, and Strauss (1989) argued that patients influence the course of their disorder by interacting with it. Further, Sayre described how an in-patient in a psychiatric ward 'expressed gratitude about having learned that her condition was a psychiatric illness and not "some frightening form of supernatural power"' (Sayre 2000: 76). This evidence supports Carr's (1988: 351) suggestion that 'delusions themselves represent coping devices in which the schizophrenic patient attempts to master a frightening and bewildering subjective state by imposing meaning or forcing an explanation upon experiences which would otherwise be meaningless or inexplicable' – and that the notion of 'secondary delusions' might be compatible with this interpretation.

In this light, delusions are extreme cases of dogmatic explanatory models, distinguished by being idiosyncratic, i.e. private to the individuals who hold them. The delusion might explain the experience to the individual, but other people do not share the reasoning and system of explanation provided. An example was Julie's experience of being persecuted by her employers, who set up a conspiracy to harass her, as described in Chapter Four. Her delusion provided an explanatory framework for

interpreting not only unpleasant experiences and feelings of being surveyed at work, but also of being harassed in her home and by the taxi driver, who all were in on the plot against her. In Julie's case, this explanation proved to be highly resistant to other explanations she was presented with, though, for example, her participation in a social skills training group and a family group.

When Julie wrote her story for the book project, one and a half years after she had started in OPUS, she still stuck with the delusionary interpretation of events. She told me that it was the first time she had had an opportunity to tell the full story about what happened to her. Apparently, no one had attempted to negotiate her explanatory model with her (cf. Kleinman 1988a: 239-244; 1988b: 155-157; McGorry 1995: 322ff.). Sayre (2000: 78) has observed a strategic hiding of delusions among psychiatric in-patients, who thereby hoped to be discharged. In this light, it is a possibility that Julie *strategically* denied, or refrained from presenting, her delusion when encountering staff and therapeutic groups, thereby avoiding having it directly challenged. During the meeting of the editorial board when Julie first presented her story, some were astonished, not only because of the intensity of the story, but by the fact that she stuck with this explanation. Questioned by Anders, Julie explained that she did not feel persecuted any longer, but she believed that what happened to her was real, and not hallucinations. Anders empathised with her by remarking that it had been very difficult for him to accept that his experiences were not real: 'I thought I had reached a higher level of understanding. And then you realise that you were just crazy,' he laughed – suggesting how absurd and demoralising this realisation had been to him. Notice that Julie and Anders here do not use the notion of 'being real' in the special moral meaning of personal responsibility, as discussed in the section above, but in the more usual ontological meaning of actual existence in the objective, intersubjective world. Julie later withdrew her story from the book project, explaining to me that she did not want people to be frightened by it.

A dogmatic one-dimensional understanding of the experience was also found among informants who did not suffer from delusions. Some embraced the biomedical and cognitive psychological explanations offered in OPUS as unquestionable, and as the ultimate truth about their experience. This was in accordance with the authority with which it generally was presented by staff in OPUS, as discussed in Chapters Six and

Seven. Dennis told me, in the fourth interview, that the words and models he learned in OPUS fully covered and explained his difficulties and the experiences he had. He explained that the understanding helped him to acknowledge that he was ill, and that he needed help. After having stopped attending the social skills training group, Dennis sometimes took out his folder and looked through it to revise and remember the situations when he was taught different things. In the folder he could find everything he needed to know about his illness.

You have got this folder, so you can just look it up. Boom! Then you have got it in black and white... you see, what its name is, what you call it.

Except for Julie and Hans, the other thirteen informants recognised that the biomedical and cognitive psychological concepts and models could explain aspects of their sensations and difficulties, and often help them to encounter these. But most challenged the notion that these concepts and models were the *only* meaningful explanations. Ranging from spiritual to existential frameworks of interpretation, alternative models supplemented or combined with the models in OPUS to provide the informants with explanations of their individual experiences. What distinguished these models from delusions was that they found resonance in the *cultural repertoire*, that is, the myths, traditions and institutional bases of authority in the wider society.

In the fourth interview, Frank described the power of spiritual or religious explanations of his experiences – echoing findings in other studies (Barham and Hayward 1995: 117-20; Corin 1990: 177ff.; Estroff *et al.* 1991; Sayre 2000; Van Dongen 1998: 179ff.). It has been pointed out that the individual's attempts to find religious explanations can be understood as 'a strategy of the self in need of a powerful idiom for orientation in the world' (Csordas 1994d: 287). Frank recognised that he had been psychotic, which he explained as a kind of 'poisoning' of his mind, similar to the effect produced by drugs, especially hallucinogenic mushrooms and cocaine taken in combination. But, at the same time, the psychosis gave him access to the spiritual. Frank told me that a problem with the psychiatrists was that they did not understand the spiritual aspects, and that it was pointless to try to tell them about his experiences when they did not even know how it felt like to have taken hallucinogenic mushrooms. He said that during our conversation, he talked more about his psychotic experiences than

he had ever before disclosed in conversations with psychiatrists or staff in OPUS. Only once, during an interview with a researcher for the medical trial in OPUS, did he feel that she understood his experiences, but, at the time, he was not ready to talk about them.

I have been sitting and talking with a researcher, and then she asks: 'But, are you God?'. And then I said 'Yes,' you see. And then she was sitting and answering some questions, and was sitting and writing on a piece of paper, some lines of some kind. And then, you see, she was trying to figure it out, if it was it, you see. I will honestly admit that maybe it was not exactly the time to talk to her at that time, a time like today, maybe, then it could be nice to talk to her. Because, she was listening and she also knew what the spiritual was, I could hear that. I could see that she knew what it was, you see.

As described in Chapter Four, Frank believed that he had special spiritual powers during the psychosis. He did not belong to any particular church or sect, but he had read about the main world religions and felt that his experiences had a lot to do with religion. He told me about Christian and Muslim prophets, and said that in his psychosis, he had a strange experience during which he saw the text 'number one' written, and felt that it was addressed to him. During our conversation, I noticed that there were some books with texts from Jehovah's Witnesses on his bookshelf, and remarked that numbers and the imminence of the Final Judgement play an important part in their beliefs. Frank said that the books did not belong to him but the guy he used to share the flat with. Frank had looked through the books a bit, but he was not impressed. And once, some people from the Jehovah's Witnesses had knocked on his door and he had invited them in to have a chat with them, but during the conversation he soon realised that they did not have any real spiritual insight. They were just repeating words and sentences they had learnt by heart, Frank told me.

Frank said that he would like an opportunity to talk to a person who had special knowledge of the spiritual. He had seen a programme about occultism on television, called 'The Spirits' Power' (*Åndernes Magt*, on the channel 'ZULU'), in which a priest of a reform church exorcised a ghost. Frank thought that he would like to have a chat with the priest concerned.

If I had a talk with him, and I told him about the things I have experienced, then he maybe would not renounce it: 'Well, maybe you experienced that.' I don't think that he would [renounce it].

Even if Frank, in this way, referred to a wider cultural and social context of interpretation and recognition of his experiences, he had not sufficient opportunity to have his personal experiences discussed and tried out against the authority of an authoritative system of explanation. In this way, his spiritual explanation seemed to come close to the idiosyncrasy of the psychotic imaginations. He was so captured by the realm of the spiritual that he even used it to explain rather straightforward physical phenomena, such as seeing himself as double in the mirror when squinting.

The situation was different for Kristina, who also interpreted her psychotic experience as a spiritual phenomenon. While Frank primarily interpreted his personal experiences as spiritual, due to the knowledge he had gained from books, television, music, or other media, Kristina was actively involved in a social environment which supplied her with these explanations. Chapter Six described how she was seeking to distance herself from some of these social environments, since she, in accordance with the stress-vulnerability model advocated in OPUS, had come to the understanding that too strong an engagement in spiritual thinking led her to psychosis. In the second interview, she told me that the perspective in OPUS was too restricted.

Kristina: It becomes a bit too categorical. You could, kind of... look a bit more at the human aspects of what happens, which are very natural, and such. What kind of conflict have I been in, you see. And things like that.

JAL: And then, what is it instead, in OPUS?

Kristina: For example, it is things such as 'that I find it difficult to be by myself,' and things like that, and we talk about warning signs and persisting symptoms, and what you can do about that, you see. And the only thing you can do about it is to listen to some music and talk to your parents, and things like that. Well, it is a bit bleak, you see, in some way. I don't know, maybe you can't expect more.

Two years after she started in OPUS, Kristina maintained that its concepts and models had been of very restricted use to her. Already in the second interview she suggested that the situation she was in was more than merely an illness-related problem, or a problem of individual psychological difficulties, it had to be seen in a broader existential perspective, as related to the general condition she was in. Kristina had

spoken to a psychologist outside OPUS, who suggested that the experience had brought her 'close to the inner core in herself.' About a year later, Kristina told me that she recently had seen a clairvoyant, who had described her experiences as connected to problems in her relationship with her father. The clairvoyant said that Kristina became psychotic because she had reached insights that she was not ready to tackle, like 'flying a plane when you don't know how to use the instruments.' Kristina found this interpretation very useful since she agreed that she had unresolved and problematic feelings towards her father. At the same time, she felt that the concept of 'psychosis' had been accurately ascribed to her experiences, since she, at the time, had 'gone so far out' that she belonged in the psychiatric ward. In this situation, the clairvoyant could have done little to help her. In fact, the clairvoyant told Kristina that she did not want to continue having sessions with her, since she feared that the intensity of the sessions could provoke a psychotic relapse. Hence, the alternative system of the clairvoyant recognised a line of demarcation in relation to the intervention area of the institution of psychiatric treatment.

In the previous interview, Kristina had told me that, retrospectively, she saw a logic in her three psychotic episodes. She believed that they had worked as a kind of therapy for her by helping her to get over her love relationships.

It was, kind of, something I was not able to deal with: 'How do you stop being in love with somebody? How do you do that? It is not possible!'. And therefore it was the only way I could do it, it was to arrange such a psychotic experience, you see. It effectively got me away from it [the love], you see, I was completely obsessed by it [the psychosis].

Irene presented a similar explanation of her psychotic episodes as reactions to demanding life situations. As described in Chapter Four, she saw a link between emotional tumult in connection with important decisions regarding love relationships and the direction of her professional career. She was especially bewildered about whether to pursue a career in the public sphere at work, which her academic training had prepared her for, or if she should take the more traditional domestic role of a wife and a mother. Hence, her existential dilemma, as well as the mental illness she was subjected to subsequently, reflected a moral conflict of cultural values related to socio-

economic changes in Danish society. Irene was, however, alone in expressing such a clear link between societal organisation and individual experience.

Irene found confirmation for her reasoning in the stress-vulnerability model. And, she told me that she had possibly prevented a psychosis six or seven years previously. I asked her what she did then:

You could say that I acted rather drastically. Basically, it was the same situation again with a boyfriend where everything was about to fall apart, a job which was extremely stressful... unfaithfulness, also... you see, emotionally a complete mess. And in that situation I got rid of the boyfriend, and I wrote to my employer that I didn't want to work there any longer, and then I took a holiday. And there I was sitting for a week, looking at the water. And I had a lot of thoughts, I clearly remember. In the night I was sitting and looking up at the stars, and I had all those many thoughts, you see. But, then I came back home, and things fell into place.

