

*Listening to the Voices in Four Scottish Adolescent
Mental Health Units: Young People, their Carers
and the Unit Cultures*

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**LISTENING TO THE VOICES IN FOUR SCOTTISH
ADOLESCENT MENTAL HEALTH UNITS: YOUNG
PEOPLE, THEIR CARERS AND THE UNIT CULTURES**

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by

ANNE CLAVEIROLE

June 2005

DECLARATION

I declare that this thesis is my own work and that no material contained in it has been submitted for another academic award

A handwritten signature in black ink, appearing to read 'Anne Claveirole', written in a cursive style.

Anne Claveirole

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ABSTRACT

Serious mental health problems among young people are on the increase in Western countries. Involving young people in their mental health care, and working in partnership with them during the treatment process, is a primary concern of all mental health services; their parents have also been promised a place in the health care team.

Research into the process and outcomes of hospitalisation of young people in specialist mental health units is complex and therefore limited. Qualitative investigations into the experience of young people as users of these services are few. Making use of ethnographic methods, this study explored young people and their carers' (both parents and staff) experience regarding treatment and participation in decision-making in four Scottish adolescent inpatient or day-care mental health units.

The findings suggest that the young people ($n = 18$) valued the personalised relationships they developed with the staff and their peers and that if these relationships were empowering, they facilitated both treatment and participation in treatment. However, the findings also show that the parents ($n = 16$) and staff members ($n = 21$) were sometimes disempowered and that this impaired the overall participative nature of the units. The unit culture was an important contributor to the effectiveness of young people and parent involvement.

Making use of concepts from the neighbouring academic field of pastoral theology to interpret the findings, the study concludes with a conceptual framework of what is required for a unit to be more participative. This theoretical framework adds significant elements to the existing knowledge regarding participation in adolescent mental health units. It places relationships of justice and care between all stakeholders at the core of successful participation, hereby drawing attention to the importance of humanistic and ethical considerations in user and carer involvement.

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CHAPTER 1: INTRODUCTION

When ethnographic methods are used, the researcher and the researched become mutually involved and interdependent. In such conditions, the researcher's culture and experience inevitably influence the process of inquiry. Since one's particular perspective cannot be set aside, the best strategy is to share with the reader the background of the researcher in relation to the research. It is with this intent that I use the first person in this introduction. The thesis itself is written in the third person in keeping with scientific practice.

In this study, I describe the perspectives of 18 young people, 16 parents and 21 staff members on the young people's treatment and participation in decision-making. I also depict the culture of the four Scottish units where I collected the data between 1998 and 2000.

My purpose was to explore how young people perceived their experience and, because of the growing importance of user involvement in mental health services, how much they participated in decision-making, particularly regarding their treatment. Participation in treatment is a complex activity. It involves the staff and, in the case of adolescents, their parents, so I investigated the perspectives of both these stakeholders. I included the unit cultures because, in the case of inpatient and day-care treatment, unit culture is a variant of the experience.

Several interwoven strands inspired the focus of this study. The first was the growth of the user and carer movement. From the beginning of the 1980s, adult users of the mental health services had been revealing powerful and frustrating stories regarding their dissatisfaction with their own health care and their lack of say in it (Lebow 1982, Campbell 1989, Lindow 1993). In 1997 when I wrote my proposal for a part-time PhD, the active participation of service users was increasingly recognised as an important dimension of good treatment. Mental health services that had traditionally been prescriptive and paternalistic (Goffman 1961, Szasz 1972) were becoming concerned to learn from the experience of their users (Department of Health 1994). The government was also committed to the support of family carers (Great Britain H. M. Government 1995). Following the NHS and Community Care

Act 1990, which had increased families' burden of care, a place in the care team had been promised to them.

The second strand was my interest, born of experience, in the treatment of young people with acute and severe mental health problems. That the user participation agenda applied to them was clear because of the progressive integration of the United Nations Convention on the Rights the Child (United Nations 1989) signed by the United Kingdom in 1991, into British law. The Children (Scotland) Act 1995 stated that children had to be consulted in all matters concerning their lives. This applied to health care and research but appeared to worry health care staff.

Both these developments affected me personally. I was working as a lecturer in a team where colleagues taught adult mental health nursing. They were developing research into the possible involvement of users and carers in the curriculum of pre-registration mental health programmes. My own subject was the mental health of children and young people. Most of my students were part-time post-registration students who worked in specialist mental health services for children and young people. Through them I had contact with clinical areas throughout Scotland. With one service, the link was personal: I had worked for several years in its inpatient unit in the 1980s. It subsequently took part in the study.

The third strand came from my commitment as a Catholic Christian. Through it I was aware of associations of people who, like the user and carer movement, had come together to demand a say in society and Church that had been denied them. The main one, called liberation theology, had originated in economically poor South American communities in the 1960s and had spread later to other marginalised groups in Europe and the USA. Another such association, to which I belonged, was that of women excluded from the priesthood. I was curious to explore the philosophical and ethical ground these movements might have in common. I will use these strands throughout the study to consider the data: they will be discussed in detail in the literature review and be brought to bear on the discussion.

To the groups of excluded and marginalised people who campaign for equal status in social institutions to which they belong, I have given the name of 'participation movements'. 'Participation' is not perfect. It is defined by Hart (1997, p. 5) as "*the process of sharing*

decisions which affect one's life and the life of the community in which one lives". It has the advantage of being broad enough to include the varied groups and motivations to which it refers. 'Liberation' is another common term, defined by Boff and Boff (1984, in Pattison 1997) as "*the social emancipation of the oppressed*", which hints of a radical political agenda. It is not a term in common use among mental health service users in Britain, which is why I have not used it, although I have encountered it in North American literature (Church 1995).

In the thesis, I investigate liberation theology ideas, particularly those applied recently to a British context (Grey 1989, Pattison 1997, Swinton 2000). Some of the ethical priorities they suggest for the success of participation movements transfer well to the health care context and I use them to propose a model of care. However, liberation theology can only be done from the inside, as a member of the marginalised group (Pattison 1997, Swinton 2000). As an outsider, my use of these ideas is made in a spirit of solidarity with young people who have mental health problems, based on my interest in them and my knowledge of what matters to them and their families. It cannot claim to be liberation theology proper.

The findings I present are based on snapshots of small periods of time, when the units may not have been at their best, or in a particularly typical phase of their existence. The samples were small and my subjectivity acted as the lens through which I perceived the data. I acknowledge these limitations (others will be discussed in chapter 3) to situate this study where it belongs: as a contribution to understanding young people's experiences in these particular units. The findings are not necessarily generalisable to other units. Nevertheless, the services that accepted to take part in the study represented, taken together, two thirds of the acute mental health care available at the time to adolescents in the Scottish National Health Service (NHS). Three of the services still operate as they did then; one unit has closed. While adolescent mental health care has moved on in the intervening period, many questions remain as to the best way of managing the treatment of young people who have acute, serious or enduring mental health problems. This study will contribute to answering some of them.

Rationale of the Study

Existing research into the process and outcomes of hospitalisation, whether full or partial, of young people in specialist mental health units is limited. At the time when the study started we knew that serious mental health problems among young people were on the increase, in all Western countries (Rutter and Smith 1995) as well as in Scotland (Bryce 1996, West and Sweeting 1996). The government was determined to involve service users in their treatment (Department of Health 1994), and young people had made it clear that mental health services mattered to them (Laws 1998). Carers had been promised a place in the health care team (Great Britain H. M. Government 1995). Qualitative research into the experience of users was limited: Chesson et al. (1995) had studied the experience of children and their parents in an Aberdeen inpatient unit for children; and Gaughan (1998) had evaluated a day-programme for adolescents. There was a need to hear from young people in inpatient and day units. Since then, a few more efforts have been made to investigate young people's views (Buston 2002, Street and Svanberg 2003, van Beinum 2003). For reasons that will be reviewed in chapter 2, these studies do not duplicate the findings of this thesis. There is still a need to hear how young people in several intensive services perceived their experience, how their views compared with those of their parents and the staff, and what the unit cultures contributed to it. In the next chapter, the literature will be explored and reviewed in detail.

CHAPTER 2: LITERATURE REVIEW

INTRODUCTION

This study is about young people's involvement in their care and treatment in four adolescent mental health units, considered from their own, their parents' and the staff's point of view. Involvement, or participation, is a core concept in the study. Health care settings that treat young people who have serious and complex mental health problems are the context. To set the scene, this chapter will focus in turn on participation, young people and adolescent mental health services, reviewing the literature related to each and exploring the connections between them.

1. PARTICIPATION

Introduction

The growing need to involve users of the mental health services and their carers in treatment initially inspired this study. A closer look at the literature on user and carer involvement revealed ambiguities in definition and terminology. Involvement can mean any level of involvement, the most significant being the delegated or shared control of decision-making. The overarching term 'participation' is often used to include 'involvement' as well as other terms like 'consultation' or 'partnership'. Participation seems to be a common word used to refer to a late twentieth century group of movements with political, ethical and religious connotations, which took place in many parts of the world. Another such reference word is 'liberation'. The deeper roots of these movements have been explored for the purpose of this study.

1.1 Involvement, Partnership and Participation

Participation has been defined as

“the process of sharing decisions which affect one’s life and the life of the community in which one lives” (Hart 1997, p 5).

In a brief historical outline, Croft and Beresford (1992) described the origins of the concept of participation. It emerged in the 1960s in the context of work with deprived communities, first in developing countries then in Britain and the United States. A populist movement, community development sought to deal with the political and economic inequalities of market economies. It was initially undertaken by community activists to respond to basic human needs for housing, employment, health care and education. Self-help and collective action were fostered among poor communities through education and politicisation (Friere 1972). The aim was to promote a redistribution of power so as to empower excluded citizens to influence directly social processes that concerned them. It was motivated by values of freedom (from oppression and discrimination) and social justice. The user and carer involvement movement which started in health and social care services in the 1980s belongs to this tradition (Croft and Beresford 1992). Banks, a lecturer in social work, explains that the definition of clients as fellow citizens came in order to re-establish some kind of power balance between social workers and their clients. It has meant that users of the services have the rights of citizens and cannot be patronised or treated arbitrarily by state officials. They should have access to the information held on file about them, and participate in planning and decision-making (Banks 2001). In Britain, user and carer participation is now government policy (Department of Health 1999, Scottish Executive 2000, 2003).

1.2 User and Carer Involvement

The participation of service users in public services, however, has had a mixed success. In a seminal paper, Arnstein (1969) described a ladder of citizen participation that went from non-participation through degrees of tokenism (including consultation) to complete transfer of power to ordinary citizens. Successful partnership for change, the third top rung of the ladder, implied involvement in decision-making (Arnstein 1969). It is this type of involvement that users of health and social services and their carers have asked of service providers and professional carers, but the partnership level of participation has been slow and difficult to reach (Banks 2001). Current reviews of the British literature on user involvement suggest that citizen participation, although central to public service policy, has made limited progress, in the mental health services as elsewhere (Rose et al. 2003, Crawford et al. 2003). The Social Care Institute for Excellence (SCIE) reports that the participation structures put in place have tended to be weak and not to fulfil expectations of user-provider partnership (SCIE 2004).

1.3 Critique of User and Carer Involvement

There is a strong argument in favour of patients contributing to decisions regarding their own health care, council tenants being involved in their housing estates, parents and children participating in the running of their schools. Nevertheless, the bottom-up movements that come under the umbrella of citizen participation have had their problems and their detractors. Some problems have been perceived from within the movement itself. Varied and conflicting viewpoints among service users, difficulties in organising representative groups, lack of an overall philosophy and economically viable infrastructure have been highlighted for a long time (Arnstein 1969, Campbell 1996). Also problematic has been the construction of an academic body of knowledge. While a large literature on citizen participation and user action is now available, it consists mainly of the recordings of individual schemes and the reviews of such accounts. Comprehensive analyses of participation movements, based on their history and geographic occurrence, are lacking, as

are outcome research and evaluation. This makes cross-learning between movements and progress to the next stage of development difficult (Croft and Beresford 1992, SCIE 2004).

Criticisms have also come from outside the movement. Sympathetic critics have drawn attention to two areas that are of particular interest in this study because both are relevant to health care. One regards the risk of overlooking available specialist expertise. Because health service users previously saw their experiential knowledge of disease and treatment disregarded, the focus is now, at the service users' insistence, on their expertise. But medical sociologists have challenged the 'expert patient' (Department of Health (DoH) 2001) concept. Contrasting professional expertise and the democratisation of decision-making in medicine, Prior (2003) has argued that lay people can be

"...plain wrong about the causes, course and management of common forms of disease and illness..." (p. 45)

because of the limited nature of experiential knowledge.

Another significant warning concerning the possible excesses of citizen participation is ethical in nature. Citizen-practitioners taking over professional territories run the risk that the new system will become in time just a mirror image of the old one, based on reversed values of hierarchy, power and privilege (Schön 1991). To counter this, Schön advocates a reflective practice in which professional and client participate equally. In the second edition of his seminal book, *The Reflective Practitioner* (1991), Schön describes a thoughtful process inspired by the supervision model used in psychotherapy. The reflective practitioner values persons and relationships and promotes the best kind of knowledge - a mixture of expertise and experience - to inform the problem-solving process.

Citizen participation movements have emerged in the context of late twentieth century capitalist economies, mainly but not exclusively in parliamentary democracies. They have influenced many social groups as well as government structures, yet they struggle to succeed. A brief examination of their cultural background and areas of influence reveals

philosophical, ethical and religious themes that may in turn shed light on the experience of user and carer involvement.

1.4 Philosophical Background

1.4.1 Postmodernism

Policies of citizen participation and user involvement find some of their philosophical roots in postmodernism. Western science, politics and philosophy, founded on ideals of humanism, progress and reason, have been criticised by voices emphasising fragmentation, pluralism and scepticism (Graham 1996). This has been named the postmodern condition.

“I will use the term modern to designate any science that legitimises itself with reference to a metadiscourse of this kind making an explicit appeal to some grand narrative, such as the dialectics of Spirit, the hermeneutics of meaning, the emancipation of the rational or working subject, or the creation of wealth.... Simplifying to the extreme, I define postmodern as incredulity towards metanarratives” (Lyotard 1984, p. xxiii-xxiv).

The term ‘postmodern’ refers, among other things, to a philosophical way of looking at knowledge, ethics and selfhood. While the eighteenth and nineteenth centuries had believed progress based on universal reason would transform the world, the tragedies and failures of the twentieth century gave rise to the postmodern backlash. Postmodernism takes a critical perspective on any contemporary project which makes other than highly qualified claims of rationality, knowledge, moral ideal or authority (Graham 1996). Lyotard’s critique of the metanarrative is made on grounds that it cannot encompass the diversity and specificity of local interests. It is too grand, too ambitious. It betrays variety, absorbs and smothers difference and imposes homogeneity where none exists. Postmodernism also destabilises an earlier version of the human self. The primacy of reason in the understanding of the human person had resulted in a devaluation of those whose irrationality was more apparent, like children and the mentally ill (Foucault 1961). By contrast, the postmodern analysis stresses a finite, contingent and embodied selfhood, only understood in the context of its history, culture and community (Graham 1996).

It is easy to see in postmodernism a context for the scepticism of citizen participation movements towards established interests, for example those of the professions, and towards the State institutions that uphold their power. Each participation movement expresses the interests of a marginalised social group (such as people who have mental health problems) traditionally unable to make itself heard against the power of long established grand narratives. Postmodernism is sometimes seen as a coming of age because it is more realistic about what can be achieved, more self-aware and more humble. But healthy scepticism can turn to nihilism and make any claim about knowledge, ethics or the self almost impossible. The mixed success of the participation enterprise perhaps shows how unable postmodernism is to inspire anything beyond scepticism. It is therefore necessary to submit the tenets of postmodernism to a process of discriminative analysis.

1.4.2 A Critique of Postmodernism and Possible Ways Forward

Graham (1996) welcomes the end of the metanarrative. Writing from the perspective of feminism (a participation movement for the benefit of women), she suggests that modernism, blind to its own biases, had claimed universal human aspirations which were no more than the aspirations of a small group of educated white men. With culturally embedded local narratives which acknowledge the bias of their author, postmodernism offers hopes of being heard to formerly silenced minorities. It is both truer and fairer. Truth and fairness, however, present a problem for postmodernism because it denies the ground of truth and ethics. Hence, says Graham, the origin of women's emancipation was not in the sceptical philosophies of postmodernism but in the idealistic metanarratives of modernism about equality and justice (Graham 1996). Any movement concerned with the emancipation of minority groups stands in an ambiguous relationship to both modernism and postmodernism by virtue of being a local narrative grounded in claims of progress, truth and value. Graham (1996) proposes an emphasis on practice, in local communities where central values like the dignity and full participation of all, especially the most vulnerable, can be articulated, embedded and maintained. Although she focuses on faith communities for the purpose of pastoral care, this can apply equally well to health and social care settings.