Irene believed that if she had not taken these drastic steps to change her life circumstances, she possibly would then have ended up in the psychiatric ward. She told me that she had presented this interpretation of events to staff in OPUS, but she felt that they had not taken it very seriously. In contrast, an innovative treatment programme for first-time psychotic patients in Finland (Seikkula *et al.* 2000, 2001a, 2001b) bases the therapeutic intervention on an effort to establish a dialogue within the family. In this social constructivist approach, they understand the psychosis as a pre-narrative attempt to make sense of one's experience and to cope with experiences that are so heavy that they have made it impossible to construct a rational spoken narrative. From the perspective of symbolic healing, discussed in Chapter Seven, there might be similarities with the workings of the family groups in OPUS, but a radical difference is that while the Finish programme uses the understandings and explanations of the different family members, OPUS presents participants and relatives with an already established biochemical and cognitive psychological explanation.

As described in Chapter Four, Lotte related her hallucinatory voices to life traumas she experienced in her childhood. She applied a psychoanalytic or psychodynamic system of explanation by describing her psychosis as an indication of the need to work with (*bearbejde*) her trauma and not to repress (*fortrænge*) the experience, and by referring to her voices as 'a little psychologist.' The theory of psychological

mechanisms was part of the cultural resource on which she drew. The broader authority of this explanation was confirmed by Per, who repeatedly requested psychotherapeutic consultations. Twice, however, psychologists – who appeared as institutionally-endorsed representatives of this particular system of explanation – convinced him that the psychosis was not triggered by his father's death, but caused by a biochemical imbalance in his brain.

Martin presented the most elaborate version of individual *bricolage* in his analytic and theory-building work, piecing together different interpretations and systems of explanation to give meaning to his experience. About a year before he came in contact with OPUS, an article by a psychologist describing general problems of low self-esteem among students changed his way of thinking about his situation. Before that, he had not attempted to explain his problems in any particular way.

Many of my problems, I thought.... I thought that it was quite natural that I didn't feel like being in the kitchen of the student flat, you see. It was not something I related to low self-esteem. ...//... I thought... for example, I was unhappy with my looks, you see. And then I thought: 'It is understandable, because I don't look good, therefore it is quite natural that I don't like being in the kitchen.'

As described in Chapter Four, the article made him think differently about his situation and his actions – the perspective it brought to him made him re-conceptualise his situation from being 'natural' to being a psychological problem, for which he could receive professional help to overcome it. His difficulties were not just due to the way he was, to the fact that he was 'a bad person,' they were expressions of a general pathology which could be recognised and treated within the society he was part of. After having started sessions of student counselling, he also came across a book about loneliness (Dessau 1994), which provided him with further explanations for his situation, this time within a literate, philosophical, and existential framework of interpretation. Starting in OPUS, he found some comfort in the biomedical notion of illness, since it relieved him of feelings of guilt for his situation. It was also useful for him to become acquainted with the cognitive psychological notion of 'negative automatic thoughts', which helped him to develop techniques to avoid or restrain derogatory ideas of himself. As his parents got to know about his problems, they suggested that his realisation during

adolescence of having diabetes might explain his difficulties, but Martin told me that he did not find this suggestion convincing. And when he, one and a half years after his inclusion in OPUS, wrote his personal story for the book project, he returned to the psychological and existential notions of low self-esteem and loneliness as the explanations which most convincingly described his situation and the problems he encountered.

As mentioned above, Eva told me, at the time of the fourth interview, that she had given up attempts to discover a unified explanation of her psychosis. Instead, she had realised that various perspectives prevailed, and that the thinking advocated within psychiatric institutions was just one out of many: 'When you leave the hospital psychiatry then it is just an institution in the society, with the world views and understandings they have there.'

Understanding the psychotic experiences and mental difficulties were crucial to all informants. Explanations provided a means of controlling their disturbing sensations and experiences by objectifying them in language (cf. Jackson 1994: 204-9). In the period of the study, Julie remained submerged in her idiosyncratic delusionary explanation, but the other informants found explanations by drawing on systems of explanation available from a variously endorsed cultural repertoire of the society. The explanation upheld by employees in their professional roles in OPUS, and taught to the participants as 'psychoeducation', provided highly influential concepts and theories. And at certain points in time, some informants, like Eva, Dennis, Claus and Per, dogmatically accepted their ultimate authority. Others, such as Kristina, Lotte and Hans, from our first meetings, told me that they did not find the biomedical descriptions of their experiences satisfying, and instead they sought alternative explanations.

Most importantly, however, the data showed that explanations generally were appropriated, accepted, rejected, and re-evaluated in a continuous process. The course of the process was influenced by the individuals' involvement in various social and institutional contexts in society, as well as through communication media, where a multitude of perspectives and systems of explanation were available. OPUS was one of these institutional contexts. Further, the individuals, to various extents, engaged in *bricolage* – innovative and creative conceptual work to appropriate and combine the different explanations to make sense of their individual situations and experiences.

Transformation of self: Existential crisis and the problem of diagnosis

The course and direction of my informants' lives had been discontinued as they were unable to engage in their normal daily activities in the period when they were actively psychotic. And, as they had come 'to their senses' again, they had come to question their own perceptions and sense of judgement, as they questioned their personal capabilities for continuing their former life projects. Their self-understandings and the dreams they were pursuing had to be revised. As such, the mental breakdown was also an *existential crisis*, raising fundamental questions about who they were and where they were going (Larsen, in press). Informants agreed that the experiences affected or changed them 'as a person,' as Eva put it. They had become aware of the possibility of other ways of perceiving reality and their own lives, and, in some respects, it changed their interests in, and perspectives on, life. As Kristina said:

You feel changed. In your life you rarely experience something that changes you totally – changes you a lot, you see. Normally, you experience that things give you a push in this direction, then in that direction. This [the psychosis] has the effect that everything is turned much more around.

She could see that others experienced the same existential difficulties:

You don't understand what happened, the fact that you were psychotic. You see, it is like 'What is this?'. I mean, your entire world view has fallen down, because what I used to do, I can't do any longer. And then it is as if there is a sense of resignation and a lack of ability to manoeuvre and find out 'Now what?...', you see. I can see that the others [who experienced a psychosis] feel like that too.

Kristina described it as a situation where 'everything is taken away from one' (*alt er taget fra én*).

Irene expressed a similar view when I, during the second interview, asked her if she felt affected by the experience:

I feel much more humble, or like that... I feel that I have much less self-confidence, you see, without much self-confidence. I really have to, I feel, also in my work, find my feet to stand on again, you see. Because I have to find out what I can take, and what I cannot take, and this is a process which is painful,

because it... it tells me that the way I used to live, I can't continue like that. And then there are some things which have to be changed.

In the following interview, Irene told me that she had changed.

Irene: I look back and think... I can recognise myself as I was these about two years ago [before the psychosis], and I think that there were some decisions I would have liked to make, but was not able to. Some decisions I have made today, which results in saying 'This is the new Irene.' But I contain... but, you see, I act in the same way as I did before, I have just made some decisions now, which I was not able to make at that time, which I also believe had a part in me becoming ill, in fact.

JAL: You mean, before you became ill?

Irene: Yes.

JAL: Which [decisions] were that?

Irene: Partly, on a personal level, it concerned whether I should continue to be a married woman, or if I should divorce. In another personal level, it concerned whether my work should eat up all my time, or if I should use some more time together with my child. So it was some huge and rather important issues I was trying to deal with in the period just before I became ill, you see. And... now I have made those decisions, and it gives me also a sense of peace, which I didn't have before. Therefore, that about recognising myself, I mean, I recognise myself in that period, but I have changed, because I have made some decisions.

In the time shortly after the psychosis, Per and Anders, too, felt that they had changed. Per did not know whether this change was compatible with 'how he used to be' or if it was a depression, and Anders wanted to escape his present feeling of introversion and become more social, as he was previously. Others described or indicated in the first interviews that they felt that they now were different, compared to how they used to be. These findings are echoed in other research (Barham and Hayward 1995: 33; Rogers and Pilgrim 1993: 627), and McGorry (1995: 320ff.) has pointed out that the process of changing notions of personal identity can take several years. Important existential issues in my informants' lives had been addressed by their mental difficulties. Generally, they explained that, apart from challenging their former perspectives on life, the experience of the psychosis had made them more introverted and socially isolated.

Further, their mental problems and the participation in OPUS provided them with a new social identity as 'mentally ill'. Seen from outside, their identities were most

clearly affected by the labelling as mentally ill specified in the psychiatric diagnosis (cf. Scheff 1999). Their roles as, first, in-patients in psychiatric wards, and, later, participants in OPUS, ignited processes of self- and other-identification (cf. Jenkins 1996) whereby they simultaneously reflected on and were subject to new group categorisations. Becoming mentally ill involved the individuals in complex processes of *social negotiation* of their identities (Larsen, in press). The informants generally found it difficult to accept that they had received a diagnosis of schizophrenia. They felt trapped in a situation as permanent ill, and negative stereotypical ideas of ‘schizophrenics’ were evoked.

Per: It took me a long time to get over it. I was speculating... the first three, four months I used to speculate about it. And it dragged me further down, you see, because I knew that it was a serious illness. When I was told it, then... it was not pleasant to be told that.

JAL: Yea... what did you think, when you heard about it?

Per: Well, first I misunderstood it, I thought that it had something to do with mood swings, as most people believe today, you see. If I ask my friends about it, then they say that a schizophrenic is a person who constantly is in a different mood and... he is a split personality, and things like that, you see. And it really hasn't got anything to do with that, fortunately.

Initially, most informants said that they were scared by being stigmatised by the diagnosis, as Anders revealed when, in Chapter Five, he described how he withheld information about his psychotic experiences because he thought that ‘schizophrenia’ sounded too crazy. With time, the informants generally became less concerned about the diagnosis, what it meant, and which implications it had for them. Eva explained that after she had received psychoeducation, it was considerably dedramatised. At the time of the second interview, she felt that the hospital staff's comparison with ‘a broken arm’ – or the even more frequently heard, ‘diabetes in the brain’ – made her feel more at ease both with the diagnosis and the psychotic experiences she had endured. The biomedical explanation also relieved her of the pressure of ‘analysing myself’; it provided an alternative to seeking explanations in her personal biography. At the same time, the diagnosis told her that she was ill.

Shortly before our second meeting, Irene had her diagnosis changed from ‘acute psychosis’ to ‘manic depression’ (in the ICD-10 classification, ‘bipolar disorder’)

in the wake of her psychotic relapse. What especially bothered her about the new diagnosis was that it meant that she was carrying the illness permanently.

It [the diagnosis manic depression] tells me that I, in fact, have a defect, or whatever we call it... you see, that there is something *within me* which I have to be *very* careful of.