Taylor (1991), teacher of social, political and moral philosophy at McGill University in Canada, has also scrutinised the contradictions of the postmodern position. He draws attention to the fact that postmodern nihilism is a grand narrative in disguise because it proclaims as truth that there is no truth. Since the nihilist position is logically untenable, Taylor (1991) investigates what he calls the 'moral underground' of Western societies in their postmodern phase and he retrieves hidden truths and values. One focus of his excavation work is individualism, a core value of our society. Taylor perceives at the heart of it a call to personal authenticity, to a more differentiated, self-aware and responsible identity. This is a powerful, if surreptitious, moral ideal, often hidden behind a façade of egocentrism. And it has an even more elusive dimension: as people value the self, self-fulfilment and self-development, so they implicitly value those who contribute inextricably to it: parents, teachers, friends, colleagues... The centrality of the individual, to be coherent, has to go hand in hand with a strong concept of social community (Taylor 1991). These 'moral fragments' need to be brought into the public eye because they are at risk from many fronts: from a naïve blindness to their own value, from a lack of confidence in rational dialogue and from a nihilism that denies all values and sources of reference. They are thus vulnerable to being swamped by unethical forces (a Nietzschean will-to-power, self-centredness, hedonism and the like) at work in most societies but empowered in the postmodern one by the apparent absence of positive values. Taylor (1991) concludes that citizens of postmodern societies need to become more perceptive and more morally committed.

In summary, the philosophical context of participation movements can be partly identified as postmodern because of these movements' focus on local interests and minority narratives as opposed to the grand narratives of modernism. However, as Graham (1996) suggested, postmodernism's modesty-cum-scepticism regarding epistemological and ethical claims cannot account fully for participation movements with their ideals of justice and non-discrimination. Yet, as Taylor (1991) showed, postmodernism may still have something to say regarding ethics. This is also the view of social analyst Zygmunt Bauman (1993). Bauman (1993) has disagreed with the postmodernists who celebrate the demise of the

ethical as the ultimate liberation, stating that this is a misreading of the postmodern perspective:

“The great issues of ethics – like human rights, social justice, balance between peaceful co-operation and personal self-assertion, synchronization of individual conduct and collective welfare – have lost nothing of their topicality” (Bauman 1993, p. 4).

Although these issues may need to be dealt with in a novel way... While ethical theories had traditionally appealed to metanarratives to deal with them, now more circumspect, embedded, culturally sensitive approaches are needed (Bauman 1993). The participation movements make a discreet and not always recorded ethical contribution, grounded as they are in local cultures, small community narratives and the support of vulnerable minorities.

1.5 Ethical Themes

Participation movements have presented themselves primarily in political terms. They have made use of the politics of the left for their analysis of situations where power has been distributed unequally on grounds of social and economic deprivation, gender, race, social class, age, health and disability. Values of social justice and solidarity have been a dimension of their motivation. Participation in local political life has also been claimed as a right. Both these ethical themes, values and human rights, have a bearing on the work of participation movements.

1.5.1 Values

Values are perhaps easiest to identify. The word ‘value’ conveys the idea of ‘worth’. In ethics, a value holds or represents an intrinsic moral good, a moral norm, which moral decision-making aims to protect (Rae and Cox 1999). There are basic human values like life, friendship, freedom or beauty, that most human beings hold in common, and more personal values, which individuals choose. We base our social, personal and professional lives on the values we hold: Tschudin (2003) emphasises the importance of clarifying them in order to enhance our motivation and decision-making.

Groups of people hold collective values. Nurses' values are found in their Code of Professional Conduct (Nursing and Midwifery Council (NMC) 2002). There, the emphasis is on respect for the patient or client as an individual and as a partner in care, informed consent, confidentiality, team work, trustworthiness, up-to-date and self-aware professional expertise (Tschudin 2003). Clients have their own values regarding their care and treatment, which include being respected and listened to, being treated with dignity, having relationships of trust with those who care for them and a say in decisions regarding themselves and their families (Healthcare Commission 2004). Tschudin (2003) stresses that health care itself is not value-free and gives examples of value-laden questions: does someone need admission or would they be better treated at home? When do the side-effects of a medication cease to be acceptable? Is the goal of treatment complete restoration of health or are self-determination and dignity more important? Whose judgement on this is the most valued, doctors, clients or nurses?

The values of an individual, group or profession may not be in harmony with each other. With regard to social work, Banks (2001) draws attention to the contradiction between a long-standing focus on respect for individual clients to help them with personal problems and the emphasis of radical models on structural inequalities and oppression within society. This latter model of course is very much along the lines of radical participation movements. It was eventually adopted in addition to the former by the social work diploma awarding body. It is interesting to read Banks' (2001) analysis of the conflict of values social workers struggle with as these models compete with each other and with others like evidence-based practice, consumerism and bureaucracy. This struggle is not unlike that faced by health workers and goes some way towards explaining why the user and carer approach in health and social care services has only been partially successful.

Sociologist Anthony Giddens (1997) defines values as being

"Ideas held by human individuals or groups about what is desirable, proper, good or bad. Differing values represent key aspects of variations in human culture. What individuals value is strongly influenced by the specific culture in which they happen to live" (p. 586).

If values are relative to cultures, participation movements must claim different sets of values, depending on the cultures in which they operate. In health and social care, it means a mixture of the values just outlined: those of clients and professional groups, of health care and state welfare. Such values are rarely made explicit outside the core group (Woodbridge and Fulford 2004).

Philosopher Bill Fulford (2002) has argued in favour of the importance of values and value-based health care using the writing of Hare (1952) and Austin (1956). Fulford stresses the need of professionals to learn about values, their own and those of other people, in order to insure that the process of health care remains humane during the pursuit of evidence-based scientific outcomes. Fulford and his colleagues suggest that successful partnership relies on the awareness of values, and on the key values of all the stakeholders being made explicit (Woodbridge and Fulford 2004). Any effort to understand how participation is practised will need to consider the status of the partners' values in that setting, and reflective practice (Schön 1991) can offer a context for this.

1.5.2 Human Rights

As well as values, an ethical theme of relevance here is human rights because the participation of citizens in decision-making regarding the services they use is sometimes alleged to be a right. The language of rights has become central to British modern ethics. There has been a recent national emphasis on the right of individuals not to be discriminated against, particularly on grounds of race or disability, and in 2000, the Human Rights Act 1998 came into force, incorporating the rights of the European Convention on Human Rights into domestic law (Booth 2003). This may have made the concept of human rights the nation's best known – if not necessarily best understood – ethical argument. It has been suggested that the concept of human rights appealed to “*powerful and widespread moral intuition*” (Gillon 1985, p. 55), and that respecting others' rights was at least a partial answer to the question ‘how ought we to live’ (Singer 1993). Nevertheless, the theory of rights has critics as well as supporters.

Some writers give it a long and hallowed history, linking it to the doctrine of natural law first developed in Ancient Greece (Almond 1993). According to this doctrine, whereas State laws were liable to err, a natural law existed, intuitively known through one's own conscience, which guided human beings towards the good. This way of thinking introduced concepts of universal moral norms regarding human life independent of national laws, although the Greeks did not talk of 'rights'. Enlightenment philosophers like Locke and Rousseau first mentioned a doctrine of fundamental human rights. They influenced the 18th Century American Declaration of Independence and the French Declaration of the Rights of Man and of the Citizen (Almond 1993). It is not until after the Second World War, however, that the importance of affirming an area of personal autonomy for individuals beyond the moral and legal reach of States took on a new urgency. By then, the danger of immoral but legal national norms had become plain for all to see (Booth 2003). The international community proclaimed fundamental individual rights based on humanitarian principles. Although the authority of international law is still shaky, its principles are being progressively integrated into national legal systems.

The doctrine of human rights is linked to liberal individualism which it has been accused of fostering by supporting individuals' moral autonomy from the surrounding community's other moral and legal considerations. For a communitarian philosopher like MacIntyre, ethical standards arise from within a tradition and a community. Any affirmation of natural or universal rights is without rational justification because without roots in a communal discourse: "*there are no such rights. Belief in them is one with belief in witches and unicorns*" (MacIntyre, 1985, p. 69). In response to this objection, it could be argued that in 1948 the notion of universal human rights emanated from an international community tried and tested by its common history and shared wartime experience.

Rights have been defined as "*justified claims that individuals and groups can make upon others or upon society*" (Beauchamp and Childress, 1989, p. 56). To be effective, such claims must be guaranteed. This implies a relationship, a kind of contract between individuals, or between individuals and institutions, where specific rights are ratified by both parties (Gillon 1985). The case of a right is more compelling when it refers to a

fundamental claim (to life or liberty, say) than when it amounts to a hopeful statement, such as a right to happiness. The strength of the more fundamental moral rights is that they are grounded in moral principles like freedom, equality or justice. A community which adopts certain rights also has the responsibility to see that they are respected: this is both a collective responsibility, through a system of rules and penalties, and an individual one, for anyone's right is limited by another's entitlement to the same right.

In so far as a right is universal, children and young people are as entitled to it as anyone. Hence the European Convention makes no specific provision for them. The United Nations, however, issued the Convention on the Rights of the Child, in order to make clear that children had some rights *qua* children: rights to protection, rights to education and, in proportion to their growing maturity, rights to self-determination. Since it signed the Convention in 1991, the United Kingdom has worked towards incorporating the Convention's principles into its legal system, more specifically into the Children Act (1989) and the Children (Scotland) Act (1995). Nevertheless, in 2002 an international watchdog for the Convention highlighted inconsistencies in the area of self-determination, including the participation of children and young people in services for them (Committee on the Rights of the Child 2002). The impact of the Convention on the Rights of the Child on UK and Scottish law is the main reason why young people are included in the health and social care services' commitment to involve users and carers. Knowledge of how this works in practice with the younger age group in specific services is useful and contributing to it is an objective of this study.

In this section, two ethical themes, one based on values and the other on human rights, have been reviewed because of their relevance to user and carer involvement. Citizen participation movements are based on values such as freedom from the oppression of powerlessness, justice and solidarity. The ethical status of these values is not always given the prominence it deserves, however. As Woodbridge and Fulford (2004) have suggested, clarifying the values of the various groups who commit themselves to citizen participation and stating them explicitly would help to detect areas of potential conflict and encourage a realignment towards shared values, thereby strengthening the motivation of the parties

involved (Woodbridge and Fulford 2004). Another ethical theme is invoked, human rights, for instance the right of service users to be involved in decisions that concern them. This ethical justification for the work of participation movements would also be stronger if the context of human rights, their significance and their limitations were more robustly integrated into the case for user involvement.

1.6 Religious Themes

As well as ethical themes, religious ones run through a number of participation movements that originated in the Christian Church. They remain influential in pastoral theology. In this section, the first and most significant participation movement, liberation theology, and its present place in pastoral care is discussed to show that there may be useful parallels to make between pastoral and health care in this respect. Three liberation models are of specific interest, two of which were devised in the last few years for the pastoral care of people with mental health problems (Pattison 1997, Swinton 2000). The third shows that social groups who want to support the liberation of vulnerable, marginalised people must become inclusive, power-sensitive communities where everyone participates (Grey 1989, 1997).

1.6.1 Liberation Theology

One of the first participation movements grew out of the struggle for liberation of oppressed communities in Latin America. In the 1960s, Paulo Friere (Friere 1972), a Brazilian lawyer, started programmes of adult education for groups of illiterate people living under oppressive economic and political conditions (Pattison 1997). His aim was to teach them to read and think critically about their environment and their own position in it so that they could take political action. This was the beginning of civic participation in Latin American countries (Pattison 1997). At that time, some people in the Catholic Church, the main religious denomination in South America, became aware that the supposed political neutrality of the Church amounted to accepting a deeply unjust social order and colluding with structures that oppressed more than half the population (Pattison

1997). Some lay people and members of the clergy decided to support and encourage emancipation efforts like those of Paulo Friere and, in time, a theology of liberation was born, based on a radical commitment to social justice and human rights. Making use of Marxist tools of political analysis, these Christian groups dedicated themselves to social change in the name of Christ and the gospel. New theological insights were born out of an encounter between the active critique of social systems of oppression and the study of Biblical texts which went on side by side in the base communities (small local groups of ordinary people committed to worship, Bible reading and political action together). The bishops of Latin America committed themselves to liberation theology at their landmark meeting in Medellin, Colombia, in 1968. Many still do in spite of the reservations expressed by the present Pope and his Magisterium regarding the use of Marxism and the Church's engagement in political action (Pattison 1997).

Liberation theology has had a wide influence. Now 40 years old, it has refined many of its concepts, has spread to other Christian denominations and geographical areas. It has also broadened its understanding of the main aim. One of the core commitments of liberation theology was defined in 1979 as being a 'preferential option for the poor' (Boff and Boff 1987). Although in the context of Latin America the poor are often economically deprived, 'the poor' is also a biblical category meaning those who are dominated, oppressed, abused or alienated, not just those who lack goods (Dussel 1988). In consequence, liberation theology has inspired a variety of Christian liberation and participation movements who espouse the cause of groups characterised by their insignificance and invisibility on the margin of society (McDonagh 2003). These theologies of liberation have provided an influential model of pastoral care for contemporary Britain (Lyall 2001).

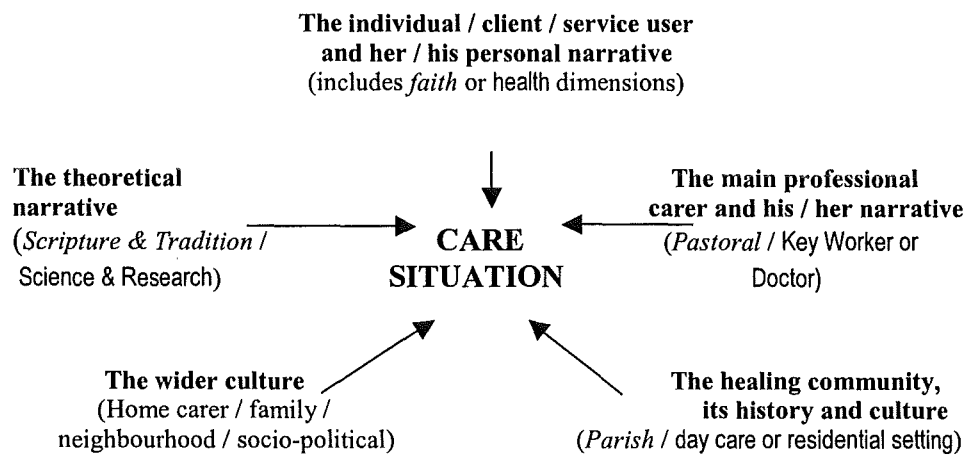
1.6.2 Pastoral Care

As David Lyall (2001) explains in his book on the subject, pastoral care is one of the practical ends of the discipline of theology. It deals with the care of individuals, relationships and communities brought together by their faith in the Christian narrative, without excluding those who are not part of that community. It affirms the value of persons

and aims to help them grow personally and spiritually, often at times of crisis. Pastoral carers are mainly members of the clergy (that is, set aside for the purpose) but they may also be lay people. While they make use of skills which originated in secular sciences like counselling and psychology, they also have at their disposal traditional resources like prayer, scripture and sacraments, which they call upon according to the needs of the people in their care. Lyall (2001) explains that under the influence of liberation theology, pastoral care now tends to take into account the social and political structures that are part of the context of care, and to see it as one of its tasks to bring pressure to change them.

Pastoral care as practice has close links with theoretical theology, which is a “*critical and faithful reflection upon the Scriptures and tradition of the Church*” (Lyall 2001, p. 24). This theology is not simply ‘applied’. A dialectic relationship with contemporary culture and the socio-political context of care brings new insights to both. Communities of faith and pastoral carers shape their own understanding of the Christian beliefs and their own interpretation of Scripture and tradition as they mull over them in a process of critical dialogue and reflection. They develop, therefore, a communal as well as a personalised “*working theology*” (Lyall 2001 p. 37) and the influence of theory on practice is also an influence of practice on theory.

According to this description of pastoral care, the pastoral situation is located at the intersection of five elements in relation: one, the person whose life calls upon pastoral attention; two, the pastoral carer; three, the faith community to which one or other or both belong; four, the wider socio-cultural context which includes family, friends, neighbourhood and society; five, the theological narrative. Lyall (2001) describes all five as narratives, either personal or communal, in dialogue with each other, the integration of which will result in the alteration of all five. These five elements can also be said to be present in the health care situation and this may be a good place to locate a comparison between the two care situations that may be of relevance to the mental health care of young people. This is attempted in Diagram 2.1.