Informants generally shared this concern that the illness, and the diagnosis, expressed something alien within themselves which made it difficult to rely on their own capabilities and know their personal limitations. But, at the same time, Irene explained that the diagnosis gave her a sensation that they, i.e. herself, her family, and the staff in OPUS, now knew what was at hand – the problem had been identified as an illness with a specific name, the diagnosis – and she anticipated that it would be easier to find the right treatment and act fast to avoid further problems arising in the future. The act of categorisation, through the diagnosis, in this way provided a sense of control. Martin presented a somewhat similar view by explaining that he found comfort in the diagnosis, and he would have liked to have it presented to him shortly after the diagnostic interview. This was, however, not general practice in OPUS, since there was an awareness that patients might feel further burdened by the diagnosis. While some research has stressed the negative consequences of the labelling (Barham and Hayward 1995: 20-32; Scheff 1999), other research has indicated that psychiatric patients benefit from being told their diagnosis and learning about what it means (Mountain 1998: 86ff., 154). In this study, however, Martin stood out from the other informants by claiming that he did not feel overwhelmed or stigmatised by the diagnosis, as he explained during the fourth interview:

Martin: No, because before I requested help I was very ashamed about my problems, and I thought that it was because of bad human traits, or... that I simply was a bad person, you see. I think that a diagnosis says... that I can say to myself 'Well, it is because you are ill,' or 'It is because something is wrong, that some chemical substances are missing,' or... so that you, kind of, have some explanation. But then, this diagnosis I have got is kind of murky, you see, that 'schizotyp' [the diagnosis 'schizotypal disorder']. Then it is better to be really schizophrenic, if you should use it as an explanation to the problems you have.

JAL: Do you mean that, that it would have been better to be really schizophrenic? I mean...

Martin: Yes. In fact I believe so, if I was going to use it as... I mean, sometimes I think 'This schizotyp, it is something they just made up because they did not really know what was wrong with me,' I can think like that sometimes, you see. Then they just put me in that box.

JAL: Yes, you would prefer a somewhat more solid box?

Martin: Yes.

Our further conversation revealed that Martin's surprisingly positive attitude towards being diagnosed with schizophrenia was related to his lack of any previous knowledge or stereotypical prejudices about this term.

In contrast, Julie was at first very angry about the diagnosis schizophrenia, since she did not perceive of herself as ill – she had no 'insight in illness', as the OPUS staff described it. The notion of 'insight in illness' or 'awareness of illness' is commonly used by clinicians in psychiatric practice to describe whether or not patients agree with them about the presence, nature, extent, and course of the illness (Estroff *et al.* 1991: 339ff.). The patient who declines to self-label as mentally ill or resists treatment is seen as lacking insight. It has been suggested that denial of being ill can be seen as a 'normalizing statement' and the individual's cry for recognition of a persistently healthy self (Estroff 1989: 190), particularly in the case of adolescents who experience first time psychosis (McGorry 1995: 320ff.). Julie felt that she had been labelled and stigmatised, and that it was unpleasant, but in the third interview, she explained that she had stopped caring too much about it, since she was happy with her life. In the later interviews none of the informants who had 'insight in illness' felt that their individual identities had been radically changed because of the psychiatric diagnosis, even if they had come to see themselves as ill, possibly permanently. As Eva explained in the second interview:

It has not been as if my entire self-conception has been changed. I don't think that my identity... has been changed by it. I don't feel so. I mean, I think that it [the psychosis] is an experience you have, and things like that, but I don't think... I mean, it brings out some different sides of yourself, but it is because it, kind of, is a crisis situation. It is not that I think 'I am ill,' and then believe that it makes me handicapped, or makes me feel less worth, or things like that.

Anders backed up this perspective in the fourth interview:

Well, the psychosis, that is just a word, you see. It was a series of very intense experiences. So it is memories for me. And it is not something... I don't really think about this diagnosis which is stuck to me. And neither of those case descriptions which are lying around the system. So, I don't really know what more there is to say about that.

By saying that the psychiatric label 'is just a word,' he stressed the same thing as Eva: what mattered was not so much the diagnosis in itself, but the personal experience and whether she in any way was limited in her actions and engagement in society. To be permanently ill and having to give up the prospect of getting work and family, that was what mattered. Therefore, she said, it would be devastating to her if she, because of the illness, had to quit her studies and apply for an early retirement pension. That would mean, she felt, that she would be outside society.

In itself, the label 'schizophrenia' – a word stuck to them in the system – did not so much influence the informants' self-understandings as it did their strategies of self-presentation. Other studies have, similarly, found that psychiatric patients who are informed about the psychiatric meaning of the terms are careful to avoid presenting their diagnosis of schizophrenia to people, who might hold traditional derogatory models of the concept (Harold-Steckley 1987: 398ff.; Lindow 1986: 396). In a later interview, Eva described how she regretted that she was unable to change the stereotypical understandings as she was manoeuvring to avoid being met with prejudices.

I never say that I have schizophrenia, because then I have to give a lecture for half an hour [to explain what it means]. You see, people... it is this unsatisfactory, kind of 'Catch 22', that if you don't say anything, then no people will ever understand it, and then it is obvious that they have stereotypical prejudices, you see. But then you avoid saying anything, because people have prejudices. And then it is like that... then it snowballs, you see, then there will never be any change [in people's understanding], and that is also unsatisfying.

Claus's bad experience, described in Chapter Six, after having told a fellow student 'I am schizophrenic' also made him decide never again to tell strangers. Even so, and unlike, for example, Eva and Anders, he expressed a *positive identification with the diagnosis*, functioning along the lines described by Martin, as an explanation of his problems and life situation more generally. It bothered Claus that his old friends did not

accept that he had schizophrenia. As discussed in Chapter Seven, he felt that they did not understand him. Other informants expressed similar positive identifications with the diagnosis – Per, for example. When I, during the second interview, asked him how he was getting along establishing social contacts, he said:

It is one of our problems... generally, you see. It is that the schizophrenic maybe finds it a bit difficult to communicate and behave when together with other people, you see.

Far from all informants identified with the diagnosis and they did not accept, at face-value, the explanatory power it possessed in the psychiatric perspective. Kristina described her doubt when we talked about whether she felt that she was perceived of as ill in OPUS.

Yes, well, they [the staff in OPUS] would say that it is because I have been ill, that I find it difficult to be by myself. You see, 'that it is part of being schizophrenic.' That is what they would say. Whereas, you could say... I mean, many people find it difficult to be alone, but they are not [diagnosed with schizophrenia]... But they say that it is because of my illness, you see. And I don't really know how I should relate to that, you see. If I should say 'Alright, then I am ill, then it is like that,' or if I should say 'I am just an ordinary person who find it difficult to just sit and do nothing,' you see.

The staff in OPUS disagreed amongst themselves with regard to this issue. During a focus group interview, some members of staff employed in the social section said that the focus on illness sometimes was a little too strong, and that there could be a tendency to 'pathologise' (*sygelligøre*) the participants' situations and problems (Larsen 2001a: 89ff.). Similarly, I found that the 'professional talk' represented by the psychiatric perspective was overly focused on illness. The psychiatric discourse tended to simplify the personal difficulties and life situations of the participants by presenting them predominantly as symptoms of mental illness (cf. J. Jenkins 1991). The quotations from Per and Kristina clearly illustrate this point. Hence, interacting with psychiatric staff, I frequently found support for this aspect of Scheff's labelling theory (1999), and the much debated experiment by Rosenhan and colleagues (Rosenhan 1973), where they found that if a person first had been identified as a psychiatric patient, his or her actions would be interpreted as indications of illness, even when in a 'normal' setting, they

would have passed unnoticed. Some informants were aware of this. For example, Eva told me that it was to her advantage that she appeared a bit bourgeois and 'grey', and not very 'artistic', 'eccentric', or having 'an alternative image,' since it could have been interpreted as indications of abnormality – and mental illness.

This is not to say that the professional gaze of psychiatry, identifying problematic aspects of the perceptions, behaviour, and life situations of the participants, was irrelevant. Because it was not, especially seen from the perspective of the staff's important task of monitoring the illness conditions of the participants, as described in Chapters Five and Six. But the problem was that this type of simplistic psychiatric perspective could make matters worse by merely *explaining* a participant's difficult situation – thereby confirming it as a static characteristic of the individual – instead of *acting* to find ways to help the person to overcome it. This problem, inherent in the practice of psychiatry, has been noticed by other scholars (Csordas 1994d; Ingleby 1981; J. Jenkins 1991; Jenner, Monteiro and Vlissides 1986), and it has been identified as a conflict in the psychiatric discipline between two main perspectives: a *static perspective*, with focuses on diagnostic classification and prescription of medicine to control symptoms, and a *dynamic perspective*, with focuses on individual development (Luhmann 2000).

In OPUS, it was not always the psychiatrists who were the strongest representatives of the static psychiatric perspective. At one staff meeting during the first months after the project's start, we discussed the use of diagnoses, and whether the participants and staff should be informed about the diagnostic conclusion reached by the psychiatric researchers who conducted the diagnostic screening interviews. One of the medical researchers said that the diagnosis was only to be used for their research, and she did not believe that it would benefit the treatment in OPUS if the diagnosis were disclosed, as recommended in the case of first episode psychosis (McGorry 1995: 324, Spencer *et al.* 2001: 135ff.). A psychiatric nurse strongly disagreed and pointed out that the diagnosis helped them in their daily work to find the right approach to individual patients (as she called the participants). During a focus group interview about one and a half years later, the same nurse said that she found it was more easy for herself to deal with the severe and potentially disturbing experiences and problems of the patients when she saw them as symptoms of their illness (Larsen 2001a: 89). And during another

staff meeting, a staff member described how one of 'her patients' had said that he preferred to perceive of his 'negative symptoms' not as such, but as traits in his personality, since it gave him a feeling that he could do something about the problems. The staff found this attitude puzzling, since it was their experience that patients preferred to see their problems as symptoms because these problems would often otherwise be 'very painful' to them. The discussion reflected the focus on *suffering* in the psychiatric perspective on the experience of mental illness (cf. Barrett 1996: 263ff., 291).

In OPUS, the static psychiatric perspective was contested through the dynamic perspective on individual progress inherent in the cognitive psychological perspective. This was illustrated in Chapter Seven by the different ways staff with different professional backgrounds approached individual problems in the social skills training groups: while the psychologist proposed a cognitive problem-solving approach, the psychiatrist suggested a medical solution. Further, OPUS's institutional structure – the multiple professional teams and the twin organisational base in the health and social sectors, respectively – provided some challenge to the authority of the psychiatric perspective.

Identity: Normality and biographical continuity

Informants' perceptions of themselves as ill, and their striving to become 'normal', have already been discussed in Chapter Six with regard both to the notion of being a 'patient' and the effect of taking medication. I will therefore restrict myself to summarising from these discussions, to argue that the notion of being ill and a patient provided a 'sick role' (cf. Parsons 1951) which temporarily allowed the informants to suspend their normal expectations of themselves and their life situations. This role was not, however, acceptable to them as a more permanent framework for self-identification. Either they rejected their need for any further treatment, since they had achieved what they perceived of as an acceptable 'state of normality,' or they redefined their situations by setting new standards of medicalised normality, thereby acknowledging their need to take medicine to maintain the right 'biochemical balance in the brain,' and accepting any possible or suspected side-effects.

But, as the earlier discussions in this chapter have demonstrated, even if informants accepted new standards of medicalised normality, they often felt the need to adjust their life expectations; to find new life projects. In the wake of the experience of disruption in their lives, it became important to restore a sense of normalcy, and negotiate what 'the normal' is (cf. Becker 1997: 142-52). Claus said, during the fourth interview, that he recently had come to a new realisation:

There is another life than the normal, what you call the normal... I mean, having a permanent job, and things like that. There is a small group of Danish people, who live a bit different and, in fact, feel alright about that.

To Claus 'the normal life' meant the way of living which is stereotypically evoked as the most common in Danish society – with independent work, individual accommodation, and a family life. Claus was coming to terms with a notion of 'normality', which the philosopher Ian Hacking (Hacking 1990, in Jenkins 1998: 17) has argued is one of the most powerful ideas in Western modern cosmology: that the normal both represents the typical or average *and* a moral imperative. Claus was in a process of accepting that his life did not have to live up to these ideals in order to be agreeable to him. Other informants had another starting point in the conceptualisation of 'normality'.

When Eva, during a session in the social skills training group, had been confronted with the concept by a member of staff, she felt offended and very angry.

[The member of staff] told me that I want to be more normal than the normal. And I think that it is a load of crap to say! I mean, when I was sixteen years old I thought about 'What is normality?', you see. I don't give a damn if I am normal. I want to become well, but I don't give a damn whether I am normal. ...//... I also feel that it was to stigmatise me. ...//... Because it is implied that if I, kind of, act normally, then I am *really* not normal, I *try to* be it. I think that this is implied. I mean, that is a load of crap!

Eva felt that this particular member of staff perceived of her, and her fellow participants in OPUS, as being trapped in the static psychiatric notion of mental illness dominating their identities. Eva thought that the staff member did not pick up the dynamic way of thinking which she otherwise thought pervaded the intervention in OPUS. In fact, this member of staff only stayed in the project for a short while, and returned to work in a

more traditional institution of psychiatric treatment. When leaving, this member of staff described the particular perspective in OPUS as 'a Scout spirit', and told me that you get very close to the patients when working in OPUS, in comparison to the 'more professional' attitude in traditional psychiatric practice.

With strong analytic powers, and her knowledge of sociological theory, Eva presented a critical reflective perspective on the concept of 'normality', which was not common among the informants. To most, 'being normal' meant getting back to a stable life condition, where they could take control of their own situation and where illness did not dominate their daily lives. As Namira explained, when, in the fourth interview, I asked her why it was important for her to get back to work: 'I would like to live my life normally, like everybody else.'

The informants' self-perceptions had been weakened in the existential crisis following the psychosis. The extraordinary experiences and the breaking of their usual life routines had made them doubt their senses, their personal abilities, and the directions their lives were taking. For example, Per said that he had become more vulnerable to criticism from other people and he described the feeling as 'over-self-centredness' (*over-selvcentrering*). In this situation, it took a lot of support from the staff in OPUS, as well from the social network, to 'get back on the feet again,' as several informants expressed it. But it also took personal strength and will-power. The particular life circumstances of the informants prior to their psychosis and their involvement in psychiatric treatment proved to be crucial as a biographical basis for individual strength to support and direct their involvement in re-establishing their lives (cf. Larsen, in press).

If an informant had a positive identification with the general direction his or her life was taking at the time preceding the mental illness, then it was possible for them to focus their efforts, and the support they received from OPUS and their social network, to get back to a position where he or she would be able to re-engage in this life project and establish a *biographical continuity* (Giddens 1991: 35-69), i.e. a sense of continuity in their personal lives (Becker 1997). Similarly, Charles Taylor has observed that selves are constituted in a moral space where narratives play a double function of making sense of our lives as a story and enable us to orient ourselves when making

decisions of 'what is good and bad, what is worth doing and what is not, what has meaning and importance for you and what is trivial and secondary' (Taylor 1989: 28).

For my informants, re-establishing a sense of biographical continuity basically meant getting back to a particular social role where they could function as active and contributing members of society, whether through a particular job or education (cf. Lorencz 1992). Eva formulated this precisely, in the fourth interview, after she told me how she had often had to overcome herself and make herself do things and participate in difficult situations.

Eva: I think that if you had a [life] course of academic study, and you were good at it, and it suddenly all went to hell, then I suppose that you would have some kind of drive to get back to it. Because, you see, what is the alternative to again studying political science? It is total chaos! It is. It is chaos in your life, it is psychological chaos. To me it has almost been imperative to return to it, I think.

...//...

JAL: So, it also concerns identity, somehow?

Eva: Yes, it very much concerns identity. I believe that your self-perception is much more determining (*styrende*) than your emotions, in fact I believe that. I believe that the self-perception is one of the things which are very determining. It determines you extremely much, I also talked to a friend about that, much more than you imagine. I believe that you do a lot of things for your identity.

JAL: And it is then this drive you have had, this it what has given you the drive?

Eva: Yes. I have been very much a school person, or ambitious (*stræbermenneske*), so a lot of my identity is dependent on the thing about the school, and it always has, because I am good at it.

For Eva it had, however, not always been straightforward. As described in Chapter Six, she received crucial support from her case manager to return to her studies. Further, she had resisted the team psychiatrist's suggestion that she should increase the dose of medication, since she knew that the side-effects would make it impossible for her to read the texts necessary to follow the courses. And, due to frustrations and temporary set-backs on the way, she told me, in the third interview, that she had developed a 'plan B', to give up her aspirations to achieve an MA degree and, instead, after the BA degree⁴⁰, take a less demanding job where she could work with people, possibly in a

⁴⁰ It should be mentioned here that, in contrast to the situation in Britain, the BA degree has only been introduced into the Danish educational system relatively recently and it is generally not accepted as providing sufficient professional competence in the labour market.

shop, and then, in her spare time, continue her interests in social and political issues by attending evening classes and possibly getting politically involved. She had become involved in a mental health user group, and had started training to become a 'user teacher'. As discussed in Chapter Seven, she later changed her mind, since she felt that the involvement in issues and social relations regarding mental illness took up too much place in her life, and were not taking her in the direction she wanted most of all – towards her 'plan A'.

Informants like Anders, Martin, Namira, and Irene were in situations very similar to Eva's. And Per also had the opportunity to continue his former social role, and establish a biographical continuity, by using his training in the job at the sheltered workshop, and aim to achieve a 'real job' with time. Other informants did not have already established life projects to return to. Even if Kristina had a positive identification with her former activities and the education she had begun, she felt that it was impossible for her to return to it, since she feared that it could make her psychotic again. She told me how she, for a long time, had been bewildered about what she should do. In the fourth interview, she said that it had been very important for her to be open-minded and actively ask and seek advice from her friends to help her to get ideas as to what she could do, to help her to get on with her life again. Kristina recognised that it required both personal willpower to move on and self-confidence and social competencies to engage with other people. Unlike Eva's strategy of struggling to find ways to get back to her former life course, and her identity, Kristina sought to establish a new direction for her life. Fortunately, a friend came up with the idea to become a teacher of gymnastics. This new social role did not have a spiritual content which could endanger her mental health, but, at the same time, it had some similarity with her former interests – with the emphasis shifted from the spiritual to the physical. Redefined in this way, she could maintain some sense of continuity. As Giddens (1991: 55) has observed, any individual narrative of biographical continuity 'is only one "story" among many other potential stories that could be told about her development as a self.' But, as Becker (1997: 199ff.) has also observed, the individual, generally, holds on to his or her narrative and only questions, or 'deconstructs', it when another provides an attractive alternative. The individual's sense of self is at stake.

Claus and Dennis were less fortunate than Kristina. They both had to redefine their social roles fundamentally, since they did not have any particular prior life project they aspired to return to. Re-establishing biographical continuity was therefore not an option; instead, the task facing them was the much more challenging one of finding out from scratch what they wanted to achieve in their lives. And since they did not have a 'plan A' to give them personal drive to overcome obstacles in their way they were, instead, subjugated by their difficult circumstances in the existential crisis following the psychosis. Their problems, in a sense, became central elements in defining, to themselves and to others, who they were and what they could do. The social status as 'mentally ill' provided them with an identity base for a re-defined life course.

Dennis said that he, at first, was very sorrowful (*vemodig*) when he was told that he was mentally ill because he had a lot of prejudices about it, and he thought that it was one's own fault. But as he got to know more about it, he changed his attitude, and, in the fourth interview, he explained that it was a help for him to realise that he was ill. In the second interview, Claus told me that he had come to know new sides of himself. He felt that he now accepted himself better, and that it had given him more confidence to get on with life (*mod på at komme i gang med livet*). Already, in the first interview, he told me that the mental illness had been a kind of eye-opener for him. He explained that he had always known that there was something wrong with him, but now he had an explanation of what it was. Per also described how he, in retrospect, could see that the mental illness had developed over many years before he came in contact with OPUS, and he could recognise some of the problems he had as the beginning of symptoms of mental illness. In this way some informants used the newly-gained knowledge taught to them in OPUS to establish a biographical continuity, in retrospect, with mental illness in the central place of the narrative about their life course. The new understanding provided them with a system of explanation, or a discourse, in which they better understood 'how they really were.'

While the dominant narrative, or 'master plot' (Becker 1997: 27), of mental illness came to occupy a central place in their self-understandings, Per told me, in the third interview, how he had begun to see himself less as ill. He said that it was because of his work at the sheltered workshop, which had given him an opportunity to 'get started again' – and focus on dreams for the future. The fear Per expressed, when he had

just started in OPUS, that he might end up as a loner because of his experience, was thus not realised due to his opportunities for active engagement in society. Similarly, Birgit, Claus, and Dennis hoped that they, in time, would work in a sheltered job. The informants supported the observation that having an active role in society is highly important by allowing them a meaningful 'self-accounting' (Barham and Hayward 1995: 41). Even if mental illness, to some informants, was important to their self-understandings, identity was continuously negotiated, and the opportunity to take up a vocational role was central to all informants' feelings of self-worth and the way they wished to present themselves to others.

Leaving OPUS

At the time of the fourth interview, most of the informants were expected to leave OPUS soon, and a few had already left. It was two years after they had started in the community intervention programme, and I confronted them with what they said in the first interview when I had asked them how they expected their individual situations would be when they left. Chapter Five identified informants by three types of future expectations: those who were overwhelmed by their situation and found it difficult to have any expectations whatsoever, those who expected to make changes in their lives compared to how it was before the psychosis, and those who expected to return to their former life projects after a period of recovery.

Table 8.1 presents a schematic overview of my informants' general life situations after they left OPUS. All of them were living 'in the community' and they had secure accommodation. Six were living by themselves in flats, two lived with their families, three lived in communal flats or houses, and two lived in sheltered flats shared with other people receiving mental health care. I did not have up-to-date information regarding accommodation for Ole and Lotte. The majority of the informants were financially provided for by the state, either because they had not finished their rehabilitation programme yet or because they were receiving welfare benefits. Three were employed under normal conditions, while precise information on the financial situations of Hans and Lotte was not available to me. With one exception, Hans, all were receiving some kind of psychiatric treatment and supervision, even if some, for a time, had stopped taking medication. In the following section, I will describe some of

the informants' individual situations in more detail to emphasise points of particular analytic interest.