<p>Legend: Characteristics common to both care situations [bold/Times New Roman] Components of pastoral care situations [<i>italics / Times New Roman</i>] Components of the health care situations of the present study [Abadi MT Condense]</p>

Diagram 2.1: Schematic Representation of a Comparison between the Components of Pastoral and Health Care Situations

Three important aspects of any such care situation about which liberation theology has something to say deserve further comments in the attempt to draw parallels between pastoral care and health care, specifically, between liberation theology and the user and carer participation movement. These are: the key position given to respectful, personal relationships, the centrality of a community and the core position held by a critical analysis of the context of care. Three contemporary pastoral theologians use liberation theology to deal with them: respectively, John Swinton, Mary Grey and Stephen Pattison. All three have in common premises of liberation: the carers choose to be on the side of the vulnerable and marginalised, to raise awareness of de-humanising relationships, institutions and social processes and to work to transform them. Together they form a healing community. A commitment to 'just' relations and mutual collaboration is necessary.

1.6.3 Liberation Theology as a Model for Participative Care

1.6.3.1 Liberating the Person (John Swinton)

In both pastoral care and health care, the value of the human person is affirmed. However, the Church's sacred narrative, the Bible, has it as its main message that human beings are important enough to be loved by God, who himself became human. This central creed gives the Church a stronger base from which to proclaim the sanctity and dignity of the human person than does the liberal humanism of the health care tradition. Although strongly anchored, the latter has to compete with other narratives as theoretical guides. The strongest of these is that of science and research, which, because of the positivist influence of natural sciences like biology and medicine upon health care, often overlooks the human narrative, even in mental health (for an analysis of the positivist dimension of mental health research see Chapter 3, p. 67).

In his book, *Resurrecting the Person: Friendship and the Care of People with Mental Health Problems* John Swinton (2000) discusses how caring people can offer those who have mental health problems liberating relationships in communities where they are welcome. He explains how he himself approaches this liberation from a position of 'critical solidarity' with the oppressed group, that is, as an outsider to it. Only from within that

community can genuine liberation theology be done. In this sense, Swinton's model is a carers' rather than a users' model.

People can be discriminated against in small and invisible ways. Non-verbal behaviour, spontaneous and unreflective comments, jokes and stereotypes, all display a lack of awareness of oppression and reinforce it. It is at this micro level of one-to-one and small group relating that the liberation Swinton (2000) suggests takes place, although he does not deny the importance of liberation at the macro level of socio-political structures. Micro level oppression can take place in the health care system itself. Although designed to help people who have mental health problems, psychiatry operates from a position of power: the power to define problems and to prescribe interventions. This power can be abused (Szasz 1997, Barker and Davidson 1998). Too often the individuality of the person disappears under the label and the illness (Barker 1998). Yet, what mentally distressed people need is a simple, equal, personalised way of relating that will free them from interpersonal and group oppression. They need humanising relationships and communities. Swinton (2000) calls it 'friendship', following the friendships of Christ "*who sat on the margin of society with those whom the world deemed unlovable*" (p. 38). The friendship described here may not be based on likeness and common interest like usual friendships but it would offer solidarity, support and compassion (McKie and Swinton 2000). It holds many similarities with Rogers' (1951) unconditional, genuine, respectful, positive regard and is not a category that should come to mental health professionals as a surprise (Sullivan 1954, Barham and Hayward 1995, Barker 1998).

Swinton writes for Church communities who, like the rest of society, are ill-at-ease with people who have mental health problems and, deliberately or not, exclude them. Nevertheless, the emphasis on this basic aspect of liberation and participation is also relevant to professional relationships and settings: people with mental health problems will not be liberated from the oppression of powerlessness and marginalisation until the primary mode of relating that others adopt towards them is one of 'friendship'. It is well documented that professional staff struggle to keep up this kind of standards (Campbell 2000, Barker 2003). Even caring and cautious health care staff find it difficult to perceive

their clients' lives as the clients themselves experience them, and see them instead from their own perspective (Roberts and Walfson 2004).

This focus on primary modes of relating between persons flourishes best in a group that identifies itself as a community committed to the participation of all its members. The second liberation theologian, Mary Grey, who describes the main characteristics of such a community in several of her books, allows us to widen the context of the liberation enterprise from the person to the immediate community.

1.6.3.2 Liberating the Care Community (Mary Grey)

In our society and institutions, says Grey, power is too often exercised in ways that serve mainly the interests of the strong, so that relationships are devalued and unjust. Oppressive situations do more than undermine relationships between people however; they also undermine powerless people's view of themselves inside their own mind so that, in time, they learn to collude with their oppression. One way to new liberating possibilities is the restoration of 'just relations' at the heart of group life (Grey 1989).

The communities Grey (1997b) envisages are counter-cultural entities, because, with their emphasis on respectful, non-exploitative, power-sharing ways of relating, they proclaim a different vision of the collective priorities and different ethical values from the usual ones of competition, individualism and consumerism. A community needs to discover the actual experience of all the people who are its members, the way they see the world, feel, think and act and give priority to the narratives of its most vulnerable members. Doing this will have a re-humanising effect on those who had previously been marginalised and will avoid discrimination. Liberation, says Grey, is a corporate process of self-development (1989).

Much depends on power and how it is used: it is non-power sharing situations that keep people oppressed. This is what users of the mental health services have described regarding their health care: when the power to decide what is wrong and what should be done about it has not been shared, they have experienced it as oppressive (Read and Reynolds 1996). They and their carers have asked for this to change. But Grey's emphasis on power-sharing

as central to the shared life of a group draws attention to the need of health care settings to organise themselves on liberating lines because to focus only on the individual relationships between mental health professionals and their clients is not enough. Institutional settings also need to be liberated, and to be liberated, they need to be self-aware and to have power-sharing policies.

Grey does not imply that forms of authority and leadership are not necessary within an institution or a community, but she suggests a different way of exercising authority, based on inclusiveness and empowerment (1997a). Power and authority need not be wedded to domination, competition and control. Power can be exercised along principles of consultation and empowerment, making sure that even the less articulate, the weak and the marginalised are drawn in. This is a challenge for any health care setting that deals with people whose powers of rationality are less than the norm, such as those dealing with children, young people, mentally distressed or disabled adults.

1.6.3.3 Liberating the Context of Care - Socio-political Action (Stephen Pattison)

Widening the context of liberation action still further, the last model to be discussed here is a socio-political one. Stephen Pattison (1997) uses liberation theology to frame a model of pastoral care focused on changing socio-political structures in the context of care. As chaplain to a psychiatric hospital, Pattison (1997) became concerned that pastoral care was *“an asocial, apolitical, individually focussed activity which takes and leaves society and health care institutions uncritically as it finds them”* (p. 189). This failure to recognise the importance of social and political factors in the context of care, leads in practice to a failure to promote justice and equality, thinks Pattison (1997). Like the first liberation theologians in South America, but this time in contemporary Britain, Pattison came to the conclusion that being neutral in politics amounted to siding with the powerful. His analysis focuses on the liberation of people who have mental health problems, particularly serious and enduring ones. At the time when he wrote his book (1996-7) Pattison noted the growing influence of the service user movement and welcomed it but he also stressed that many patients were not militant or effective promoters of their own liberation. Therefore his model focuses on pastoral carers' active involvement with the service users' struggle for liberation. Like

Swinton (2000), he writes from a perspective of pastoral care but his model transposes well to professional health care.

Liberation, an activity to free people from domination and oppression, needs to take place on a social level, against collective oppression, as well as on an individual level. In Pattison's model, sociology, politics and social policy are used to support a thorough social and political analysis of the context of care, looking for structures of injustice and disempowerment at several levels: in the local setting, in the wider institution and finally, in society. However, Pattison (1997) acknowledges that changes in large systems are long term goals, requiring strategic political action over many years.

In as much as it is used to analyse the local care setting itself (the care community), Pattison's model overlaps with Grey's vision of the liberated community. But Pattison's model applies mainly to wider systems whose structures of oppression affect the immediate one. A critical analysis of a specific mental health care setting will include an analysis of the usual variables of oppression: being mentally ill, being black, being female, having a low socio-economic status, being young or old. It will rally to its help literature on the subject: the classics like the Black report and its updates (Townsend et al 1995), Foucault (1961), Goffman (1961), Illich (1977), Szasz (1972, 1997), Clare (1980), but also current sociological and political articles. It will focus on the power structure of the whole establishment, not only the position of the people receiving treatment, looking for "*sources of inhumanity*" (Jenkins 1976 in Pattison 1997, p. 68). As the groups in need of support and advocacy reveal themselves (they may include carers and members of staff as well as service users), professionals can then make a preferential commitment to their support and put their skills at the service of their cause. The model involves a number of steps and is outlined in Box 2.1.

The professional carer would:

1. Analyse the social and political context of care, making use of the literature available.
2. Take a preferential option for the most vulnerable and oppressed group(s). Action would include seeing reality with their eyes by spending time with them, listening to them and giving them a voice, believing what they say about their lives, helping them make the changes they want to make and that will empower them and liberate them.
3. Put his/her skills at the service of the disempowered group's cause: write, campaign or take action, and whatever is useful towards raising consciousness and validating them. Not forcing some form of orthodoxy of thought or norm on behalf of the system would be important.
4. Work with other groups doing this kind of work.
5. Use 'unfinished' models of social and political action: liberation is never achieved, so there is a need to go on spotting and working with new forms of oppression.
6. Continue to care for individuals, helping them to detect and work with sources of oppression in their own lives (the best forms of therapy are liberating: by listening, helping individuals take themselves seriously, raising self-esteem and empowering them to recognise their needs and gifts).

Box 2.1: Model of Socio-political Care (Pattison 1997, Chapter 17)

In this section, models of pastoral care that originated in the Church, like liberation theology and more recent liberation approaches geared to the empowerment and inclusion of people marginalised by our contemporary society, have been discussed. They have been designed with a single-minded interest in promoting a justice agenda and they appear coherent. They might therefore have something to offer health and social care contexts that aspire to the participation of people with mental health problems but have to compete with other priorities (like medical science and bureaucracy) making coherence difficult. It may be useful therefore to see if the priorities highlighted by Swinton (2000), Grey (1989, 1997)

and Pattison (1997) regarding relationships and communities of justice, aware and active at a socio-political level, are met by the care settings in the study, and if not, why not.

Conclusion

User and carer involvement, which includes young people and parent involvement, belongs to a late twentieth century group of movements which aim to reclaim to right of vulnerable and marginalised citizens to participate in decisions regarding them and their lives. While citizen participation has become government policy, particularly with regard to health and social care, the level of partnership in decision-making aspired to by users of the services has been difficult to achieve. Participation movements are driven by strong but covert ethical motivators, which often remain hidden in the ambient scepticism of our society's postmodern culture. In the context of health and social care, they also compete with contradictory priorities of public policy. Some participation movements that originated in the Christian Church are more explicit in their values and priorities and may offer useful parameters for the involvement of people with mental health problems in their own health care. The focus of this study is adolescent mental health care; so the focus of the next section will be young people.

2. YOUNG PEOPLE

Introduction

In this section, literature regarding young people, their development, social role, mental health and the health care system specialised in their treatment is reviewed. Some of this literature talks of 'children' when meaning 'children and young people'. The same use of the word children is made here unless otherwise specified.

The focus of this study is the client group of adolescent mental health services. When the study started in 1998 the age boundary varied from unit to unit, between twelve to fourteen

at the younger end, and eighteen to twenty-two at the upper end. Recent efforts to reach a national standard have been largely unsuccessful because individual variations in the completion of adolescence's physical, emotional, intellectual and social components mean that standard age boundaries are arbitrary. From his experience of working with young people, Gaughan (1998) argues that, for the majority, adolescence is contained between the ages of twelve and twenty-one. In England, the National Service Framework for children and young people (Department of Health 2004) places an upper limit of eighteen years of age to mental health and social care services.

2.1 Adolescence as a Developmental Phase

As a developmental phase, adolescence attracted the attention of development specialists later than childhood phases. Freud presented the case of the adolescent Dora in 1905, the same year that psychologist George Stanley Hall (1905) published his book *Adolescence* in the USA (Evans 1982). Adolescence became the focus of psychoanalytic studies in the 1960s and 70s with Anna Freud (1958), Erikson (1968) and Blos (1967, 1972). These experts influenced the beginnings of adolescent psychiatry as a branch of child psychiatry, leading to the establishment of separate services for young people with mental health problems. In 1979, the term 'adolescent' was added to the name of the 'child psychiatry' section of the Royal College of Psychiatrists (Parry Jones 1995).

Adolescence is a long and complex stage of development between childhood and adulthood. Several theories attempt to explain its biological, affective, intellectual and social aspects. Only theorists whose impact has been long or lasting are referred to here. Much more is worthy of mention than space allows, in particular feminist and other critiques of the theories presented here (Chodorow 1978, Gilligan 1993, Santok 2001).

Biologically, adolescence starts with puberty. This is a hormonal process of physiological maturing which takes the body from its childhood shape to that of adulthood. There are two major types of changes: one is a spurt in physical size and strength, the other the maturation of sexual organs and the appearance of secondary sex characteristics. Together they result

in a child achieving, over the period of a few years, the biological functioning of an adult, particularly the reproductive capacity (Thibodeau and Patton 2003).

Intellectually, Piaget described the final phase of mental development as the ability to think abstractly and situated it during, and consequent to, the final phase of physical development (Piaget 1954, Beard 1994).

In terms of emotions and relationships, psychoanalytic theory has been particularly influential in the work of adolescent mental health services. Therefore this theory will be used here to describe adolescence. It is an approach that has been accused of being based on young people seen in consulting rooms rather than in normal environments (Coleman and Hendry 1999). Yet some of the experts were versed in the study of normality: Blos was a biologist as well as a psychologist and Anna Freud was a teacher (see *Normality and Pathology in Childhood, 1965*). Psychoanalytic theory is helpful in outlining the maturational tasks of this stage of development and the many ways in which they can go wrong. It is not possible to give much detail in this literature review however, and this account only summarises briefly some of the main aspects.

Psychoanalytic theory focuses on the person's inner world, built by a process of internalisation of personal and interpersonal experiences from infancy onwards (Bateman et al 2002). According to this theory, adolescence has three main maturational objectives. The first is an internal distancing from the relational objects of childhood, particularly parents, in order to develop a reasonable capacity for separate existence (Blos 1967, Evans 1982). The second is the assimilation and integration of sexual maturity, with all it entails of increased desire for sexual activity, into a stable system of respectful and caring relationships with peers (Evans 1982). The third is the development of an identity robust enough to provide a sense of uniqueness and continuity across the many different roles demanded of adulthood (Erikson 1968). The psychoanalytic approach suggests that these objectives are challenging and that adolescents meet them in stages, by a process of trial and error, with stops and starts and a certain amount of individual and family trauma. Hence the reputation of adolescence for being a time of stress and turmoil. In actual fact, probably only a minority of adolescents develop emotional, behavioural or psychiatric problems (Offer et al. 1988), and those who do have been put at a disadvantage by

problematic childhood, environment and genetic inheritance. Nevertheless, there has been concern in recent years that young people's psychological problems are increasing (Meltzer and Gatward 2000). This will be discussed in the section on adolescent mental health.

2.2 The Sociology of Childhood

A serious question lies at the heart of developmental psychology regarding its relationship to culture. Developmental theories have portrayed child development as a universal experience, unconnected to local cultural influences: such an assumption underpinned the work of developmental psychologists like Piaget (1954), Erikson (1968) and Bowlby (1980). In 1988, Offer and his colleagues (Offer et al 1988) confirmed this view after their administration of Offer's self-image questionnaire for adolescents (OSIQ) to 30,000 teenagers in ten countries, which, they said, showed adolescence to be a universal phenomenon (Gaughan 1998). And indeed, such results suggest that the development of body and mind leads to predictable experiences, irrespective of the culture in which these experiences take place. This claim lies at the heart of the current trend towards globalisation by which Western development experts advise the United Nations and the World Health Organisation on the needs of children worldwide, and textbooks are traded across the world.

Yet as early as 1928, the anthropologist Margaret Mead had met Hall's statements (1905) about adolescence with scepticism. On the strength of her study of Samoan culture she had argued (Mead 1928) that Samoan youths had quite a different experience from that described by Hall as generally typical of adolescence.

Since the late 1980s, sociologists of the interactionist and constructionist schools have also stressed the significant effect of children's social experience on their development, suggesting the primacy of a socially constructed childhood (James and Prout 1990, Chisholm et al 1990). According to this perspective, childhood is different from biological immaturity and it is not a standard feature of human life. It is a social variable with specific cultural components and it interacts with other variables like history, class, gender and

ethnicity. There are 'childhoods' rather than a universal phenomenon called 'childhood', to be described once and for all (James and Prout 1990).