	Activity	Income	Accommodation	Mental health service
Anders	Full-time student	Rehabilitation scheme	Individual flat	Contact with psychiatrist at community mental health centre (CMHC)
Birgit	Working part-time in special work scheme	Early retirement pension	Individual flat	Contact with CMHC (considering accepting case manager)
Claus	None (starting part-time work in special work scheme)	Early retirement pension	Individual flat	Contact with CMHC – consultations with psychologist
Dennis	None	Early retirement pension	Sheltered shared flat	Contact with CMHC
Eva	Full-time student	Rehabilitation scheme	Student house of residence	Contact with CMHC
Frank	Participant in project for unemployed youth	Social welfare benefits	Individual flat	Contact with CMHC
Hans	Unemployed	Unknown (possibly unemployment benefits or social welfare benefits)	Individual flat	None (possibly being re-admitted in OPUS)
Irene	Working full-time	Salary	Flat with husband and daughter	Consultations with psychiatrist
Julie	Working part-time in special work scheme	Early retirement pension	Sheltered shared flat	Contact with CMHC
Kristina	Full-time student	Rehabilitation scheme	Private community house	Contact with CMHC – consultations with psychologist
Lotte	Unknown (possibly part-time work)	Unknown (possibly social welfare benefits and part-time salary)	Unknown (possibly rented room)	Contact with CMHC
Martin	Working full-time	Salary	Private community flat	Consultations with psychiatrist
Namira	Working full-time	Salary	Flat with mother and brother	Contact with CMHC
Ole	Unknown (possible none)	Early retirement pension	Unknown (possibly individual flat)	Contact with CMHC
Per	Working part-time in sheltered workshop	Early retirement pension	Individual flat	Contact with CMHC

Table 8.1: Social situation of informants after leaving OPUS

In the two-year course, only a few of the informants had largely achieved the goals they originally set up. Anders came close to having accomplished his objectives even if he had not completely put ‘the illness hustle’ behind him. He had started studying again, become more physically active, and become more sociable and attentive towards other people – not being the one who had to ‘be considered’ and appearing as ‘a black hole’, sucking in all the social energy and creating a dead space around him, as he felt that he did at the time of the first interview. Two years later, he said that he had worked on and achieved improvement with regard to all these aspects, and even if everything was not totally perfect, he assessed his story, all in all, as having been very ‘rosy’ (*rosenrød*). Towards the end of his involvement with OPUS, staff agreed with Anders that he could stop taking the antipsychotic medication, of which he, for a long period, had received only a minimal dose. But as he began to feel unmotivated and depressed about his studies, he agreed with his new psychiatrist in the community mental health centre, where he came for bi-monthly meetings, to start taking a small dose again. Anders feared that otherwise he might experience a psychotic relapse. Anders told me that starting in the community mental health centre gave him an opportunity to ‘start afresh’. He expected that he might have a different, more equal, contact with the mental health staff when they only knew him as he was now, and had not seen him in the poor condition he had been in just after the psychosis and hospitalisation. These expectations were, however, not fully met. As an epilogue for the story in the book project, he wrote in February 2002 that he felt that the psychiatrist ‘schematised’ him – looked at him through a lens, classifying symptoms – and he longed to be met with a more ‘humanistic’ approach, which he had experienced with psychologists.

Birgit, too, was very content with the development in which she had been helped through her time in OPUS. She had originally hoped that she would be able to be more active and possibly get a small job, so that she could get out and meet people. She had achieved these goals, and she told me that she felt generally better about herself. Staff in OPUS had helped her to establish contact with the community mental health centre when she left the intervention programme. At the centre, she had been offered the opportunity to get a personal case manager she could meet regularly, but she had declined, since she felt that she could manage on her own. When she told me about her

present situation, she, however, came to the conclusion that maybe it would be good for her to have somebody she could share her thoughts with. I supported her in this view, and she said that she would maybe ask them if the offer was still available.

Per had also hoped for 'a happy end', but, like most of the informants, it had been his experience that it was a more strenuous and slow process to re-establish his life following the psychosis. During the fifth interview, more than half a year after he had stopped in OPUS, he told me that he had started consultations with a psychologist at the community mental health centre, since he had again started wondering whether the experience of his father's suicide had caused some unresolved emotional conflict in him. But, again, the consultations had convinced him that there was nothing to come to in this approach to his problems. Still, Per felt that he was moving in the right direction with his life. Together with the early retirement pension, the flexible part-time work in the sheltered workshop provided him with security, a daily activity, and a social role which allowed him to preserve his vocational training as a central part of his identity and keep his dreams for the future alive. When I spoke to Per again, around Christmas 2001, more than three years after his inclusion in OPUS, he said that he had talked with his boss in the workshop about starting training to become a locksmith.

After my fourth interview with Frank, when he told me about his psychotic experiences and his inclination towards spiritual explanations, I was genuinely concerned for him. At that time, I was happy to know that his condition was supervised through the regular meetings with his case manager in OPUS. On my subsequent visit, I learned that, shortly after the interview, he had lost his part-time job. OPUS had, however, found him a special education programme for young people, where he could practise his dancing, and they arranged group discussions in which he could tell the other participants about his psychotic experiences. He remained in contact with OPUS until the early summer, which meant that he was included in the programme for more than two and a half years. He told me that he felt better with the new type of medication he was receiving. He still sometimes had a feeling that a voice was speaking through him, but it did not really bother him. He was generally happy about the contact he had with the community mental health centre and he expected soon to find an education programme or a job.

When I confronted Irene with her expectation when starting in OPUS, that she would be 'well-functioning in all aspects of life' after two years, she told me that this prophecy had not been entirely fulfilled. She said that because of her previous experience of a psychotic episode ten years earlier, she had assumed that she would have been 'back on her feet' after some months. But this time it had been more difficult. In particular, the relapse she experienced within the first year of her time in OPUS had lowered her expectations, as described in previous chapters. She also discovered that people at her work place had not been as supportive as they first appeared, and eventually she had left this job. In her new job, she decided that she would not tell them about her experiences with mental illness, since she did not want to run the risk of being met with prejudice. Even if she started working full-time again, she said that she would be careful not to put herself in too stressful a situation again, and that she wanted to have time for her daughter. When I spoke to her after half a year, in the spring of 2002, she told me that it was difficult to keep the work pressure down. As a precaution, she kept taking medication since she was not certain that her husband would notice if a new psychotic episode started up. Occasionally, she called her former case manager in OPUS to get advice, and she had private consultations with a psychiatrist from OPUS.

Martin achieved his engineering degree with excellence and was happy that he could stay in OPUS in the difficult period while he was looking for a job, and in the first period of his employment. The contact gave him a sense of stability and personal support. Like Irene, he decided not to tell his employer and work colleagues about his experiences with mental illness. He, however, told me that at job interviews, his social problems had been noticed and that they had been given to him as reason for rejections, since they did not think that he would be outgoing enough to work as a team member. After finishing his studies, Martin moved out of the student flat and found a place in a community flat with other young people. He told me that it was important for him to be around other people to prevent him from isolating himself. He thought that the people were nice and that he was generally accepted. The job he was offered, and accepted, was not his 'dream job', but Martin thought that it allowed him to be 'a bit special' since many of the other engineers employed were also a bit socially withdrawn. Like Anders, he had stopped taking medication for a while, but after he started in the job he was advised to take a low dose to control his social angst. His boss recognised Martin's

social difficulties at work, and had suggested that he should register for a course in 'assertiveness training'. This illustrates the important point that participation in social activities not only provides an opportunity for informal training in social competencies, but, in this case, anyway, also provides opportunities to receive non-stigmatising formalised training – then labelled 'courses' and not 'treatment'. For Martin, an important sign of the improvement he had experienced was that he was now actively looking for a girlfriend, and had already been on some dates. From mid-2001, Martin took over as co-ordinator of the book project, communicating with the editor at the publishing house and distributing information to the other authors through the e-mail group we had established on the Internet.

Some informants said, in the fourth interview, that they were looking forward to finishing in OPUS, and being able to put the experience behind them. For example, Anders said that the regular meetings with staff were painful reminders that he had been ill. He looked forward to being allowed to forget about the experiences, which was similar to what Ole said in his first interview, reported in Chapter Five. Others feared that the break with OPUS would mean that they would be without the security of the monitoring mentioned in Chapters Five and Six, and that the termination of the regular meetings with staff in OPUS would make them more lonely and socially isolated. On my subsequent visit, more than half a year later, the informants, however, told me that they felt that they had benefited from the break in the contact, since it had made them prove to themselves that they could 'stand on their own feet.' Of the eleven informants I interviewed in this round, only Dennis did not express this view. He told me that he missed the meetings in the family group. A few times he had thought about giving his former case manager a ring, but he thought that she would probably be busy. He also told me that he would have preferred it if the contact with OPUS had overlapped for a period with his start in the community mental health centre. He felt a bit nervous about having to come a new place, and he argued in favour of overlapping by saying: 'To make sure that that I am delivered in a good condition.' His tone of voice indicated that he had a joking, or ironic, distance to the presentation of himself as an object to be taken care of. Nevertheless, he basically had accepted this position in relation to mental health care. He had established himself with a career as mentally ill (cf. Angrosino 1998; Braathen 1994; Estroff 1981). At the time, he was not engaged in any activity, but in the

spring he considered returning to his previous sheltered part-time job as a gardening assistant. He was, however, not that happy with the job since it was quite lonely and there was not much to do, so he had also discussed other possibilities with the professional helpers who came for regular visits to the flat. He considered to start helping out in swimming classes for people with physical disabilities.

Claus was one of the informants who most dreaded finishing in OPUS. In the fourth interview, he said that he felt it was a huge challenge to stop seeing his case manager regularly and to start coming to the community mental health centre instead. He did not have any energy to consider other future plans. In the following interview, Claus explained that, to his surprise, it had been a positive experience to find out that he could manage with a less intensive contact. Previously, as discussed in Chapter Six, Claus felt that it would be irrelevant to talk to a psychologist, since the biochemical and cognitive psychological explanations of his problems were sufficient for him at the time. But now, when he no longer met regularly with a personal case manager, he thought that it might help him to discuss his situation in more detail, and at the community mental health centre, he had discussed the possibility of starting consultations with the psychologist. He had also been helped to find a sheltered job as a part-time assistant in a film production company, which he was starting the week after our conversation. Claus said that he was looking forward to having something to get up for in the morning and that he was happy that he would have something more interesting to say when, in the future, he was asked the question ‘What are you doing?’. He told me that he was coming to terms with ‘living life as mentally ill’ – accepting that he would find some things more difficult than other people, especially when it came to social contact and communication.

In the fourth interview, Namira said that she was happy about the support she had received in OPUS to help her come back to her former training and the job as a sales assistant, and ‘live a normal life.’ When I met her again, more than half a year later, she seemed better than I had ever seen her before – more attentive, relaxed, and talkative. She told me that a few months after leaving OPUS, she had decided to quit her job in the retail store and that, instead, she had started working as a home assistant mainly for elderly people with disabilities, helping them to do the cleaning and go shopping. She had realised that the job as a shop assistant was too stressful for her.

When she applied for the job as a home assistant, she did not say that she had experience with mental illness, since she was afraid that it would have made them overlook her. She did not reveal it to her employer until, after four months of work, she had to take some days on sick leave after a particularly stressful time at the job. Namira was happy that she had proved that she could manage the job. This example proves the very important double point that the intensive support in OPUS might help participants to manage difficult situations, which they can be forced to quit when this support is taken away; but, at the same time, this situation forces the individuals to reconsider personal abilities and *might* help them to 'stand on their own feet', finding new personal aims and challenges which are more attainable.

When I called Lotte to arrange the fourth interview, she told me that in the previous interviews she had already told me what she had to say, and that she did not want to waste time by meeting again. We talked on the phone for about 15 minutes and she explained that she had not got anything out of OPUS. As in the previous interviews, mentioned in Chapters Five and Six, she said that she would have liked to talk to a psychologist, but her request was turned down by her case manager. Lotte did not feel that she had been helped in any way by talking to a nurse she had nothing in common with, and in the community mental health centre, where she had started, she was content just to meet with the psychiatrist and get her medicine. I told her that I would be ending my job as evaluator by the end of the year, but if she got time to meet before Christmas she was very welcome to give me a call. Lotte told me that she would not bother to take my number and that it was about time both of us moved on. On my follow-up half a year later, I gave her a ring again, but she did not want to meet this time either.