Children themselves are active agents in the construction of their lives and they contribute to the construction of the lives of others (James and Prout 1990). They are the best informants regarding their world and no social study is complete without a description of children and young people's perspective in their own voices (Borland et al 2001). The sociology of childhood reproaches traditional developmental psychology for making young people invisible: by stressing their incompleteness and making adulthood the goal of their existence, it has devalued children's social status. Until they are grown up, adults protect children, speak for them and treasure them but they also diminish them (Hockey and James 1993).

In the preface to the second edition of their book, James and Prout (1997) expressed pleasure that the paradigm of a socially constructed childhood was gaining ground, that the challenge to developmental psychology had been taken up and a cultural psychology was emerging (Woodhead in James and Prout 1997). But they and their contributors also pointed to the danger of cultural relativism. Unless some universally valid standards of child welfare were stressed across the world, based on a knowledge of "*what a child cannot do without*" (Boyden in James and Prout 1997), culture would be at risk of being used as an excuse for the neglect, abuse and exploitation of children. An example of this came at the time of writing: on 30th September 2004, the British media reported the arrest of seven Pitcairn men (50% of the colony's adult male population) on charges of rape and indecent assaults of local girls as young as twelve. In the defence of these men, local women claimed that underage sex was part of the culture and consensual. That these men were arrested is a victory for universal standards of child welfare.

Seeing children as social beings in their own right, then, means keeping a critical eye for cultural assumptions in developmental psychology whilst also questioning cultural statements about children's needs. Above all, it means listening to children and young people, and assuming that they have something to say about the world in which they live. That children have specific rights is the focus of the next section.

2.3 Children and Young People's Rights

The last decade of the twentieth century saw a national and international emphasis on children's rights. Apart from the main human rights, children have entitlements to support and protection due to their biological immaturity and lack of life experience. In the wake of the 1948 Declaration of Human Rights (United Nations (UN) 1948) and in order to spell out children's specific rights, the UN drew up the final draft of its Convention on the Rights of the Child in 1989 (UN 1989).

This Convention highlights three main areas of rights for children: firstly, rights to protection from exploitation, abuse and neglect; secondly, rights to the provision of services that facilitate growth and development; and thirdly, rights to participation in decisions that affect them (Children's Rights Development Unit 1992). These three areas are linked: in order to protect children and to provide services for them, it is important to find out what their views are (Marshall and Parvis 2004).

Every country in the world has ratified the Convention except two (the United States and Somalia). These states have committed themselves to meeting, as soon as possible, the Convention's provisions and obligations. However, the implementation of children's rights has encountered a variety of obstacles. The Convention speaks in general terms and each country tends to interpret it according to its own cultural interests (Boyden 1997). In developing countries, the protection of children and the provision of services depend on a nation's income. In Britain, reforms in child care law and public policy (for instance the Children Acts of England and Wales, and Scotland, 1989 and 1995 respectively) have taken place but progress has been inconsistent (Marshall et al 2002, Hill et al 2004). In particular, children's right to participation, although largely accepted in government and increasingly enshrined in law, has caused anxiety to many adults in charge of children (Sutherland and Cleland 2001).

2.4 Young People and Participation

Participation has been described as the process of taking part in decisions which affect one's life and community (Hart 1997) – (See 'participation' section p. 1). As members of

society, children and young people are entitled to taking part in decisions, even though adults tend to underestimate their potential for responsible decision-making (Marshall and Parvis 2004). Children and young people themselves say that they want to participate, particularly in decisions of current relevance to their lives like their education, leisure and health care; but if their views are ignored, they become disillusioned (Borland et al 2001).

‘Involvement in decision-making’ is the index of the ‘partnership’ level on Arnstein’s ladder of participation (Arnstein 1969) – not the top rung of the ladder but that looked for by users and carers in health and social care services. Hart (1997) adapted Arnstein’s ladder to young people and offered a three-stage continuum, based on the young people’s level of control in the initiative, process and outcome of participation: control can remain with adults, be shared with young people or delegated to them. Less control spells lower levels of participation, which feel more tokenistic and unsatisfactory to the young people. As users of health and social care services, young people might look for the equivalent of partnership, that is, sharing power and making decisions together with the staff.

Sinclair (2004) however, states that other important dimensions come into participation activities with children and young people and modify their impact, apart from sharing power. Ruth Sinclair is the Research Director of the National Children’s Bureau in England and an expert in the field of child participation. According to her (Sinclair 2004), the focus of the decision to be made (whether it is an individual or a policy-making decision), its scope and consequences, for one child or for a group of children, and the particular characteristics of the young people involved (such as their age, mental capacity, gender, disability and culture), all affect participation. She stresses that adults who intend to facilitate children and young people’s participation need to be aware of all these dimensions of participation, match the young people’s involvement to the decision-making context and choose the appropriate level of power-sharing. Only then, when participation activities have been carefully thought through, can children and young people be engaged with honesty (Sinclair 2004). This contrasts with making blanket promises of participation that, because of circumstances, cannot be kept and lead young people to be disillusioned. Such considerations are helpful for the participation of young people in decisions regarding mental health care because these decisions vary in focus and in scope. Decisions about the

young people's own treatment must take into account the life-threatening character of some of these decisions and their short and long-term consequences, as well as the age, level of disability and mental capacity of each particular young person. Examples of views from young people regarding mental health care are given in Chapter 4, p. 109.

The rhetoric about children and young people's participation has made much progress during the time of this study. Nevertheless, the sociological literature evokes repeated concerns that national policies aimed at improving children's lives in fact apply more and more control over them, particularly in their schools and communities (Prout 2000, James and James 2001, Hill et al 2004). It seems that the State, while fully supportive of the involvement of children and young people, increasingly interferes in their lives in a bid to improve education, control crime and supervise parenting. Participation is then relegated to individual children in specific circumstances. These contradictions will indirectly affect services providing health and social care to children, young people and families.

Involving children and young people in decisions seems to trigger adult anxieties. One focus of anxiety is that children's rights undermine adults' authority and adults' own rights (Hill et al 2004). In response to this, Marshall and Parvis (2004) stress the mutual respect and collaboration that works best between parents and children. Hill et al (2004) also suggest that power and rights are best understood as personal assets that are enhanced by constructive partnerships, not as finite goods that one party acquires at the expense of the other.

Another focus of anxiety is that children will not have the capacity to make good decisions.

2.5 Mental Capacity and Decision-Making

Young people have a right that decisions made about them are in their best interests (UN Convention on the Rights of the Child, 1989, Article 3). To make these decisions themselves, they need to be able to assess what their best interests are, that is, they need to have the mental capacity to understand the decision, its context and its consequences. Since they are growing beings, their mental (neurological, emotional, cognitive and social)

capacity is not fully developed. Therefore a balance must be struck between their right to protection and their right to participation. The key to this is an assessment of their psychological maturity. Fundudis (2003) proposed ways in which children and young people's capacity could be assessed. Age and cognitive functioning are often used as sufficient indicators of mental competence but Fundudis (2003) argued that emotional maturity (mental state, mood stability, attachment relationships, educational progress) and socio-cultural factors (family values, religious and cultural beliefs) were also necessary to determine a young person's psychological maturity. Such an assessment can guide adults to reckon how much help a young person might need in understanding a decision and taking it. Younger children might express wishes that can be taken into account while older ones might make their own decisions, perhaps with some support from their parents and expert advice from professionals. To be able to assess young people's competence however, adults must have a thorough knowledge of them, their world and the way they develop (Greig and Taylor 1999).

Medical decisions, particularly consent to treatment, are a group of decisions for which there is legislation. In Scotland, young people over 16 are legally adults, while the Age of Legal Capacity (Scotland) Act, 1991, Art. 2(4), considers children and young people under 16 to be capable of giving consent to medical treatment as long as they understand what is involved (Norrie 1991). A similar provision was made in England by the Gillick case (Gillick vs Wisbech and W Norfolk AHA 1985). Orr (1999) however, highlighted a degree of confusion amongst professionals regarding the right and competence of children to give their own consent and Coyne (1998) recommended that professionals share their competence with each other and debate their difficulties so that they can benefit from each others' experience.

In the case of young people with mental health difficulties, mental state is an important component of overall mental capacity. Young people who are acutely psychotic are temporarily impaired mentally but this should not be ground to exclude them from contributing to decisions regarding their care if they are able to express wishes which can be taken into account. Once their mental state is more stable, their ability to take decisions improves, therefore an ongoing assessment of their mental capacity by someone used to

adolescents with mental health problems is best (Claveirole 2004). Even young people compulsorily detained should be fully involved, so far as they are able to be, in all aspects of their care (Scottish Executive 2004).

2.6 Young People's Mental Health

The mental health of children and young people has been defined as: the ability to develop psychologically, emotionally, intellectually and spiritually; the ability to enter into and sustain mutually satisfying personal relationships, and the ability to become aware of others and to empathise with them. It includes a developing sense of moral right and wrong. Mentally healthy children's playing and learning lead to attainments appropriate for age and intellectual level; their psychological distress is absorbed into the developmental process and it does not hinder or impair further development; distress and maladaptive behaviour are within normal limits for the child's age and context (Health Advisory Service (HAS) 1995). This definition makes it clear that good mental health is of overriding importance in children and young people's quality of life. Mental health problems are difficulties and disabilities experienced in the areas outlined in the definition. They may arise from congenital, constitutional, environmental, family or illness factors (HAS 1995). In studies of children and young people's mental health, a distinction is often drawn between mental health problems and mental disorders. This distinction is not adopted in this study because of the stigmatising effect of the word 'disorder', a term disliked by young people (NHS Education for Scotland (NES) 2004). The distinction is nevertheless useful to make sense of statistical data. The term 'mental disorder' is used in the tenth revision of the International Classification of Diseases - ICD-10 (World Health Organisation (WHO) 1992). It implies a "*clinically recognisable set of symptoms or behaviours associated in most cases with considerable distress and substantial interference with personal function*" (Melzer and Gatward 2000 p. 1). The term 'mental health problem' is wider and includes "*a very broad range of emotional or behavioural difficulties, which may cause concern or distress*" (HAS 1995, p 15).

It has been estimated that around 20 to 25% of children and young people have mental health problems at some time during their childhood (Mental Health Foundation 1999). Statistics based on mental disorders are more conservative. In a study of children aged five to fifteen in Britain, Meltzer and Gatward (2000) reported a prevalence of mental disorders of 10 to 11%. In the sample group, five to ten year old boys had more mental disorders than girls, while the opposite was true in the eleven to fifteen age group. A strong association was found between mental disorder, family income and social class (Meltzer and Gatward 2000).

Fonagy et al (2002) highlight a convergence of research results that indicate higher rates of mental disorders in adolescents. This is partly due to the increase in frequency of psychotic disorders like schizophrenia and bipolar affective disorder, which are very rare before adolescence. However, there is increasing evidence that psychosocial disorders in young people in Western countries are rising (Rutter and Smith 1995, Collishaw et al 2004). The problems targeted by Rutter and Smith (1995) were conduct and eating disorders, substance abuse, depression, suicide and self-harm. It is difficult to come to reliable conclusions about time trends because diagnostic criteria, assessment methods and official reporting practices change over time, making comparisons difficult (Collishaw et al 2004). Nevertheless, a recent study sponsored by the Nuffield Foundation has managed to compare data collected in Britain by similar methods in 1974, 1986 and 1999. This study reports a substantial increase in conduct and emotional disorders, although not in hyperactivity disorders (Collishaw et al 2004). The authors stress that the causes of this increase are not clear but they point to social changes in family structure, economic conditions and youth culture as potentially fruitful directions for further research.

From a large scale longitudinal study of eleven to sixteen year old adolescents in the West of Scotland, Sweeting and West (2000) also draw worrying conclusions regarding the deteriorating mental health of these young people, psychological distress being notably worse at age fifteen than at age eleven, particularly among girls.

“It is clear from our finding that all is not well with young people today”...[and] “that we have a mental health problem of considerable magnitude among young people” (Sweeting and West 2000, p. 40).

It appears that young people are responding to the pressures in their lives with psychological distress, low self-esteem, anxiety and depression. These pressures are judged to come from the need to succeed in extrinsically defined ways by the family, the media and particularly the peer group, rejection by whom can have '*potentially devastating consequences*' (Sweeting and West 2000, p. 40).

Conclusion

Adolescence is the developmental stage between puberty and adulthood. The biological and psychological changes it covers have both universal and cultural characteristics. In spite of their temporary status however, children and young people are full members of society and their social contribution deserves to be noticed and studied in its own right. At whatever age, children and young people have a right to participate in matters that concern their lives, which should not be decided without their involvement, even when their mental capacity is affected by age or mental health. Sadly, there is evidence that children and young people experience increasing levels of mental health problems, particularly adolescents.

The present level of mental health needs of young people and their families greatly exceeds the resources available to help them (Davis et al. 2000, Public Health Institute of Scotland (PHIS) 2003). The provision made by the National Health Service to deal with young people's mental health problems is the object of the next section.

3. ADOLESCENT MENTAL HEALTH SERVICES

Introduction

In Britain, paediatric and psychiatric hospitals started to include outpatient services for children and adolescents with mental health problems and to use the term 'child psychiatry' in the 1930s (Parry Jones 1994). At that point, the term 'child' was meant to include adolescents. The 1940s saw the opening of the first psychiatric inpatient units for children

and young people (HAS 1986). The expansion was slow until the 1960s, followed by rapid growth in most parts of the country in the 1970s and 1980s (Parry Jones 1994). The first adolescent inpatient unit in Scotland opened in 1958.

This study comprised four units, two inpatient and two day-care settings. Inpatient care is reviewed first because it includes many aspects of treatment also applicable to day care. Day-units were diverse and relatively few in 1998 (Goldberg and Collier 1999). They are reviewed at the end of the section.

3.1 Intensive Treatment Settings

Services for young people who have mental health problems have greatly developed and diversified since their early days. The development of inpatient services however, did not progress logically or systematically, and it is best understood historically (HAS 1986 and 1995). Therefore a historical context is necessary to make sense of the culture and functioning of the units involved in this study. It will be presented in two phases: the first up until 1998 when the study started, the second during and since the data collection.

3.1.1 Historical Development Prior to the Start of this Study (pre-1998)

In Britain, the first efforts to attend to children and young people's emotional and behavioural problems took place in the mid-nineteenth century in the context of schools or homes for deprived and disturbed children. No distinction was made between social deprivation, bad behaviour, mental health problems or learning disability and the emphasis was more likely to be punitive than supportive. Concurrently, the admission of some children and young people to adult asylums was recorded throughout the nineteenth century (Chisholm 1996).

In the early part of the twentieth century however, some educational institutions adopted organisational principles developed in the USA. Support and understanding of the child were replacing previously punitive regimes, and an emphasis was placed on self-management and shared responsibility between the young people and the staff, with the aim

of creating an environment, the healing and recuperative qualities of which would facilitate emotionally wounded children's growth. The best known of these progressive institutions were Homer Lane's Little Commonwealth community set up in Dorset in 1913 and A. S. Neill's famous and ongoing Summerhill School, founded in 1921 (Hoeben 2004). Both Lane and Neill were influenced by Freud's ideas, and by Aichorn's adaptation of them to the care of '*Wayward Youths*' (Aichorn 1935).

After the Second World War, psychoanalytic principles were further adapted to the residential treatment of severe mental health problems, in children by Bettelheim (1950), in adults by Main (1946) and Jones (1952), resulting in the development of therapeutic communities and the movement known as social psychiatry. Bion (1962) also used psychoanalytic principles to turn small groups of people with mental health problems into therapeutic opportunities, initially with soldiers destabilised by their war experience.

It is in this context that the adoption of milieu or community therapy by the new child and adolescent psychiatry inpatient units of the 1950s must be understood. Such a philosophy of care was still going in many units in 1998, although by then it was increasingly under threat (Chesson and Chisholm 1996, Green and Jacobs 1998).

3.1.1.1 Milieu Therapy

The importance of using the whole unit as a form of therapy was highlighted throughout that period (Barker 1974, Pfeiffer and Strzelecki 1990, Chisholm 1996, Green and Burke 1998). To be therapeutic, a milieu must resist the onslaught of life in residential treatment settings, such as staff and patient turnover, inevitable disruptions and conflicts as well as the residents' distress, despair and occasional destructiveness. It must remain stable, confident and hopeful. Green and Burke (1998) describe it as "*a coherent culture*" (p. 102). Relationships with the world outside the unit also need to be managed to protect the milieu from intrusion and over-damaging influences (Green and Burke 1998). For this reason, many units have tried to control young people's admissions, time them and space them out to protect the existing patient group from unmanageable disruptions. In the case of acute emergency referrals however, this can be difficult to achieve and unpopular with the

wider system of care to which the referrer belongs (YoungMinds 1997, Green and Jacobs 1998).

Cultural and moral as well as professional values are an integral part of milieu therapy. Some of these values come from the therapeutic community movement on which the first units' philosophy of care was modelled. Therapeutic communities are institutions which capitalise on the potential for *'living-learning'* processes (Jones 1968) – social learning through experience – provided by settings where people spend a lot of time together. Therapeutic communities still exist, although they and their ethos have been unfashionable since the 1980s and many have closed. The movement still makes a convincing case for the organisation of health and social care settings to be based uncompromisingly on humanistic values (Campling and Haigh 1999). Rex Haigh, psychiatrist and member of the Association of Therapeutic Communities, describes the main characteristics of a therapeutic environment as one where people, whatever their status, have a strong sense of belonging, feel safe, experience openness and good communication, participate as equals in the life of the community and feel empowered to take responsibility (Haigh 1999). In the case of child and adolescent mental health services, these principles must be adapted to the age and mental health of the residents. The therapeutic community ethos of most adolescent units has been diluted over the years to adapt to modern health care, and in particular to make space for other forms of therapy and a more eclectic approach to treatment. As a result, units talk of a therapeutic milieu rather than a therapeutic community as being their goal.

The importance of offering young people a responsive and empathic environment where genuine relationships of trust with special individuals are possible has been emphasised (Green and Burke 1998, Rose 1999). The milieu's capacity for good interpersonal relating depends on a variety of factors that need to be constantly monitored. The key-worker system operated by nurses can allow each young person to establish a special relationship with a member of staff and seems to be a significant factor (Paice 1996). This type of relationship must include a strong emotional commitment from the nurse and a clear message about the limits of acceptable behaviour. Although this is a demanding task, it is also a rewarding one (McLeod 1996). However, anything that interferes with the nurses'

capacity to get involved in this way also interferes with the therapeutic milieu. When staff members have too much to do and too many young people to respond to, their ability to relate diminishes. Therefore another significant factor is a good nurse/young people ratio. On the basis of their review of current literature, Green and Burke (1998) suggested 1:2 to 1:3 during the day, depending on the level of therapeutic activity, and 1:6 during the night. This ratio only applies to shift staff; practitioners from other disciplines who work regular hours must be counted over and above that.

Apart from individual relationships between young people and their key-workers, good standards of mutual respect and care must be fostered all round. Small therapeutic groups during which young people learn to co-operate, trust and support each other are a suitable context for this kind of learning. The peer group is important in adolescence: it provides a stepping stone between the family and a more autonomous life style. Group activities capitalise on this and on the fact that feedback from peers can be more effective than feedback from adults to promote self-awareness (Bateman et al. 2002). Therapy groups can be dedicated to many different forms of therapeutic activities. Therapeutic communities have traditionally held community meetings and some adolescent units still do. Community meetings nurture collective responsibility. They take place daily to discuss day-to-day living, particularly its problematic aspects, from individual relationships to standards of behaviour and practical issues. All groups need ground rules and guidelines to relieve the natural anxiety people feel in them (Campling and Haigh 1999).

In units run along therapeutic community lines, however adapted, young people have been expected to share responsibility for their treatment with the staff and to learn something about themselves, their feelings and their needs (Singh 1987). Self-awareness and the ability to understand interpersonal and institutional processes can be very useful for the staff and have been promoted in some units. Insights into one's own and others' inner world is typical of a psychodynamic philosophy, the use of which had decreased by 1998. It now tends to be limited to a few staff teams, mainly for the purpose of understanding themselves and the settings in which they work (Bateman et al 2002).

3.1.1.2 Young People Participation

Equal participation of all members in the life of the community is one of the principles of the therapeutic community movement for a truly therapeutic environment (Haig 1999). In therapeutic communities for adults, control and organisation is delegated in large part to the residents. While this type of participation is inappropriate with young children, it can be adapted to teenage use so that control and organisation is shared between young people and the staff. In health care settings that have been modified to become deliverers of eclectic treatment regimes however, participation has had to compromise with the medical model (Tennant 1997b).

In 1998, the influence of the UN Convention on the Rights of the Child (1989) and of the Children (Scotland) Act 1995 on child and adolescent mental health services was still at an early stage. The exercise of involving children and young people in decisions regarding health care, particularly inpatient mental health care, was in its infancy and few investigations of the topic had been completed. Some efforts to consult young people about health services had been reported (Goodie and Redman 1996, Oppong-Odiseng and Heycock 1997, Holyoak 1997), although most of them concerned physical rather than mental health. Ways of consulting young people about health care were being investigated (McCormack 1997). On the whole there was a tendency to consult them by quantitative rather than qualitative means, thereby imposing the consulting institutions' agenda on them (France et al 2000). The quality of participation has improved since then. Reports on young people and their carers' views regarding specialist mental health services designed for them are reviewed in a later section (see page 54 and 56).

3.1.1.3 Involvement of Carers and Families

Narrow definitions of the family and its key attributes, which would not encompass the current spectrum of family diversity, risk being damaging because they might lead to oppressive expectations of client families who do not conform. Therefore definitions need to be broad (Walsh 2003). Government documents on family policy have been criticised for their implicit acceptance of a traditional definition of the family (Baggeley and Kean 1999) or for definitions that include competing elements (Wasoff and Hill 2002). Wright and

Leahey (1994) pragmatically state that the family is who they say they are. In this study, where the views of the young people's parents or main carers were sought regarding their experience of having a child in treatment, parents were defined as the adults who assumed the responsibility of caring for a young person at home on a daily basis. The family was defined as these adult carers plus any sibling living under the same roof and related by bonds of mutual care. A recent study of inpatient units in England and Wales reported that both parents were the main carers for 51% of young people, one parent for 37% and the local authority for 12% (O'Herlihy et al. 2001).

In 1974, Barker recommended engaging with parents or carers while working with children and young people who have mental health problems residentially, unless this proved to be contrary to the young person's best interests. A crucial reason for this is to minimise both the disruption to family relationships caused by separation and the potential for competition between parents and professional carers (McLeod 1996). All the units for children and younger adolescents (twenty-nine) consulted by Green and Jacobs (1998) reported working with parents.

The best way for the staff to relate to parents is to collaborate with them as equals and to have the same treatment aims (Lask and Maynerd 1998). There is evidence that successful family involvement is linked to parent satisfaction and may contribute to successful treatment outcomes (Resendez et al 2000). But in inpatient services where therapy focuses on the young person, making time for the family is a challenge to the staff (Lask and Maynerd 1998). It requires that some staff members take time to learn about the family, their culture, their perception of the problems and the admission itself. Ensuring the growth of a positive relationship between the staff and the young people's carers is a task which requires time and complex skills that can be underestimated. Friedemann (1989) suggested these skills belonged to what Benner (1984) called the 'expert' level of practice. While not all nurses or health care workers need to function at this advanced level to support carers, many family experts agree that specialist skills are required (Tennant 1997a).

Nolan et al. (1996), reporting on several years of research into family care, highlighted a lack of professional experience and expertise in working with family carers. Only a

“*paradigmatic leap*’ in the professional psyche” (p. 157), would change this but it could not happen without a great deal of education and support. Six years later, Fonagy et al (2002) claimed to detect an implicit but developing trend in therapeutic work with children and young people: that of intervening at several levels, individual, family and wider network. They welcomed this but called attention to health care workers’ need to acquire the necessary skills to do it effectively.

3.1.1.4 The Staff

In 1998, the largest group of staff in both day and inpatient units for young people with mental health problems were nurses. Other disciplines, like psychiatrists, psychologists, occupational therapists and social workers, were represented by one or two people each who often also saw outpatients (Green and Burke 1998). There were no national guidelines and within this general description, the variations were wide (HAS 1995). Nursing teams, for instance, varied considerably in their skills mix, from large numbers of untrained nursing assistants to none, and greater or lesser numbers of higher grades (Townley 1998).

The role of the nurses is primarily to maintain the therapeutic nature of the unit milieu (Paice 1996, Green and Burke 1998). For this they need a sophisticated understanding of emotional growth (Rose 1999). The qualities required of them have been variously described as human ordinariness, emotional openness and intellectual curiosity (Singh 1987), warm heartedness, personal stability, tolerance of anxiety and a sense of humour (Barker 1974), empathy, self-awareness, energy, co-operation and playfulness (Cotton 1993 in Green and Burke 1998). Children and young people themselves have described a helpful grown up as someone who is empathetic, available, confident, understanding, who knows how to listen, is trustworthy, and powerful enough to make things happen (Farnfield and Kaszap 1998).

In a therapeutic milieu, nurses use themselves as therapeutic tools and Green (1998) stresses the importance of supervising and supporting them if the therapeutic nature of the milieu is to be maintained. Milieu staff need to feel safe and contained themselves in order to offer safety and containment to their charges (Green 1998).

Apart from the nurses, another key member of staff is the psychiatrist who, in the most senior position, directs the service and takes responsibility for the young people's overall treatment. Other disciplines' involvement in inpatient and day-care settings varies from unit to unit (Joughin et al. 1999).

3.1.1.5 The Role of the Unit

Following the recommendations of the Health Advisory Service in 1995, a wider range of services for the treatment of children and young people with mental health problems was beginning to be established in each region. Social services, schools, the NHS and voluntary organisations were expected to provide a first level of primary care support. Young people with diagnosable mental health problems were to be referred to specialist professionals working in the community or in the outpatient departments of specialist services, while day and inpatient units would only see the most distressed, ill or at risk young people (HAS 1995). Although this service structure was far from being fully established, in 1998 the role of inpatient units was acknowledged to be the assessment and treatment of the most serious and complex combinations of mental health problems in a few children and young people. The typical length of admission in Britain was from three to nine months (Green and Jacobs 1998).

In the 1990s, however, the rising appeal of community care had caused many units to close following a belief that new forms of therapy like Family Therapy and Cognitive Behaviour Therapy would allow even serious problems to be dealt with on an out-patient, or at the most a day-patient, basis. In 1997, at the time when Green and Jacobs collected their evidence, five children's units were under threat in England and Wales (Green and Jacobs 1998, YoungMinds 1997). In Scotland, there were four inpatient adolescent units, one of which was about to close (Bryce 1996, YoungMinds 1997). The growing shortage of beds was compensated by a substantial number of admissions to adult psychiatric wards, settings unsuited to the task of assessing and treating adolescents. Concern was expressed that serious mental health problems might go under-recognised and under-treated if specialised residential settings ceased to be available (Green and Jacobs 1998). This was the state of affairs when the study started.

3.1.1.6 Outcomes

Inpatient units are expensive and they cause maximum disruption in young people's lives by separating them from their main carers, schools, friends and environment. It is therefore important to know how effective they are, particularly by comparison with cheaper and less disruptive alternatives. Research into the efficacy of residential treatment, however, brings with it many methodological challenges because of the number of variables involved. Pfeiffer and Strzelecki (1990) highlighted ten variables. One of their findings was that the availability of specialist inpatient treatment was strongly predictive of a positive outcome, although they stressed that much more research was necessary (Pfeiffer and Strzelecki 1990).

In a four-centre prospective study of adolescent psychiatric inpatient admissions, Rothery et al (1995) provided an account of sixteen treatment goals and their outcomes for a cohort of 276 young people. Of the four groups of goals (remission of symptoms, improvement in significant relationships, facilitation of specific maturational tasks and improvement of psychodynamically understood intra-psychic functioning), they found that the first group (remission of symptoms) had the most positive outcome while improvement in the three other groups was less clear. The authors concluded that improvement in these areas were more difficult to achieve with relatively short admissions (Rothery et al. 1995).

Another study investigating the progress made by inpatient adolescents in one unit by its own staff found that improvements, once noted on discharge, were maintained for the follow-up period of six to eighteen months (Jaffa and Stott 1999). The sample was small however, and not randomly selected, and the young people were the researchers' own patients. The authors concluded that the results were promising but that further research was necessary.

3.1.1.7 Day-care

Day-units present a number of advantages: they keep the separation between young people and their environment to a minimum, their client group overlaps with that of inpatient units and they are cheaper (Brown 1996). Yet there were few of them in 1998 (Goldberg and Collier 1999). In spite of the arguments in favour of day-units, it is difficult to make a case for replacing inpatient units with day-units because day-care has limitations that must be attended to. Families, who shoulder a greater part of the burden of looking after the young people at home, need extra support (Brown 1996). Acutely psychotic, suicidal or severely under-weight anorexic young people need a residential setting to ensure their safety (Goldberg and Collier 1999). And the intensive, direct interpersonal work with young people that day-units have to do in order to be effective makes them costly in their own right (Jacob and Green 1998). Brown (1996) and Jacobs and Green (1998) argued that day-units were a valuable facility that could relieve some of the pressure on inpatient units but not replace them altogether.

Regarding a philosophy of care, Brown (1996) stated that it should above all be coherent, a similar view to that of Green and Burke (1998) about inpatient units. Brown recommended the use of a therapeutic milieu, with the opportunities for qualitative relationships it entails, but drew attention to the fact that therapeutic relationships take longer to establish due to the shorter time spent by young people in a day-unit by comparison with an inpatient one.

Martin Gaughan, who evaluated the work of one of the units involved in this study in 1997, showed in his own literature review that research into day services for young people with mental health problems was scarce and our understanding of the variables involved in their functioning limited (Gaughan 1998). The conclusion of his evaluation, which used a complex mix of quantitative and qualitative instruments, was that most young people referred to the unit went on to be assessed and treated – a success in itself – and that the treatment programme satisfied the young people more than their parents. The results yielded by objective measures were ambiguous, in part because the sample was small for this kind of instruments. Overall, the study's findings suggest that day-units for the treatment of young people with mental health problems make a positive contribution.

3.1.2 Developments 1999-2004

During and since the data collection, the speed at which changes have taken place has increased. Consultant psychiatrists and other health care staff have grown increasingly concerned at the inadequacy of existing services (Griffiths 2001). Amongst them, Drs Jonathan Green and Brian Jacobs, who wrote and edited much of the material which has informed this review, remain at the forefront of research and development. In 1999, the Royal College of Psychiatrists issued a report regarding guidance on staff ratios for inpatient units. In it, Green and his colleagues take up the staff/patient ratio recommendation for shift staff quoted earlier (p. 42), and add further recommendations for other disciplines (Green et al. 1999).

In 2001, an investigation into the characteristics and use of child and adolescent psychiatric inpatient units in England and Wales, commissioned by the Department of Health, was published (O'Herlihy et al. 2001). It highlighted several concerns: wide variations across units in the age group admitted, the staff skills mix and in treatment practices; poorly trained nurses; a significant number of admissions to adult wards; an insufficient number of beds and a lack of emergency beds. The report noted the use of the therapeutic milieu in a number of units, but also a growing emphasis on trends inimical to community and social forms of therapy like individually tailored treatments and a shift to shorter admissions. The problems of the young people admitted were of growing severity and complexity, with the result that inpatient units functioned increasingly like intensive care ones (O'Herlihy et al 2001). Green and Jacobs had stated their concern in 1998 that inpatient units might become '*short-term triage or superficial symptom control*' settings, making nonsense of the important notion of residential psychological treatment (Green and Jacobs 1998, p. 5). The new model of short-stay, high turnover units is also growing in popularity in Australia (Worrall 2002). As has been remarked earlier however, the more intensive end of children and young people's mental health care has been poorly researched and the changes, which entail abandoning the therapeutic milieu, are not made on the basis of robust evidence (O'Herlihy et al. 2001). Staff recruitment for all disciplines but particularly nurses is also a growing problem for many inpatient units, making therapeutic relationships with young

people more difficult to maintain (Street and Svanberg 2003). Street and Svanberg (2003) recommend support and supervision for the staff and better career structures to make this kind of nursing more attractive than it has become of late.

In Scotland, similar difficulties have been highlighted, in particular the decreasing capacity of inpatient units, and the need for research (Public Health Institute for Scotland (PHIS) 2003, Grant 2004).

The most comprehensive study of inpatient services for children and young people to date is now ongoing (Green and Jacobs 2004).

3.2 Treatment Issues

It is not possible to review the literature on the mental health problems of adolescence here: it is extensive and knowledge of the detail of what lies under each diagnostic category is not indispensable to an understanding of this piece of research. Similarly, it is not possible to review the catalogue of treatments available, such as cognitive behaviour therapy, medication or family therapy. A little has been said about key therapies, like the therapeutic milieu and the use of groups, because of their relevance to all the units in the study and to the current discussions regarding inpatient treatment nationally. One other approach to treatment has become central to the management of adolescent mental health services, the treatment of psychosis (Wrate et al. 2003). Therefore this topic will be briefly reviewed.