I did not talk to Hans at the time of the fourth interview, but as I was arranging the following round of interviews in August 2001, almost three years after the informants had been included in OPUS, and about two years after he had decided to leave it, I was able to reach him on the phone. I told him that I was making follow-up visits to give a copy of the evaluation report to those who provided key information for it, and to hear what people thought of OPUS in retrospect, and how things were. We chatted for a while, but soon he started telling me about strange experiences he had had at consultations with the psychiatrist in OPUS, where he had been shown a video of a woman giving birth. He kept on telling me that he had had the bizarre sensation of

somebody talking through his neck and that recently a person had pretended to be the actor Jack Nicholson, and that somebody had tricked him into believing that he had gone to Hollywood. He guessed that they had used a flight simulator to give the impression of the plane, but he was still trying to figure out how they had managed to make the beach and who had pretended to be the actress Jane Fonda. Further, he told me that somebody had taken him and thrown him out of a train as it was speeding over the bridge to Sweden, and he sank deep into the water, yet somehow he managed to climb to a small rocky island, but the water had risen and risen.

Hans did not accept that his experiences were a product of his imagination. I told him that I had heard about similar experiences from my other informants in OPUS, and that they had benefited from talking to the staff in OPUS, since they knew about such experiences and what to do to prevent being overwhelmed and scared by them. After I learned that he had been unemployed for half a year and was spending most of the time alone in his flat, I asked him if he would allow me to contact his former case manager in OPUS, and hear if he would contact him. Hans told me 'It's up to you to decide.' He, however, changed his initial friendly talkative attitude to me and became defensive. It was no longer possible for me to arrange a meeting with him. After I put down the phone, I called his former case manager and left a message on his answering machine. The following day he told me that they had discussed my request in the team and decided that they would offer Hans once again the opportunity to be included in OPUS.

Establishing life projects: Making sense and finding a direction

The experiences of active psychotic hallucinations, and the related mental difficulties, profoundly challenged the understandings of the world my informants applied during their everyday lives. As they sought to integrate these experiences in a meaningful way into their perspectives on life, some informants developed explanations which, because of their individual particularity, further alienated their experiential worlds from other people in their surroundings. These delusions were, however, both fed and challenged by alternative systems of explanation provided in the surrounding society.

Informants drew on varied sources in the cultural repertoire to give meaning to their experiences and life situations. The perspective provided in OPUS, through

focused efforts of psychoeducation and the general practice of symbolic healing, was appropriated, evaluated, accepted, or rejected by the individual in the light of these explanations. Informants adopted competing explanations in complex ways, ranging from the dogmatic acceptance of one all-explaining system, to creative ways of supplementing or merging various systems of explanation in individual efforts of *bricolage*. These strategies changed over time as individuals found themselves in different life situations, under different social circumstances, and under influences of different efforts to convince them to accept a particular explanation as true and relevant. Even if they were crucial actors in setting up their individual life project, they were thus not in positions to choose freely between lifestyles, as Giddens (1991) has suggested. The 'project of the self' is reflexive in the sense that the individual's understanding and active engagement are crucial directive forces, but social circumstances and cultural repertoires are equally determining for the availability and choice of life projects. As Jenkins has observed: 'The world is not really *everyone's* oyster' (1996: 51).

Further, following on from these points, Giddens' (1991) observation of the individual lifespan as 'internal referential' is right in the sense both that the individual does strive to establish a biographical continuity, presenting a consistent life project, and in the sense that it directs life choices. But, as Giddens (1991: 55) has observed that many potential stories could be told about an individual's development as a self, it is important to be aware that this internal referentiality is a *narrative construct* consisting of happenings in the life of the individual, which can be retold as significant events using another 'master plot' when other circumstances prevail. This is, however, not to say that the continuity in life is an illusion, as Becker (1997: 190ff.) has suggested. As an element in the narrative construct, 'continuity' is used to create order in the life story when selecting life events and dreams for the future within culturally specific discursive frameworks.

The mental illness produced an existential crisis by raising doubts about the veracity of basic perceptions, and the attainability of future expectations. As my informants embraced and combined new explanations, they sought to (re-)establish a stable sense of self through a narrative of biographical continuity. The narrative provided a sense of continuity which directed their future expectations, plans, and initiatives. Their understandings of their experiences of mental illness, as well as of its

consequences for their senses of self, and its meanings with regard to their social positions, were integral parts of their individual narratives. For some, 'being mentally ill' was 'a silent part of the self' (Barham and Hayward 1995: 155; 1998: 169), it did not take any significant place in their self-accounting, while others embraced it as a positive identification of their identities. For them, the development of mental illness came to represent a 'master plot'.

At the end of the two-year period of the intervention in OPUS, my informants found it difficult to assess whether their initial goals when they had started in OPUS had been achieved. Many had undergone a process during which these goals and general life expectations had been reconsidered, in order to take account of the situations and difficulties they found themselves in. It was, however, a general sensation among my informants that OPUS had provided crucial support to help them to re-establish their lives and find a direction to follow.

The next, and last, chapter will summarise the study and bring together the various perspectives in a conceptualisation of the process experienced by my informants while they were recipients of early intervention in schizophrenia.

Chapter Nine

Conclusion and perspectives

This study has presented individuals' experiences and reflections in the period following first episode psychosis. Diagnosed within the 'schizophrenia spectrum', they received intensive community treatment and support in an early intervention programme set up by psychiatric and social services in Copenhagen, Denmark.

Within an overall person-centred ethnographic approach, the study has applied an existential and cultural phenomenological perspective to describe recipients' experiences from their own points of view, as situated within specific cultural and social contexts. During the ethnographic study, I had an active role as a member of staff and I participated in various social settings of the intervention. The study followed fifteen informants from shortly after they started in the project, throughout the two to two and a half years of their participation in the project until they left it and, in most cases, were referred to standard treatment facilities in either community mental health centres or private psychiatric consultation. A dialogic approach involved the informants as active partners, or associates, of the research, and seven of the fifteen informants contributed with individual stories about their experiences for a book, to be published independently of the project or this study.

In this concluding chapter, I will summarise the main findings from the previous chapters and present a broader, theoretical perspective on identity and the transformation of self in the period during early intervention in schizophrenia.

Experiences with early intervention in schizophrenia

The study provides an exploration within the 'black box' of the intervention programme – describing social relations and mechanisms of treatment and support. From the recipients' perspectives, the community intervention programme was not an island of social structures and it was not unchallenged or the sole authority in providing a coherent system of explanation. Even in the 'total institution' of the psychiatric hospital, the workings of the formal and authoritarian social system were challenged by an

‘institutional underlife’ (cf. Goffman 1961). But as the therapy and support was provided in the community, outside the walls of confinement, attention to recipients’ active roles in affecting the workings of the intervention became even more crucial.

The informants had all experienced stresses in their lives prior to their mental health problems: unemployment, financial problems, pressure at work or in their studies, conflicts in personal relationships, distress caused by the use of street drugs, and/or general insecurity about their individual directions in life. The mental problems and psychotic experiences accentuated an intensified sense of life: full of varying sensations of anxiety, fear, and excitement. They felt saturated by perceptions and emotions. Twelve of the fifteen informants became in-patients at psychiatric wards and while some went there to seek refuge, others were admitted against their will. Their experiences at the hospital were mixed: while most, in one way or the other, reported feelings of restraint and humiliation, some felt that the time, generally, passed in obscurity, and others emphasised experiences of captivity and physical violence. While most informants recognised the hospitalisation as a necessary part of their treatment, many also felt that it was a traumatic experience which added to the existential crisis they found themselves in following first episode psychosis. As a result, some expected their lives to change, while others wanted to resume their former lives as soon as possible, and a few longed to be able to have dreams again – their problems overshadowed any plans and hopes for the future.

When they started as participants in OPUS, they had positive expectations to being helped to overcome their difficulties and re-establish life projects. Two of the three informants who had not been admitted to a hospital were hopeful that psychological counselling would provide immediate relief. All three were concerned that their participation in the project could compromise other people’s regard of them, or that they would be challenged by people in their social network. For those who had been hospitalised, information management strategies were of secondary concern; first they needed to feel better by minimising symptoms and avoiding the side-effects of medication. Many were sedated with antipsychotic medication and were unhappy that they felt apathetic, asocial and unmotivated. Some informants, in this phase, longed for the fullness of life they had experienced during the psychosis. This craving was also reported by some informants in later phases as they gained more energy, but found

themselves socially isolated, struggling to find new directions in their lives and engage in new life projects.

In the longer term, recipients of the intervention preferred to see themselves as 'participants' – and not 'patients', which implied a passive and temporary role subordinated to the staff. The individual case managers in OPUS met weekly with the participants and supported them both when they were in the hospital and when they were trying to re-establish their lives in the community: they helped with practical issues concerning housing and financial support; they supplied the antipsychotic medication and informed them about mental illness; they provided personal support, advice and counselling; and they acted as mediators with regard to relatives and institutions of work or education. The relationship was personal, but professional and not private. Most informants were sceptical about taking the provided medication although they acknowledged that they needed it to avoid a psychotic relapse. For some, it was perceived as a temporary necessity, and the medication symbolised the 'illness', which they looked forward to putting behind them. Others came to accept a new sense of medically sustained normality and took the medication 'to keep up the balance in the brain.'

Apart from the individually-focused treatment and support, the intervention in OPUS sought to strengthen and develop the social resources of the participants. Two types of therapeutic groups directed attention to the relatives, and the social competencies of the participants, respectively. In family groups, participants were joined by family members in an effort to facilitate mutual support and a better understanding of mental illness. In social skills training groups, participants were further introduced to biochemical and cognitive psychological explanations of mental illness, and they practised how to become a 'well-functioning' person in society. Informants also found support in informal social environments. In the period after psychosis and hospitalisation, some were happy to meet and exchange experiences and ideas with others who were in similar circumstances. Some of my informants engaged in complex social strategies to support them in the process of recovery. The financial, vocational, and educational programmes of rehabilitation provided by the Danish social welfare system, and accessed through the staff in OPUS, were crucial to the informants' opportunities for recovery.

The therapeutic efforts in OPUS worked through processes of symbolic healing, whereby the participants were introduced to explanations of their experiences and problems. These explanations were, however, not always dogmatically accepted by the participants but negotiated with other systems of explanation available in the cultural repertoire of society. The informants' demands for explanations were closely intertwined with aspects of identity.

Transformation of self: Integrating experience and meaning in life projects

In the literature on the phenomenology of schizophrenia, there is a general concern with the pathology of 'the self'. It has been demonstrated that this interest, along with the concept of 'schizophrenia' itself, is related to the culturally-specific notion of the split person and an ideology of degeneration in Western thought (Barrett 1996: Chapter 7). While such a historical and culture-critical approach contributes to our understanding by identifying the conceptual and ideological background of ideas about mental illness, it does not take into consideration the experiential realities of individual situations. This thesis has laid out an empirical foundation which allows such an understanding, by applying the cultural phenomenological approach (Csordas 1994a) and focusing on the individual-society interaction in the dialectic process of social identification (Jenkins 1996).

The existential approach of this study has taken individuals' experiences and strategies as vantage points of the investigation, and explored individual and social moves towards creating meaning following extraordinary individual experiences of mental illness. Laing (1990 [1959]) identified the existential situation of the individual suffering from schizophrenia as characterised by *ontological insecurity* and experiences of anxiety and danger as a consequence of this insecurity.

The individual in the ordinary circumstances of living may feel more unreal than real; in a literal sense, more dead than alive; precariously differentiated from the rest of the world, so that his identity and autonomy are always in question. He may lack the experience of his own temporal continuity. He may not possess an over-riding sense of personal consistency or cohesiveness. He may feel more insubstantial than substantial, and unable to assume that the stuff he is made of is genuine, good, valuable. And he may feel his self as partially divorced from his body (Laing 1990: 42).

While Laing convincingly depicted the experiential reality of the individual situation, his theoretical understanding suffered from a static and reifying conceptualisation. He described this sensation of life as a defining characteristic of the individual with schizophrenia. More precisely, he located the pathology in the individual's sense of self. The evidence presented in this thesis indicates that it is counterproductive to perceive the situations of the informants of this study as statically defined by ontological insecurity. In the period following the first psychotic episode, their self-perceptions and life projects were continually reflected upon and (re-)negotiated, influenced by their particular social circumstances and the interventions directed towards them.

In the wake of the florid psychotic state, often when controlled by medication, the absurdity of the extraordinary perceptions and experiences they endured constituted major obstacles to the individuals who sought explanations and began questioning the veracity of their perceptions and understandings of everyday life. Further, the individuals questioned their abilities to return to life as it had been before the episode of mental illness. Their sense of biographical continuity was disrupted (cf. Barham and Hayward 1995: 2, 91; Becker 1997) and it was accompanied by ontological insecurity: they lacked a sensation of processing a narrative of self demonstrating their integrity as persons and assuring them of their position and direction in life (cf. Giddens 1991: 35-69). This existential crisis was reinforced by the loss of supportive social relations and positive societal roles, which often resulted from the period of preoccupation with their psychotic experiences and, sometimes, with paranoid ideas (cf. Estroff 1993).

Data presented in the previous chapters do not allow an investigation into the situations and general life sensations of the individuals prior to their psychotic episodes and contact with the early intervention programme, but they do allow us to scrutinise the effects of the psychotic experiences and the events in the period that followed. These suggest that rather than viewing the ontological insecurity as a reified and defining characteristic of the individual diagnosed with schizophrenia, this experiential reality has to be seen in conjunction with the existential crisis initiated by the psychotic experiences.

All the informants of this study stressed the crucial importance for them of establishing a stable and focused foundation for their lives – no matter whether they wished to return to former life projects or they were in the process of finding a new

foundation for their lives and new dreams for the future. This was a process during which the individual identity, or the sense of self, functioned as a crucial and directive force – it was a focal point of moral orientation in the individual's life (cf. Taylor 1989). This study has demonstrated that social intervention, both in the form of an effective medical treatment to control the illness and psychological and social help and support to assist the individuals to re-establish their lives, is integral to this process. The wider theoretical point to be made about 'the reality of the experience of schizophrenia' is, thus, that attempts to define 'what people with schizophrenia are like' has to take account both of *the experiential reality* of the individuals in question, and of *the specific social circumstances* – considering the medical and therapeutic systems of treatment and the conceptual frameworks of interpretation offered, as well as considering the possibilities for social integration due to the organisation of the labour market and the specialised welfare services.

Informants' understandings of their psychotic experiences were crucial to the recovery process by affording meaning to the absurd experiences of psychosis. Available systems of explanation were creatively combined and adjusted by individuals to provide the building blocks for personal narratives. Depending on individual differences in access to cultural resources and analytical capabilities, this work of *bricolage* was applied by individuals to varying degrees.

Dimensions of identity

The arguments I have presented in this ethnography concern identity as a general concept of analysis, as a factor in understanding the existential situation of people with experiences of severe mental illness, and as a relevant aspect when analysing social and health policy.

First, identity has to be understood as suspended in an individual-society dialectic (Jenkins 1996): it is constantly negotiated and re-evaluated through the individual's *nominal* assumption of specific social roles and positions in the society, and by the *virtual* consequences of these social roles and positions to the way each particular individual is understood by self and others. Identity is not a mask worn by the individual covering an 'inner self' behind (cf. Burkitt 1991: 70ff.). Rather, the self is best perceived as an engagement in processes of self-awareness (Csordas 1994a). In

these processes, conceptual models of interpretation play a crucial role, binding together, and creating an internal logic between the biographical elements which, at any given moment in time, constitute the notion, and sensation, of inhabiting a coherent identity. This is the ever-evolving foundation for the ideal sensation of ontological security. The conceptual models of interpretation, systems of explanation, or frameworks of meaning function as discursive contextualisations of individual life events, providing a narrative logic describing the course and direction of the individual life. The individual's sensation of possessing a stable identity and a continuity of self – or 'a core inner self' – is preserved, or can be re-established, through these narrative constructions.

In the light of this general theoretical conceptualisation of the interrelated processes of self, identity, and cultural systems of explanation, the second point can be made. The experience of psychosis challenges the individual's everyday taken-for-granted perceptions and understandings of reality. It shatters former notions of being-in-the-world and disrupts the individual narrative which secures them of the sensation of a stable identity and continuous self. It is an existential crisis. The individual seeks to repair the damage to the sense of self by creating or adopting systems of explanation which are able to encompass the experiences and the individual's situation in a new unifying narrative, transforming the absurd into meaning. The explanation can either 'seal over' the experiences, by classifying them as irrelevant or 'non-experiences', merely side-products of the imagination or a biochemical event in the brain, or it can 'integrate' the experiences as meaningful in the light of, for example, biographical events, as in the psychodynamic approach, or as spiritual phenomena. Social interventions of symbolic healing provide the individual with a culturally acceptable redefined narrative and self-understanding, as the successful end-result. In the form of an individualised explanatory model (cf. Kleinman 1980: 104-118) various systems of explanation are *tailored* to the individual by integrating selected biographical events. It remains to be continuously negotiated as the individual relates the self-understanding to present engagements and future goals. The narrative provides the individual with ontological security – a necessary foundation to act as a morally responsible agent, active in, and responsible for, his or her own life course.

Thirdly, these processes happen within the concrete, material, and institutional environment of particular social relations, in a physical space with social rules and provisions of welfare support. The OPUS project provided the immediate environment for the informants in this study. By giving ethnographic details and by paying attention to individual circumstances, it has been demonstrated how the intervention enabled individuals to make sense of their experiences, establish a new sense of self, and follow dreams for their lives. The research has demonstrated that social and health policies do make a difference to the lives of individuals. This does not mean, however, that more intervention is always better. The intervention in OPUS generally achieved a suitable balance between providing intensive support in an especially sensitive period and putting the individuals in fresh and more individually challenging situations when they were ready to meet the challenges. The flexibility to meet individual needs was, for example, demonstrated by the extension of one of my informants' period of inclusion.

A further theoretical and culture-critical point following on from this is that mental illness and its individual consequences has to be understood in the context of individual-society interaction. The ideology of biological reductionism, generally, enjoys an unjustified level of visibility and authority in contemporary public debate and policy decisions. The determining force of mental illness in the life courses of individuals cannot be reduced to an inner biochemical malfunction or genetic, or psychological, disposition. Evidence presented in this thesis has demonstrated the viability of an alternative anthropological and sociological perspective. The experiences of mental illness and the individuals' attempts to make sense of these are encompassed within culturally specific conceptualisations; and the consequences of these experiences for individual lives are shaped and directed by social reactions and policy interventions.

Suggestions for further research

This study has addressed a number of general themes and specific issues worth further investigation. Due to this study's limited scope and exploratory character, it would be important to discover if the general processes reported here can be found in similar projects of early intervention in schizophrenia, and by researchers who apply similar methodological approaches. A focus on the possibility of varieties between urban and rural regions, as well as cross-cultural comparisons, would be relevant.

Research on early intervention or 'crisis resolution' services in the area of mental health could pay attention in particular to their ritual qualities as 'passing out ceremonies' to mark the person's transformation back into health. The workings of such mental health interventions have to be addressed directly – with regard to institutional and therapeutic organisations, social dynamics, cultural meanings, and psychological necessity. To ensure that we know what 'the active ingredient' is, large-scale quantitative effect-studies in the field of social and health policy should be supplemented by thorough qualitative studies. A related problem concerning the large-scale controlled randomised trials, currently favoured in policy research, is the danger of 'evidence capture', when that research directs political attention and economical resources to certain intervention areas and methods of intervention, while less studied fields, requiring less popular (and less new) techniques of intervention, risk being neglected. Researchers and policy makers alike have to be aware of this danger.

The applicability of the concept of symbolic healing when theorising processes of recovery from schizophrenia ought to be further examined. It is important that this process is not solely conceptualised as an individual, psychological accomplishment, but understood within the social and cultural context which provides the individual with a therapeutic environment and a repertoire of explanations to make sense of perceptions and experiences. Further, the extent to which delusions can be understood as individual attempts to make sense of otherwise disturbing experiences and sensations should be investigated. A psychiatric labelling of such individual meaning-creating work as pathological seems to derive from a poor understanding of the individual's need to make sense of sensations and experiences.

Some of my informants revealed that they contemplated returning to the fullness of life they experienced during the psychosis. Further research on the experiences and motivations of psychiatric patients must avoid reproducing the 'narrative of suffering' dominating the psychiatric understanding of mental illness. It has to consider the florid psychotic state, and other conditions defined by psychiatry as mentally pathological, as a potentially positive experience and a possibly desired state of the individual.

The documented processes of transformation of self during early intervention in schizophrenia suggest further research to explore interrelations between identity and

individual life projects, on the one hand, and, on the other, symptoms of schizophrenia, notably 'ontological insecurity' and 'negative symptoms', such as social withdrawal. Specifically, it has to be further demonstrated whether positive support to help individuals to re-engage in life, and establish a stable social role and a secure sense of self, has the effect of diminishing or countering detrimental developments in schizophrenia.

The ethnographic and longitudinal design of this research has yielded valuable data on processes of change and the developing experiences of individuals as they participated in the intervention programme. It would be fruitful to extend the investigation of about two and a half years, to follow the individuals as they have further experiences in life. What problems do they encounter? Will they continue to need psychiatric treatment? How, in the long term, will the mental health problems and experiences of psychiatric labelling and treatment influence their self-perceptions and strategies of information management? Will the rehabilitation provided in OPUS, and by the general Danish welfare system, help them to live independent lives? Will they fulfil their dreams, or, again, reconsider their life projects?

I will end this 'wish list' of further research on a methodological note. This study has combined an ethnographic study of a policy intervention with an in-depth study of recipients' experiences and uses of this intervention, seeing them as agents within individual life processes. I recommend this methodological approach, as focused intervention programmes are increasingly used in social and health policy to help, and impel, individuals to qualify as competent 'well-functioning' citizens of the society. The approach facilitates a description both of the mechanisms within the 'black box' of the intervention programme and of the variety in the individuals' motivations and strategies of appropriation, rejection and negotiation of the new understandings and competencies they are presented with.