The use of nursing observation as a way of managing the safety of some young people will also be reviewed in this section, because of its contentious nature and the significant changes that have taken place during and since the study.

3.2.1 Psychosis

For the purpose of this review, the work of Dr Patrick McGorry and his team at the Early Psychosis Prevention and Intervention Centre (EPPIC), in Melbourne, Australia, has been chosen as a primary source of information because of the completion of their manuals close to the start of the study (McGorry and Edwards 1997). The content of the manuals was

relevant to the work of the units in the study and one of the services had drawn its philosophy of care from it. The EPPIC centre had devised a specialised treatment model for young people suffering from a first episode of psychosis on the basis that best practice in early psychosis was different from best practice in the later stages. As a result of this work, they claimed to see a significant reduction in the disability and disruption usually associated with these disorders in young people (McGorry et al, 1996). Early intervention in all cases of psychosis is now strongly recommended (Department of Health 2000, Wrate et al 2002, National Institute for Clinical Excellence (NICE) 2003).

A psychotic episode is characterised by the experience of a cluster of symptoms which make it difficult for a person to relate to reality in the way that most people do. It is a condition which affects the mind and its symptoms are confused thinking, false beliefs or delusions, hallucinations, changes in feelings (like mood swings, depression or excitement), and changes in behaviour, which may become uncharacteristic, irrational and unpredictable (McGorry and Edwards 1997). McGorry and Edwards (1997) suggest a prevalence rate of three per cent in people aged sixteen to thirty. In their Scottish study of adolescent-onset psychosis, Wrate et al (2002) suggest a low prevalence for the younger age-group (five to eighteen) of 6 per 100.000. There are several types of psychoses. Some are well known, like schizophrenia, bipolar affective disorder and psychotic depression. Others are less so, like drug-induced psychosis (which is becoming more common with the use of recreational drugs), organic psychosis (the result of physical damage to the brain) or brief reactive psychosis (a response to major stress followed by complete recovery).

McGorry and Edwards (1997) use the word 'psychosis' and they recommend diagnosing no more than an 'acute psychotic episode' at this early stage in the onset of a possibly long-term psychotic illness like schizophrenia or bipolar affective disorder. This is to avoid misclassification due to the fluidity of symptoms at the beginning of these illnesses.

The causes of psychosis are not fully understood. Much emphasis has been put in recent years on genetics and biochemical changes in the brain, but the influence of environmental stress in triggering the first and subsequent episodes is also recognised and stress-vulnerability models have been elaborated (Zubin and Spring 1977). These models view

biological vulnerability factors (inherited or acquired) and environmental stress as combining to lower the individual's psychosis threshold (Harris et al 2002).

In families, an association has been found between 'expressed emotion' ('EE', defined as critical comments, hostility and over-involvement) and the course of schizophrenia, high EE increasing stress and the risk of relapse (Brown et al 1972, Leff and Vaughn 1985). The findings of several studies have established that high EE is associated with a variety of mental health problems, including relapse from schizophrenia, although there is no hint that this mode of relating causes schizophrenia (Leff 1998).

For a young person, an acute psychotic breakdown is a frightening, distressing and often overwhelming experience. For the family, which is the main provider of care to this age group, it is a personal disaster and it stretches members' coping capacity to the limit (McGorry and Edwards 1997). Secondary prevention is the aim of treatment: it means limiting the worst effects of the first episode and preventing further relapse. Since, according to the stress-vulnerability model of psychosis, biological vulnerability factors and environmental stress combine in lowering the individual's psychosis threshold, treatment consists in raising this threshold and keeping it high. It involves the use of medication as well as psychological and social interventions to address disturbances of development, self-esteem and social relationships (McGorry and Edwards 1997). Psychoeducation is an important component. It consists in explaining to the young people and their families what is known about psychosis and its treatment. Better understanding improves young people's quality of life and enhances their recovery. Psychoeducation, however, needs to be applied sensitively, with due regard to the young person's stage of illness and ability to assimilate new, challenging and potentially distressing information. Psychoeducation is done both individually and in groups, with young people and with families.

The over-sensitivity to high EE of young people who have been psychotic makes the usual therapeutic milieu, with its challenging relationships and groups, over-stimulating and overly stressful (Harris et al 2002). Guidelines on the early detection and treatment of psychosis have recommended specialist services for the purpose of treating these young

people in alternative environments (Department of Health 2000, O’Herlihy et al. 2001), although few existed at the start of the study. In the absence of such services, young people in an acute psychotic state would be nursed in isolation from the main foci of unit life, particular from the groups.

Specialist services for the early treatment of psychosis are becoming increasingly common. The recent evaluation of one of these services through the views of its users has revealed their appreciation of the human approach as a key to recovery. Particularly praised were collaboration over treatment decisions, service flexibility, the staff’s willingness to behave as ‘friends’, as well as symptom control and the provision of a daily structure (O’Toole et al. 2004).

3.2.2 Nursing Observation

One fifth of young inpatients have been reported to be on special observation (O’Herlihy et al. 2001). Nursing observation, also called client/patient observation or mental health observation (NHS Lothian 2004), aims to protect vulnerable individuals, who represent a serious risk to themselves or others due to their mental state, by keeping them under the close observation of a nurse. In Britain this procedure is regulated locally. To implement uniform policies and practices across Scotland, the Clinical Research and Audit Group (CRAG) on mental illness issued national guidelines in 1995, which were revised in 2002. Three levels of observation were adopted: ‘general’, ‘constant’ and ‘special’. General observation refers to the nurses on duty knowing where their patients are, whether in or out of the ward area. Constant observation refers to a designated nurse being aware of the precise whereabouts of a patient through sight and hearing at all times. Special observation requires a nurse to be in sight and within arm’s reach of a patient in all circumstances (CRAG 1995). This treatment measure is frequently experienced as intrusive and adult service users have complained of being watched by unknown nurses or by someone sitting outside their room, of frequent changes of nurses, and of not being informed about the procedure (Bowers et al 2000, Jones et al 2000). Being observed by someone who doesn’t interact makes them feel angry, resentful and alienated (Campbell 2000). The burden can

be alleviated by involving the client in the risk assessment (Barker 2000), explaining clearly what being observed entails (Ashaye et al. 1997) and engaging the person in supportive interactions (Jones et al 2000, Bowles et al 2002). The CRAG 2002 revised guideline focuses on observation as a therapeutic intervention necessitating engagement between the nurse and the patient (CRAG 2002). It acknowledges that higher levels of observation can cause people significant distress and that it is a skilled task for which nurses need preparation.

3.3 Young People's Views on Mental Health Services

Policies regarding the inclusion of children and young people's views in health care decision-making have made some progress since this study began in 1998, both in the UK and in Scotland. The application of young people's right to participation (UN 1989) to children and young people's mental health services was recommended by the Health Advisory Service (HAS) in 1995. In 1999 however, the Audit Commission reported that only 35% of health authorities had consulted children and their parents about their views, and that these views had not always been used to inform service development (Audit Commission 1999). Trusts and health boards appear to have found partnership principles difficult to apply. For example, a strategic document for the development of child and adolescent mental health services in Lothian (Lothian Health 2000) set itself the 'key' task of involving young people and their parents in the implementation and monitoring of the services. However, the planning group did not succeed in recruiting either parents or young people to contribute to the strategy document and its follow-up. It gave no reason for this failure but stated that it would rely on established patient partnership structures set up for adult services in the future (Lothian Health 2000).

The Scottish Executive's policy document outlining its strategy for child health *For Scotland's Children* (Scottish Executive 2002) made participation the corner stone of all work with children. The consultation with children and their parents that preceded the publication of the document highlighted a certain neglect of participation activities on the part of health and social care staff, in spite of good intentions.

Regarding mental health services generally, the Needs Assessment Report on Child and Adolescent Mental Health (Public Health Institute for Scotland 2003) took from its consultation with young people that they wanted to understand mental health better, to access support more quickly, and to be treated as individuals by staff who should be more available.

As mentioned in the section of this review on young people's participation (p. 43), qualitative methods yield richer and more person-centred messages from participants, which is why such methods were chosen for this study. Three qualitative pieces of research into young people's perspectives on their mental health care have been completed in the last two years. One was a YoungMind investigation of inpatient services in England and Wales for which 61 young people were interviewed. The young people reported to be frequently bored due to lack of activities and to want more information, choice and involvement in their treatment. They found their peers helpful, but also frightening at times, because of their difficult behaviour. They valued an attractive looking environment and wanted the unit to be homely. The authors concluded that involving young people in inpatient settings was a challenge which some staff did not know how to meet, although many tried. They recommended the development of philosophies that encouraged open communication and respect, and that promoted staff availability (Street and Svanberg 2003). The conclusion of this study suggests clear parameters for a participative philosophy of care and thereby meets Street and Svanberg's (2003) recommendations.

Two other studies were Scottish. Buston (2002), finding that qualitative research into the experiences of young people with diagnosable mental health problems was particularly lacking, embarked on the investigation of young people's views about the help they had received through 32 interviews with fourteen to twenty year olds in Greater Glasgow, Lanarkshire and Forth Valley. The study's findings included many comments about the young people's views regarding their relationships with professionals. The importance of being listened to came out as paramount but what is most striking and rewarding in this study is the detail of the findings – which makes the importance of such small qualitative studies abundantly clear (Buston 2002).

Last year, psychiatrist Michael van Beinum (2003) interviewed 41 young people between the ages of twelve and nineteen referred to outpatient mental health services in Glasgow. Most had found being referred to a psychiatric service profoundly stigmatising, in spite of feeling in real need of help. This left them with a dilemma that each solved in their own way (for instance by keeping it a secret from their friends). Van Beinum took a constructionist approach to his data analysis and criticised other health care studies for their lack of sophistication in treating respondents' views as simple truths instead of seeking to interpret their positions as social actors. The author found his young respondents subtle, thoughtful and socially aware (van Beinum 2003).

These three recent studies, done in the same spirit as this one and at approximately the same time demonstrate the growing interest in the subject of young people and mental health problems. The dearth of such research using qualitative methods is evident from all the literature reviews and noted by all authors. None of the studies supersedes the current study. Buston (2002) investigated a wider range of services than inpatient units and Svanberg and Street (2003), although centred on young people in inpatient units, dedicated a large part of their study to quantitative measures of inpatient services characteristics. Their interview sample was drawn from adult and paediatric wards as well as inpatient units and the focus of their interest went beyond treatment to deal with access to treatment and post-discharge follow-up. Inevitably, the resulting findings were broader and more superficial. Van Beinum (2003) focused on outpatient services and recommended a similar study with inpatient units' client group, a recommendation which this study fulfils.

3.4 Carers' and Families' Perspective

Parents' views are also important. They play a significant part in referral and young people's successful engagement in treatment depends largely on their parents' attitude to the clinic. Therefore meeting their needs ought to be a service's major goal (Rey et al. 1999). As with the young people's views, the carers' views can be sought by qualitative or quantitative methods, with the usual advantages and disadvantages of each (Stallard 2001). Much of the existing research has been done using quantitative instruments.

In 1997, the Mental Health Foundation started a programme designed to improve services for young people with serious mental health problems. As part of it, 30 parents were interviewed and gave an account of their experience (Mental Health Foundation 1997). They reported that when their adolescent child started showing signs of disturbance, they felt scared and did not know what to do. They initially wondered if it was a normal part of adolescence. Once they became sure something really was wrong, they often found their daughter or son did not share this view and did not want help. Help, once it was accepted however, was slow and difficult to access. Care at home was a 24 hour-a-day, seven day-a-week demand. There was no time for anything else or any other thought. Siblings lost out. Parents' relationships with each other became strained. Social life disappeared. Work was compromised. Most parents blamed themselves and felt in desperate need of support, but looking for it at such difficult and busy times seemed self-indulgent (Mental Health Foundation 1997).

Other studies have also highlighted what parents think they need from specialist services. Parents are more likely to ask for help because they can no longer cope, or because their child's school place has broken down, than because the young person's mental difficulties have got worse (Bailey and Garralda 1989, Bradley and Clark 1993, Rey et al 1999).

Parents interviewed at the time of their child's admission to an inpatient unit and six weeks later did not appear to understand their child's problem, the treatment, or the way the unit worked, better at the second interview than at the first. They found the unit meetings daunting and inhibiting (Chesson et al. 1997). The authors recommended more focus on communication with parents and further research to identify obstacles to understanding and communication. They also suggested specific training for nurses, since they had a key role in imparting communication in inpatient units (Chesson et al. 1997). Parents' wish for more and better information was also mentioned by Gaughan (1998) and in the Bright Futures report (Mental Health Foundation 1999).

Some parents reported being dissatisfied with the outcomes of treatment because the home-based aspects of the problem had not changed (Bradley and Clark 1993, Chesson et al.

1997). Bradley and Clark (1993) attributed this to poor communication between staff and parents and highlighted the need for regular contact between unit and family in order to review progress and voice concern. Chesson et al. (1997) pointed out the importance of client defined outcomes. The need for congruence between the unit, the young person and the family's goals has been repeatedly stressed (Bailey and Garralda 1989, Subotsky 1992, Chesson et al. 1997, Rey et al 1999).

Conclusion

Mental health services for young people have a history that spans approximately forty years, although the units in the study were less than thirty years old. Many inpatient units adopted milieu therapy as a philosophy of care, based on therapeutic community principles adapted to a younger age group and modified to incorporate multiple therapeutic modalities. Core characteristics of milieu therapy included a reliance on strong therapeutic relationships between young people and staff, a structure of peer relations based on therapeutic group activities and a commitment to the involvement of young people in the life of the unit. Such a philosophy of care made these units participation-friendly, even if participation was not an explicit commitment on their part. In 1998, the adoption of the user and carer approach was at an early stage. Day services were few and their philosophy of care varied.

Since 1998, residential services for young people have experienced difficulties because of an increase in the seriousness of the problems of the young people being referred, a national capacity diminished by bed closures and shortages of staff. The therapeutic milieu has been challenged by a short-term, symptom-control approach to treatment, although it remains advocated by specialists like Green and Jacobs (2004). Throughout the literature, there is a strong message that more research is needed. With regard to the views of young people, there have been a few recent qualitative studies focused on young people with mental health problems, although none has looked in detail at the inpatient/day-care patient group across multiple sites. This study aims to fill the gap.

CONCLUSION

People's participation in public services that concern their lives has become an important priority in our society, not only for adults but also for children and young people. It is particularly relevant to health care services, although in adult mental health care, it has only been partially successful. The literature on inpatient and day-care settings for young people prior to 1998 when the study started did not demonstrate a strong sense of commitment to participation, or much research on its development. Nevertheless, good patient-staff and peer relations and the involvement of young people in the life of the unit were priorities of the services committed to milieu therapy, which may have facilitated the growth of participation. This study was timed to investigate how aware adolescent mental health units were of the young people's right to participation, and structured in such a way as to see the young people's own perspective in the context of the unit culture and of other stakeholders' views. Findings from the study should lead to recommendations regarding the most pressing requirements of participation in these complex and vulnerable settings.

The aim of the study was formulated as follows:

'To explore young people and their carers' experience regarding treatment and participation in decision-making in four Scottish adolescent inpatient or day-care mental health units.'

The epistemology, design and methods of the study are developed in the next chapter.

CHAPTER 3: RESEARCH DESIGN AND METHODS

INTRODUCTION

In this chapter, the scientific context of the study and its methods are addressed. In the first section, broad historic and current epistemological concerns are discussed in order to situate the study with regard to scientific knowledge. The second section deals with research methods and the approach chosen to collect, record and analyse the data. In the third section, each step of the research process followed in the study is examined in turn.

1. EPISTEMOLOGY: THE NATURE OF SCIENTIFIC KNOWLEDGE

1.1 The Object of Knowledge

The goal of science is to generate knowledge about the world through a systematic process of exploration, analysis and reporting. Early in human history, human beings discarded mythology as a suitable way of explaining external phenomena and turned to observation, measurements and reasoning to advance their understanding of the world around them. In the last 200 years, improved methods of enquiry have brought the scientific approach to knowledge generation to a powerful position. Scientific disciplines, each with methods of enquiry suited to the investigation of their particular field, have grown and specialised.

The way in which knowledge is generated depends on the nature of the object being investigated and the type of relationship the researcher establishes with it. The dominant scientific paradigm however, particularly in the area of health care, is that of the natural sciences. It demands that phenomena be accurately observed to provide objective evidence, experiments devised to verify observations, variables tested and causal relationships identified and reported. The goal is the discovery of generalisable and predictable natural laws (Bolton 2002). Distance between the object under investigation and the researcher,

and control of the relationship between them, is considered to be crucial to ensure objectivity throughout the research process, the results of which must be both valid and reliable.