Finally, seven of my fifteen informants wrote individual stories about their experiences with psychosis, psychological problems and mental health care. The stories were part of a book project and, as work-in-progress, the participants met regularly on the editorial board to discuss the texts and provide mutual assistance in the writing process. The method provided the opportunity for a *facilitating* rather than a directing and controlling role for the researcher, and it revealed intense and personal information.

It would be interesting to see this method further developed as part of a multiple-method approach in qualitative studies.

Appendix A

Overview of informants: Age, treatment, support and diagnosis

		Anders	Birgit	Claus	Dennis	Eva	Frank	Hans	Irene	Julie	Kristina	Lotte	Martin	Namira	Ole	Per
Age at inclusion (years)		24	39	25	29	26	21	29	36	30	28	27	25	20	38	24
Individual case manager		√	√	√	√	√	√	√	√	√	√	√	√	√	√	√
Multiple-family group		√		√	√	√				√	√		√			√
Social skills training	Group		√	√	√	√				√	√		√	√		√
	Individual		√													
Cognitive psychotherapy sessions		√ ¹				²			√							√
Consultation with vocational advisor					√		√		√ ³	√						√
Medication (low dose atypical anti-psychotic)	Throughout the period in OPUS	√		√	√	√	√				√					√
	In some of the period in OPUS		√					√ ⁴	√	√		√	√	√	√	
	Compliant (judged by OPUS staff)	√		√	√	√	√		√		√		√	√		√
Hospitalised in psychiatric ward	Prior to OPUS								√		√					
	At inclusion in OPUS	√		√	√	√	√		√	√	√	√		√	√	√
	Re-admitted while in OPUS			√			√								√	√
Psychiatric diagnosis (ICD-10)	Schizophrenia	√	√	√	√	√	√			√	√	√		√	√	√
	Schizotypal disorder							√					√ ⁵			
	Bipolar disorder								√ ⁶							

¹ Anders did not formally receive psychotherapy, but due to his descriptions of the content of the meetings he had with his case manager, who was trained psychologist, I estimate that it is most correct to say that this service was provided to him.

² It was arranged for Eva to have meetings with the team psychologist, but twice Eva forgot to come to the initial session and then she decided to cancel it.

³ On the initiative of her case manager, Irene received advice from a vocational expert connected to a community mental health centre at a time prior to the employment of a vocational advisor in OPUS.

⁴ Hans only took antipsychotic medication once, when he felt under pressure by the OPUS team psychiatrist who, in Hans's words, threatened him with hospitalisation if he did not take the medication.

⁵ Martin's diagnosis was later changed to social phobia.

⁶ At inclusion in OPUS, Irene was diagnosed as suffering from acute and transient psychotic disorder, but the diagnosis was changed after her psychotic relapse.

Appendix B

Interview guides

Interview guide no. 1

Inclusion in the project and present situation

1. What do you think about having started in the project?
2. Do you think that your participation in the project gives you opportunities to get better? (How? Why?)
3. What is characteristic of your present situation?
4. What do you wish the project could help you with?
5. Is there anything that has been difficult in relation to starting in the project? (Has it been difficult for you to accept your situation/illness, and the fact that you need help?)
6. How have people in your social network reacted to your illness and the fact that you have started in the project? (Family, friends, acquaintances)

Future

7. What do you wish for the future? (Health, education, job, travel, friendship, partnership? Near future? Distant future?)
8. What is necessary for your wishes for the future to become fulfilled? (In relation to personal, health, situation? In your environment?)
9. Do you think that your participation in the project can help you to realise your wishes for the future?
10. What is the best that can happen to you?
11. What is the worst that can happen to you?
12. How do you see yourself in two years? (What are you doing? How do you feel?)

Interview guide no. 2

0. What are you doing at present?
1. What do you think about participating in OPUS?
2. Follow-up on personal themes presented in the previous interview (Wishes and hopes in relation to OPUS, individual situation, progress)
3. Has your situation improved since we talked last time? (Is it easier for you to deal with the problems you had?)
4. Until now, have your expectations of OPUS been fulfilled?
5. What in OPUS has especially helped you? (Medication, case manager, multiple-family group, social skills training group)
6. How much does OPUS mean to your life?
7. Have you received help in OPUS to create or maintain contact to work or education? (The normal life)

8. Is there anything in OPUS which has meant that your situation has deteriorated?
9. Staff in OPUS differ in whether they call you, who are participating in OPUS, 'participants' or 'patients'. Which term do you prefer them to use? (Why? What do you think when you hear the phrase?)
10. Has the fact that you have had mental problems and that you have participated in OPUS influenced the way you perceive yourself? (Do you feel that you now are different from what you used to be? Are you different from other people?)
11. What do people in your social network (family, friends, and acquaintances) think about your participation in OPUS, and the fact that you receive help from a social psychiatric project?
12. Has it changed your expectations and hopes for the future that you had mental problems and started in OPUS? (How? Why?)
13. What do you think you will be doing in half a year when we talk together again? And how do you think you will feel then?
14. Is there something important we have not talked about?

Interview guide no. 3

1. What are you doing at present?
2. Follow-up on personal themes presented in the previous interview

Case manager

3. What do you think about having a case manager in OPUS?
4. How often do you meet?
5. What do you talk about when you meet?
6. Explain what a typical meeting is like (Where do you meet? For how long?)
7. Have you had meetings with your case manager which were different? (Tell me about them)
8. How would you describe the relationship you have with your case manager? (Roles?)
9. How is the relationship compared to the relationship you have with family, friends, and acquaintances?
10. Are you missing something in your meetings? (For example doing something together)
11. Do you talk to your case manager on the telephone? (How often? What do you talk about?)
12. Has your relationship with your case manager changed from when you first started to meet? (Where and how the meetings are conducted? Roles? What do you talk about?)
13. What determines whether a case manager is good?
14. Have you talked about what is going to happen when you leave OPUS? (What are you going to do?)

Medication

15. Do you receive medication in OPUS? (If no: Have there been periods where you have taken medication? Why did you stop? Have you been offered medication or

- have you been advised to take medication in OPUS? Do you think medication is used in a good way in OPUS? - and jump to question 26)
16. Have there been periods, while in OPUS, when you have not taken medication? (Why?)
 17. Does your case manager help you with regards to medication? (Advice? Delivery?)
 18. How do you feel about taking medication? (Do you take it voluntarily?)
 19. Does it affect you to take the medication? (How? Why not? The way you experience and sense things? The way you act and behave?)
 20. Are there things that become possible or easier for you when you take the medication?
 21. Are there things that become impossible or more difficult for you when you take the medication?
 22. Is medicine used in a good way in OPUS?
 23. Does it mean anything to you that the medication is for free in OPUS? (What if you would have to pay yourself, would you buy it?)
 24. Do you receive sufficient information regarding medication?
 25. Do you receive good support regarding the use of the medicine (Type and dosage)
 26. Are there good opportunities to get to talk to a doctor about medication?
 27. Do you think meetings with the doctor are important?
28. Is there something important we have not talked about?
29. Presentation of the book project

Interview guide no. 4

Status and finishing in OPUS

1. What are you doing at present?
2. Has it been decided when you are to finish in OPUS?
3. What do you think about the fact that you are about to finish in OPUS (or have finished)?
4. How have you prepared your self to finish in OPUS?
5. What has been done in OPUS to help you to finish in OPUS? (Contact to district psychiatry, clubs, special social services for the mentally ill, education, work)

Plans and the future

6. What plans have you got? (Activities, source of income) (Near future, distant future)

Assessment of OPUS

7. What have you participated in or received in OPUS? (Case manager, medication, social skills training group, multiple-family group, psychologist, work consultant, informal social meeting – ‘Friday Get-Together’)
8. What have you gained from your participation in OPUS?
9. Has it lived up to your expectations?
10. What has been good in OPUS?
11. How could OPUS have been different and helped you better?

12. Were you surprised by anything in OPUS? (Disappointed, negative? pleased, positive?)
13. How much has OPUS meant to your life in the two years you have participated? (In what ways?)
14. How are you now, compared to when you started in OPUS?

Understandings

15. Today, what do you think about your psychosis/mental experiences/problems? (What were/are they? Why did they evolve?)
16. Did you also have this view/understanding when you started in OPUS? (Which other understandings have you had? What/who has influenced your understanding of this?)
17. Have you encountered other views/understandings of your psychosis/experiences/problems in your social network (family and acquaintances) or from other areas (reading, media...)?
18. Have you, in OPUS, learnt new words and concepts - ways of thinking, explanations, and models? (Which? 'Schizophrenia', 'racing thoughts'...)
19. Is it your experience that these words are useful to you? (How?)
20. Have the words got limitations? (In relation to your situation and your experiences)

General assessment of OPUS

21. What has it meant to your future (your plans for the future) that you became psychotic/experienced mental problems? (Did you previously have other plans for the future? Before illness/problems)
22. What has the psychiatric treatment and OPUS meant?
23. How do you think your situation would have been without OPUS? (Or other psychiatric support)
24. Expectations of OPUS presented in the first interview - have they been fulfilled?

About the interviews

25. What has it been like for you to talk to me during these interviews?
26. (If participated in the book project) What has the book project meant?
27. (If not participated in book project) What was the reason you did not want to participate?
28. Are there important subjects we have not talked about?
29. Is it okay that I contact you to talk again during the summer of 2001? (Then I want to ask you what you think about OPUS after some time has passed and you can look back on it)

Interview guide no. 5

Status

1. What are you doing at present? (Work, social activities, special social services for mentally ill, accommodation)
2. What are you living on at the moment? (Type and source of income)

3. Are you in contact with psychiatric services? (Mental health community centre, psychiatrist, receiving medication)
4. What are your plans for the future? (Activities, education, work, free time, place of living)
5. What did you do before you started in OPUS? (activities, source of income, accommodation)

OPUS

6. What do you now think of the time you spent in OPUS?
7. Have you been in contact with OPUS after you finished? (If yes: which kind of contact have you had? how often? If no: have you spoken to your previous case manager in OPUS?)
8. Do you miss the contact with OPUS? (What do you miss? Why?)
9. When you now look back, what has your contact with OPUS meant to you?

Self image, attitudes and strategies

10. Has the fact that you experienced mental problems and that you have participated in OPUS influenced the way you perceive yourself? (Do you feel that you now are different from what you used to be?)
11. Do you think that you are mentally ill? (If yes: why? If no: have you got mental problems?)
12. What does the diagnosis you received in connection with OPUS mean to you today?
13. How much do your (previous) mental problems mean to your life now? (Is it something you often think about? Do they limit you? In which situations? How?)

Social relations

14. Has your relationship with your family changed from what it was like before you started in OPUS, compared to how it is now? (What do you talk about? How often do you meet? What role do you have in your relationship now?)
15. Did you meet new friends in OPUS? (Are you still in contact?)
16. Has your relationship with your former friends and acquaintances changed from what it was like before you started in OPUS, compared to how it is now? (Have you got new friends? Where did you find them? What do you do together?)
17. Have you had a girlfriend/boyfriend or partner since you started in OPUS and till now?
18. Do you tell other people about your (previous) mental problems? (Whom? In what situations?)
19. Do you tell other people that you have participated in OPUS? (Whom? In what situations?)

Conclusion

20. What has it meant to you to be out of OPUS for a period of time? (Good and bad)
21. Is there something important we have not talked about?

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