At the end of the nineteenth century, human beings and their social world became the focus of the human quest for knowledge. Several disciplines such as sociology, anthropology and psychology developed, broadly known as social sciences (Grawitz 2001). In Britain however, where positivism dominated the philosophy of science in 1930s and 1940s, the scientific paradigm of the natural sciences was promoted as the scientific canon, which led social sciences like sociology to adopt it (Hammersley 1992). As a result, methodologies such as those of anthropology, based on close relationships between researchers and their informants, were criticised as being subjective and unscientific (Lofland and Lofland 1995).

This climate has changed and a radical shift has taken place away from narrow positivist definitions. The social sciences have moved from positivism to post-positivism and positivism has almost become a term of abuse between social scientists (Hammersley 1992). Post-positivism does not in itself imply a clear epistemological position however, other than a distancing and abandoning of the positivist one. It accommodates several ways of thinking about the scientific endeavour. It tends to adopt a broader understanding of the claims of science, and is more tolerant of other disciplines' quest for knowledge than positivism used to be (Trochim 2000). But the shift from positivism to post-positivism has been slower in health care research where knowledge draws on both the natural and the social sciences, particularly in mental health (Bolton 2002). This study comes under the umbrella of social science research. The object of its investigation is human experience in the context of adolescent mental health care and qualitative methods of the kind criticised by the positivists have been used. Many believe however, that there are alternative criteria to those used by researchers from the positivist tradition against which such studies can be judged (Bartlett 2002).

1.2 The Status of the Object of Knowledge

An important epistemological challenge for any researcher is to position themselves regarding the reality or fictitiousness of the social world under investigation. For the purpose of this thesis, the advice of seasoned ethnographers like John and Lyn Lofland (1995), Martyn Hammersley (1992, 1995) and Paul Atkinson (1992) has been followed and a certain social realism, which asserts that some form of reality exists independent of human thinking, has been assumed. This is a position which has been criticised as epistemologically naïve. It has been accused of treating records of the utterances of research subjects as accurate and realistic renderings of their experiences, whereas Denzin (1992, p. 125) states that *“subjects may not know what they think, change their minds, or deliberately mislead an investigator”* and that *“language only distorts what it represents”*. The realism assumed here, however, is a critical realism (Trochim 2000); it does not deny that the researcher’s perception, culture and use of language filter the communication of the research subjects, or that research participants construct their messages to researchers making use of their culture, feelings and social positions. Both the researcher and the researched share a languaged community, with a network of common practices and interpretations, which make shared meanings likely (Kerr 1986). While scientific findings may not be the objective rendering of an illusive reality, they remain *“larger than and different from human consciousness”* (Polifroni 1999, p. 57). Critical realism substantially qualifies realism by affirming the fallibility of all scientific endeavours. The goal of science is a communal enterprise. Its discoveries do not belong to individual scientists but to the community of scientists who check each other’s work. Trochim (2000) compares those that endure such intense scrutiny to the species that survive the evolutionary struggle.

In the next section the complex relationship between quantitative and qualitative methodologies will be discussed and applied to the context of health care and this qualitative study will be introduced.

2. METHODOLOGY

2.1 The Quantitative-Qualitative Debate

The object of social science research is human experience but the techniques used in its investigation vary. The main contrast is between quantitative and qualitative methodologies. Quantitative researchers look for facts about large groups of people. They collect factual data, which they measure and quantify. Although the data are about people, they are collected from a distance via documents or questionnaires. They can then be processed statistically and presented numerically (Clifford et al 1996). In contrast, qualitative researchers look for the meaning of particular situations to small groups of people. They collect data in situ, by getting involved with people and recording what they observe in situations of which they are part (Clifford et al 1996). Qualitative researchers want to capture “*a holistic perspective which preserves the complexity of human behaviour*” (Denzin and Lincoln, 1994).

Under the influence of positivism, quantitative researchers claimed that their scientific enquiry was closer to that of the natural sciences because their numerical results were more precise than the theories yielded by qualitative researchers. The latter countered that their findings were closer to people’s ‘real’ experience than reams of statistics about their various activities. The qualitative-quantitative debate is perhaps ‘much ado about nothing’ and there is value in combining both methods whenever possible (Trochim 2000). A distinction must be made, however, between the philosophical grounds of these approaches and the data collected by corresponding methods. Whereas the methods can marry, some epistemological positions are incompatible (Richardson 1996).

2.2 Ethnography

The aim of this study was to investigate the experience of young people and their carers in four mental health care settings. The data collection methods had to give a voice to selected individuals but also to offer ways of exploring the relationships between the various social

actors and the complex social settings where the care was taking place. Clear and rigorous but person-centred methods of data collection and analysis were required. A qualitative design seemed to be well suited to the task (Bartlett 2002). Ethnographic research methods derived from anthropology and developed over many years to study the practices and activities of social groups, not only in remote parts of the world but also in subsections of society at home, were chosen (Silverman 2000, Bartlett 2002).

2.2.1 Main Characteristics

Ethnography is concerned with gathering information about groups of people by observation and direct enquiry. It produces descriptions of cultures and subcultures in society. Ethnography refers primarily to a set of research methods characterised by detailed personal investigation requiring close involvement on the part of the researcher (Hammersley and Atkinson 1995). The two main and complementary data collection methods are participant observation and intensive interviewing. The researcher's analytic work consists of interpreting this data to produce ethnographic records. Ethnographic findings are characterised by descriptions of cultures and people in their own terms, as much as possible. Bartlett (2002) affirms that the single most important distinction between ethnographic and quantitative methods is the importance the former attaches to the categories of meaning of the culture under study, whereas the latter uses pre-existing categories of analysis. This strategy gives ethnographic research the scope "*to incorporate the unforeseen and the unexpected into the process of inquiry*" (Bartlett 2002, p. 130).

Because the data are so detailed, the scope of studies based on ethnographic methods is narrower than, for instance, that of surveys which can bear on hundreds or even thousands of people. The number of people sampled in this study was 55, a small number by comparison, which may limit the nature and type of claims that can be made as a result of this research process. However, the data collected was rich and detailed and much was learnt about the practices of the four social settings.

2.2.2 Epistemological Underpinning

Ethnographers attempt to fit into the culture they study and to keep disruption of it to a minimum. Therefore they make no attempt to control variables and can draw no conclusion about causal or correlated relationships between them (Hammersley and Atkinson 1995). Their main concern is to be sensitive to the social world they are discovering and to respect its practices (Lofland and Lofland 1995). The relationship between the researcher and the respondents is close. This leads to specific methodological and ethical requirements to regulate the relationships between researcher and participants (regarding ethics, see section 3.6, p. 98).

The fact that the relationship of the researcher to the setting is not controlled leads to the generation of a particular type of knowledge. Ethnography accommodates a range of philosophical approaches to knowledge, such as symbolic interactionism, phenomenology and hermeneutics (Hammersley and Atkinson 1995). The position taken in this study is, as mentioned earlier, broadly liberal and post-positivist. All these philosophical positions would support the notion that human actions are better understood in terms of social meanings (like the motives, beliefs, rules and values of the participants and settings), than in terms of causal relationships between variables and of universal laws. Some ethnographers like Lofland and Lofland (1995) and Glaser and Strauss (1967) insist on the importance of generating a theory from the data characterised by its close reflection of the data and its ability to capture the complexity of social settings (Hammersley 1992, Hammersley and Atkinson 1995). Others turn to the literature or to existing theory to structure their findings (Morse and Field 1996). This is the case of the present study. A detailed description of the settings and the participants' positions is followed by a discussion of the findings in the light of existing concepts of significance to the phenomena under study. There is always a risk, however, that conceptual frameworks may oversimplify the picture evoked by the data or force it into distorting theoretical structures (Denzin and Lincoln 1994).

Ethnographers are now very aware that researchers' social backgrounds and pre-existing assumptions affect their interpretation of the data: the cultures under study cannot be captured purely on their own terms. Even research writings are, like all writings, rhetorical and stylistic strategies, not transparent messages from the real world (Hammersley and Atkinson 1995). Some ethnographers have abandoned realism altogether, stating that no distinction is possible between the world of the researcher and that of the researched, so that all there is is an ethnographic text, to be assessed on its own terms, aesthetically (Denzin and Lincoln 1994). For most ethnographers however, what is important is to recognise the researcher's effect on the findings, monitor and minimise it, while still trying to grasp a reality beyond the researcher, and leaving the production of knowledge at the centre of the research enterprise (Hammersley and Atkinson 1995). The researcher's own role at the interface between the knowing subject and the object of knowledge is then included into the focus of the research in a process called reflexivity (King 1996). Ethnographic research based on this kind of epistemology can be assessed against certain criteria, similar to the validity and reliability of quantitative research, but adapted to the process and outcome of reflexive ethnography (Hammersley and Atkinson 1995, Gomm et al. 2000).

2.2.3 Credibility

Research findings need to do what they say they do: if an ethnographic study claims to describe certain phenomena, it must do so accurately. Although of course, from a position of critical realism, there can only be a correspondence between the situation and its description, not total accuracy. What is more, it will never be possible to ascertain that the findings are true; but the researcher must offer evidence for claims made (Hammersley 1992). Since the validity of all evidence may be challenged, how do researchers and practitioners decide that the evidence is good enough? Hammersley (1992) suggests that the researcher's claim must be plausible in the context of existing knowledge, and credible in what we know of the circumstances of the research. For this the researcher must anticipate the judgement of other researchers, and also, but perhaps on slightly different grounds, that of practitioners. The importance of the claim(s) made by the researcher will affect the

amount and quality of the evidence needed to support it. If the claim is central to the findings, more and better evidence will be needed. If the findings claim to describe a situation, evidence must relate to the time, place and events described. It is a more modest claim than a theoretical one, the validation of which is more complex. Assessing the validity of a study will involve identifying its main claims, and judge each claim's plausibility and credibility in the context of the evidence given.

2.2.4 Relevance

The discovery of truth is not sufficient justification in itself (Hammersley 1992). Research findings also need to be helpful, to serve a purpose: they need to be relevant to a world beyond themselves (Dittes 1973). Studies based on ethnographic methods tend to be narrowly focused. They may only appeal to small audiences, among them fellow researchers and practitioners in the field of study. The relevance can be methodological but it is primarily related to the topic and its place within a field of wider social interest, where it can contribute to the literature and to the field of practice, perhaps together with other studies on similar topics (Hammersley 1992). Hammersley points out that although practitioners often expect research that will be directly translatable into practice, this is rarely the case.

2.3 Ethnography and Mental Health Care

Health care is a field where qualitative research of the ethnographic kind has been slow to be recognised, although medical researchers like Greenhalgh (2001) assert that qualitative research methods are now given a significant place in health care and biomedical research:

“Qualitative research is now increasingly recognised as being not just complementary to but, in many cases, a prerequisite for the quantitative research with which most of us who trained in the biomedical sciences are more familiar” (Greenhalgh, 2001, p. 167).

Nevertheless, Evidence-Based Practice (EBP), which is now one of the main drivers of governance in health care practice, does not necessarily recognise qualitative studies as

significant contributors to the production of 'scientific' knowledge needed in health care, as this excerpt from the Cochrane Collaboration Reviewers Handbook (Cochrane Collaboration 2003, Introduction) shows:

"The Cochrane Collaboration Reviewers Handbook focus particularly on systematic reviews of randomised controlled trials (RCTs) because they are likely to provide more reliable information than other sources of evidence on the differential effects of alternative forms of healthcare".

Qualitative studies do not figure in the hierarchy of evidence and medical researchers who dominate the field rarely grant them more than pre-evidence status, as do Green and Britten (1998) in a British Medical Journal article aimed at explaining to doctors the advantages of qualitative research. These authors describe the role of qualitative research as that of clearing a confusing field before proper evidence can be collected.

The debate about EBP remains emotive, hiding the fact that evidence-driven medicine has improved patient outcomes, particularly in primary care (Greenhalgh 2002). Carefully scrutinised, the health care literature reveals articles testifying to the importance of other types of evidence, such as costs (Wilshaw 1999), humanistic values (Fulford and Williams 2003) and patient preferences, the latter being best elicited by qualitative means (Williams and Collins 1999).

The narrower field of psychiatry and mental health, where biological and social research should go hand in hand, has in fact remained more positivist than other medical fields. For example, a recent textbook for mental health nurses stated that work in evidence-based mental health care was overwhelmingly biased towards Randomised Controlled Trials (RCTs) and meta-analysis of RCTs (Newell and Gournay 2000). Also worth noting is an analysis of the proportion of articles using qualitative methods published in the medical literature between 1990 and 2002 (Crawford et al 2003). The results revealed that the proportion of such articles had risen considerably during the period, even though findings from qualitative research studies had remained a small proportion of the total. However, and despite this, there was no corresponding increase in two widely read psychiatric

journals (The British Journal of Psychiatry and Psychological Medicine) over the same period, suggesting a relative absence of qualitative methods in the field of psychiatry.

This position does not negate the view that qualitative studies are necessary. Dingwall (1992) suggested that qualitative studies were best suited to investigate the human dimension of the health care process because of their ability to capture the dynamic aspects of the organisation by watching, listening and studying the documents its members produced. While outcome studies are important – and they are a dominant strand – it is important not to lose sight of the process to ensure that it remains person-centred. Research into the views of people who use services tends to paint a broad picture when it is done on a large scale. This does not necessarily reflect the deep-felt experience of the service users. Lovell (1995) reported that studies investigating the perceptions of adult mental health service users were more likely to elicit positive views when they used quantitative methods and negative ones when the methods were qualitative. Elbeck and Fecteau (1990) and McIver (1991) pointed to a methodological problem as one of the reasons for such results: it is managers and professionals who design quantitative measures with their own priorities in mind. This can lead to misleading findings, whereas qualitative methods are more likely to allow the researcher to take on the users' agenda.

In summary, ethnography is a set of qualitative research methods fit for the purpose of studying social settings and the experiences of their members, which is why it was chosen to investigate young people and their carers' experiences in specialist mental health units.

3. DESIGN AND METHODS

3.1 Aim of the Study

To explore young people and their carers' experience regarding treatment and participation in decision-making in four Scottish adolescent inpatient/day-care mental health units.

3.2 Research Questions

1. How did the young people perceive their care and treatment and their participation in decision-making in four Scottish adolescent inpatient or day-care mental health units?
2. What was the perspective of the young people's parents or main carers on their child's care and treatment, and what was their contribution to the context of care?
3. What was the staff's perspective regarding the young people's participation in decision-making and the parents' involvement?
4. What did the unit cultures contribute to young people and parents' experience of treatment and participation?

3.3 Design

The chief concern of the study was to explore the experience of a number of stakeholders regarding the care and treatment of young people in adolescent mental health units. Each of the first three questions focused on a different group: the young people, their parents or parent substitute and the staff. Their views were documented in transcripts of interviews with a sample of young people, their parents, their key-workers as well as with the consultant psychiatrist in charge and the nurse manager of each setting.

The fourth question concerned the exploration of the unit cultures as variants of the experience. For this purpose, the researcher spent from five to eight weeks observing each treatment setting to learn more about their structure and functioning, resulting in a set of fieldnotes. Texts devised by each unit to describe themselves, such as unit philosophy and mission statement, young people and parents' information sheets, as well as the data collected were also used to answer this question.

3.3.1 Sites

The social settings in which the data were collected were adolescent mental health services providing intensive forms of treatment, either on a residential or on a day-care basis. There were six such centres in Scotland at the time of the data collection and four of them were involved in this study. In order to sample a range of practices, centres were selected for their contextual contrasts. Three were urban services: two day-units and one seven-day residential unit in different parts of Scotland. The fourth was a rural, seven-day unit, in which some young people were day-patients and others inpatients.

The researcher was known to some of the staff in each centre because she was running specialist educational programmes about the care of children and adolescents with mental health problems. Some members of staff in these units had been involved in the development of the programmes while others had attended them as students. This offered advantages and disadvantages. On the positive side, being known meant that access to the research sites was facilitated by the existing trust between the unit staff and the researcher. It also meant that the researcher's existing knowledge of health care practice in such settings accelerated her understanding of the young people's problems and the functioning of the settings. On the negative side, being known by several nurses as their teacher gave the researcher an unsought for authority which may have restrained the process of natural interactions necessary for the research. As the researcher spent several weeks in each setting, however, these inhibitions seemed to be progressively removed through a growing familiarity. The impact of the researcher's identity, life experience and previous involvement with the sites and respondents in her study will be commented on later in this chapter.

3.3.2 Samples

In qualitative research, samples are smaller than in quantitative research because data collected by qualitative methods, such as observation, group discussions or interviews, are

proportionally larger and richer and yield more information than those collected by quantitative methods. Samples are chosen for their representativeness of the phenomena under study, here the stakeholders involved in young people's care, particularly the young people themselves, and the units in which the care took place. Such samples are called theoretical or purposive (Clifford 1997) because they are selected on the basis of existing knowledge regarding the phenomena. In this study the health care settings, time spent in them and the young people themselves were sampled.

The settings were selected to represent a range of intensive mental health treatment units for adolescents in Scotland. Together, these settings offered a selection of geographical areas, treatment approaches in both inpatient and day-care settings, and urban and rural contexts. The point of including these different factors in the sample was to explore the differences they might make by comparing their influence in the situation (Gomm et al. 2000). The researcher spent six weeks in the first setting, two weeks in the second (which was very small) eight weeks in the third because it was bigger and more complex, and five weeks in the fourth. The time allocation was decided according to the size and complexity of the units, number of young people and members of staff. During those times, two main sets of data were collected: observation of the settings generated fieldnotes and interviews with respondents were taped and transcribed. In addition a small number of documents were collected.

Time in the unit was sampled according to the criteria of visibility, activity and predictability. Those times which young people were willing to share with an adult (visibility), those when activities were many and varied (activity) and those which were spent in unpredictable ways (predictability) were observed most often. In day-units, the choice was more restricted than in inpatient units because they only operated from 9 a.m. to 5 p.m. In inpatient units, the times selected for observation were from early morning to late evening. After hearing several night reports in each inpatient unit, the researcher decided that night observation was not the best way to use limited time because the nights were uneventful. This decision was based on night staff's reports of what happened, reports which, admittedly, must have been incomplete and biased. However, what was clear from

them was that events, reported or not, were small – had they been serious, community living would have made them impossible to hide – and therefore difficult to observe in the intimacy of a dormitory or a bedroom. For the same reason, the researcher selected for observation fewer mornings before 9 a.m. and evenings after 6 p.m. In the morning, like many teenagers, young people frequently did not get up until the latest possible time before the first activity. Most did not sit down for breakfast unless they were contracted to do so because of an eating disorder. Such supervised breakfasts were observed a few times but other supervised meals were observed later in the day. In the evening, young people often spent time with visitors or in the privacy of their bedrooms. Evening activities were selected for observation. The observer also spent time with staff at informal times during the day and in formal meetings.

Respondents were selected according to the same principles as the settings. Each unit catered for ten to twelve young people at a time. A young person was likely to stay in a treatment setting from six weeks to three months. Five young people were chosen in each setting, in an effort to combine such factors as diagnostic characteristics, age and gender. In a small day-unit, only three adolescents were selected. In total, eighteen young people were interviewed.

In order to have time to build relationships with young people good enough for the purpose of the study, and to learn about them in some depth, the following inclusion and exclusion criteria were imposed on the sample:

- Young people were included when receiving treatment in the unit and likely to be resident or attending regularly for the whole period of observation.
- Young people were excluded when 1) their discharge was planned to take place during the research period, 2) they were admitted later than two weeks after the start of the research period.

Young people who had been selected and became psychotic during the research period were not withdrawn from the sample but they were not interviewed during the crisis.

The young people's main carers were usually one or both parents except on one occasion, when the main carers were grandparents. In another case, no carer was available, parents having recently withdrawn. In a third, the mother failed to come to three separate appointments and was not interviewed. A total of sixteen mothers or couples were interviewed.

Each selected young person's key worker was interviewed. These were mainly nurses except when, in one unit, workers were drawn from a mixture of professions, which at that time meant the inclusion of an occupational therapist. In one unit where several nursing assistants were employed and appeared to play a significant part, one was interviewed. The selection of this new interviewee was based on the concept of snowball sampling where one respondent recommends another or an unpredicted opportunity arises (Clifford 1997). A teacher and an occupational therapist were also interviewed on that basis, because the observation of the unit suggested that they played an important role. In order to grasp the many factors involved in the structure and functioning of the treatment settings, the consultant psychiatrist in charge and the nurse manager of each unit were also interviewed. Together the total number of staff interviewed was twenty-one.

3.3.3 Data Collection

3.3.3.1 Participant Observation

The purpose of each period of observation was to explore the structure and functioning of a unit as the context for the young people's experience. The aim was to know what happened over a period of a day and a week, what therapeutic programmes took place, how decisions were made, how people related to each other, how young people spent their time, with whom, and where. The resulting data consisted of extensive fieldnotes, typed at the end of each day, describing everything that had been observed that day. During the day, it would have been conspicuous, and therefore tactless, to write in the presence of the people observed. Notes were jotted down in a small notebook at intervals when it was possible to withdraw. These brief notes described details of the physical setting and people present, themes discussed and comments made in enough quantity to jog the memory later. In the final notes, a distinction was made between descriptions and commentaries. Descriptions

aimed to follow Lofland and Lofland's (1995) advice to be as behaviouristic and concrete as possible, in order to avoid the inevitable inferences involved in summarising and abstracting. Although a degree of unconscious researcher selection must be inevitable in what is described, any comment involving judgement is best avoided. However, while making notes, the researcher did sometimes develop understanding and interpretations regarding the data which could be useful at the analytic stage. These were noted in brackets.

Feelings experienced during fieldwork, or evoked by people and events, were also noted in brackets. For example, during one period of participant observation, the researcher experienced high levels of anxiety and noted that she was relieved to leave the unit at the end of each day because she was never sure of her relationship with a group of respondents. This was not fully explained at the time but analysis of the interviews revealed consistently high levels of hidden staff conflicts and unhappiness. This suggested that the respondents were unsure of their relationships with each other and unhappy in their work setting, plausibly leading to similar feelings in the researcher whom they were not able to welcome whole-heartedly. Emotions are a way of perceiving which can lead to a better understanding of shared events. The anxiety felt by the researcher became an indication of how respondents might be feeling and validated the findings regarding staff unhappiness. Private feelings also, such as intense anxiety about the researcher role in certain contexts, can further illuminate the fieldnotes and assist the researcher to perceive her own biases (Lofland and Lofland 1995). The place of the researcher in the research will be examined in section 3.5, p. 92).

Gold was one of the first researchers to set out in detail the different possibilities offered by observation as a method of data collection (Gold 1958). His original paper is available in a book edited by McCall and Simmons (1969). Gold used four categories to describe the role of the observer in fieldwork, based on the combination of researcher involvement versus non-involvement. The first category refers to an observer who is a 'complete participant': the people observed do not know that she is a researcher. This was the approach adopted by Goffman at St Elizabeth Hospital: the patients believed him to be the athletic coach's

assistant (Goffman 1961). The second category describes those researchers who are 'participant observers'; they are known to be researchers and as such they become part of the setting under observation over a period of time. Towell (1975)'s study of psychiatric nursing in a large psychiatric hospital was of this kind. The third category is concerned with an observer who is no more involved than is necessary for an interview or two, such as Melia (1987) was in her study of student nurses. The complete observer of the fourth category is removed from the interaction. In this study, the researcher's involvement with the young people and unit staff fitted into Gold (1958)'s second category, while her brief interactions with parents belonged to the third.

Gold (1958) used these categories to highlight some of the dangers that threaten scientific rigor during fieldwork. The very involved researcher, not known as such by her informants, may find it difficult to keep up the demand of her role for an appropriate and necessary degree of detachment. The danger is that she will lose her perspective as an outsider and become an insider ('go native'). At the opposite end, and more of a risk for the observer of the fourth category, is the danger which Gold calls 'ethnocentrism'. Here the researcher may not be close enough to her informants to have an empathic grasp of what it is like for them. The participant observer of this study spent from two to eight weeks in each field. The challenge was to be a regular enough presence for young people, staff and researcher to build trust in each other and be at ease in each other's company. These were the conditions necessary for the researcher to capture in her data the events of the settings and the informants' spontaneous actions. For the researcher to come too close to young people, parents or staff, however, could lead to two risky outcomes. On the one hand, if the respondents identified too much with the researcher, they might give her what she wanted to hear instead of what they wanted to say. On the other, the researcher herself might lose the detached perspective necessary to the research. The answer Gold suggests is to take time out to cool. Occasionally the plight of one informant made it difficult for the researcher to see the perspective of others in the setting. Two things were then found to be helpful: one was the note making time spent every night in front of the computer, recollecting from notes the sequence of the day's events. This allowed the researcher to enter again into other informants' perspectives and to reflect on her own feelings. The other

was the time spent away from the unit, attending to other commitments. This was truly cooling in the sense meant by Gold and it could not last long without researcher and informants losing a mutual sympathy too recent not to remain fragile.

When performing the role of participant observer, the researcher may find herself in a position where she is called upon to participate in a role which may not befit that of a detached observer. Nurses caught in health care emergencies may have no choice but temporarily to drop the researcher role and use their professional expertise to tender help (Melia 1987). While this did not happen in the study, the fieldnotes record a few occasions when the distinction between participant observer and member of staff became blurred. One such event happened during an emergency when all the nurses were called by the sound of a colleague's alarm, leaving behind the researcher as the only adult available to support the young people and keep the routine going:

"I sat there and they told me how upsetting it was to see someone in Mary's state. Rosie especially who said she was just getting better and seeing Mary like this made her depressed again... Later I left the room to see what was going on and found the lunches had arrived from the hospital kitchens. It was 12.45 so I went to get the kids for lunch and started to serve it up. Eventually Liz came, then Liam [staff-nurses] and things went back to normal. [I think this was my 'participant' bit: just to act as a caring adult]"
(Rannoch, week 5, day 1, p. 5).

Morris and Charlotte Schwartz, who did field work in an American psychiatric hospital in the 1950s (see Stanton and Schwartz 1954), also wrote about their experience of direct observation (Schwartz and Schwartz 1955). They highlighted the importance for the researcher to relate to informants at a basic human level, using courtesy, interest and empathy in ordinary interactions. This natural human contact allows the observed to recognise in the observer a fellow human being in a shared experience.

3.3.3.2 Interviews

Research interviews serve to collect information from respondents and, depending on the focus of the information required, they can be more or less structured. Structured interviews ask closed questions, the simple answers to which can be scored numerically. At the

opposite end of the spectrum, unstructured interviews, also called depth interviews or intensive interviews, allow the researcher to be led by the respondents' agenda. Lofland and Lofland (1995, p. 18) described them as "*a guided conversation whose goal is to elicit from the interviewee rich, detailed materials*".

Lofland and Lofland (1995) stressed the mutuality and complementarity of participant observation and intensive interviewing. This was certainly the case in this study. Informants were interviewed during the period of observation, usually after the first couple of weeks, so that they and the researcher had had time to become acquainted with each other. Interviewees were selected during this period, according to the sampling guidelines described earlier. All young people and staff knew at the outset that the researcher would wish to complement her observations by asking some of them for their views. This was explained orally as well as conveyed through information sheets that were distributed to staff and young people before the beginning of the observation period.

Once young people had been identified as possible interviewees, the researcher spoke to them individually about her interest, explained to them what would be involved and gave them a copy of the information sheet (see Appendix 4). At this point the confidentiality of interview contents was stressed. Although most young people responded quickly and positively, they were always asked to think about it for twenty-four hours before making an appointment and signing a consent form. It is interesting that, with the exception of a mother who eluded being interviewed by not turning up for appointments, all other respondents seemed willing, and some keen, to give their views. Sarantakos (1993) notes that intensive interviews elicit high response rates because they provide the respondents with personal attention and support. This supportive aspect of intensive interviews was valuable in this study because of the vulnerability of the young respondents. The researcher worried, however, that some young people who were not asked for an interview might interpret it as a negative statement towards them. When she sensed this might be the case, she explained to that young person why she had not approached them.

Young people and staff chose to be interviewed in the units, while many parents chose their homes. All took place in private. The researcher did all the interviews. They lasted between

thirty minutes and an hour. Out of 55 interviews, 53 were tape recorded and transcribed. One informant refused to be taped, so notes were taken instead. On one occasion, the researcher forgot to switch on the tape recorder! Notes were made from memory straight after the interview and a fuller account was typed before the end of the day.

Interview guides were used. Lofland and Lofland (1995) described the themes that make up the informal type of guide used in intensive interviews as questions which the researcher has teased out from existing understandings of the field under study. In this study, the field was hospital mental health care and the experience young people had of it. Relevant areas of interest were the process of referral and admission, the type of mental health problems the young people thought they had, their experience of hospitalisation and so on. The themes selected for further investigation are listed below:

- Reasons for coming to the unit (as understood by them)
- The problems they felt they had
- Their experience of being in the unit
- Some facts (key-worker / doctor / treatment etc.)
- What had the experience been like?
- Had it helped and why?
- Who was making the decisions?
- Good things / bad things about the experience
- Family involvement
- The future

The topics in the guide were deliberately couched in straightforward language to facilitate communication with the interviewees. Such broad and neutral themes were likely to elicit more information than was necessary to answer the research questions. For example pre-admission data and data on the future did not contribute directly to an understanding of the young people's experience in the unit, although they helped the researcher understand the young people at the time. Later, during the analysis, these data were set aside.

A chronological order was given to the topics to offer a reasonable sequence. The third theme, concerning experience in the unit, was central to the study and had to be sub-divided into smaller, more manageable sections. Interview guides for parents and staff followed the same themes but each was slanted slightly differently. For example, with the nurses such words as referral, diagnosis and treatment methods were used. Staff members were also asked about the effect their work had on them and how they felt about it. Parents were asked about the part they played in decisions regarding the treatment of their child and about the practicalities of being involved in the unit, such as distance, transport and so on. The interview guides used with the psychiatrists and nurse managers differed from this model. They were derived from the period of observation, after questions had formulated themselves in the researcher's mind. They included questions regarding their roles in the unit, their priorities, and the rationale for treatment approaches in connection with psychiatric and psychological theories. Although they were similar from one unit to the next, they were not identical.

The interviews themselves were '*guided conversations*' (Lofland and Lofland, 1995, p. 85). Melia (1987) highlighted the potential contradiction involved in balancing the use of an agenda, which gives a theoretical direction to the interview, with a conversational style that makes it possible for the interviewee to say what he wishes. The key, stresses Melia, is in the informal style of the interview which, although the researcher has a clear aim in mind, can be flexible enough for the accommodation of new ideas introduced by interviewees. The guide is only that: a guide. In this case, the themes were not always taken in order and new or complementary themes were sometimes brought in. All informants were shown the interview guide at the beginning of the interview to give them an idea of the areas about which the researcher was seeking their views. Themes were then explored, sometimes in a different order from the interview guide, sometimes with a fair amount of prompting, sometimes with very little.

For each interview, facts about the interviewee were noted, such as their name, age and gender, the place and length of the interview (see 'Ethics' section p. 102 for issues of confidentiality). Another section was included after the interview, consisting of the

interviewer's reflection about the interview, the interviewee, and her own reactions (thoughts and feelings) before, during and after the interview.

Interviews began with a few interviewee-centred interactions. The interviewer thanked respondents for being willing to help in this way, assured them again of the confidentiality of what they would say, invited them to sign a consent form (which included a reminder that they could pull out at any time), and checked their preferred way of having the interview recorded. These formalities offered an opportunity to create a climate of companionable safety. Carrying out research interviews involves interpersonal skills. Clifford (1997) points out the transferability to research of interviewing skills already possessed by health care workers. Unstructured interviews call for non-directive communication skills such as putting people at their ease, listening and facilitating disclosure, and paying attention to non-verbal communication (Rogers 1951, Heron 1990). Nurses use many such skills in the course of their work. In this study, the researcher – also a mental health nurse – was aware of using and adapting her counselling skills. Interviewing adolescents with mental health problems meant having the ability to ask about emotionally painful issues in a warm and empathic way that would allow further exploration. As in counselling interviews, the interviewer had to remain unobtrusive so as not to influence the content of communication, while offering understanding and emotional support. Liberal use was made of nods, eye contact and affirming grunts ('yeah', 'uhum', 'sure', 'ok' etc.). Towards the end of an interview, it was often necessary to lead an adolescent gently out of a painful topic towards more superficial, 'here-and-now' considerations. A short period of general chitchat can help someone gather themselves to go back into ordinary life. Interviewing young people involved parenting skills. With staff, the style of communication was that of professional peers. With parents, the interviewer became a fellow human being, united in the experience of solving life's problems.

A number of interviews with parents yielded rich data. The researcher often sat on the floor in order to keep the small microphone close enough to record all parties. This position, which played down the status of the researcher, had the advantage of empowering interviewees. Some spoke movingly and at length of what had been difficult times for them

and their families. One particular interview with a couple took place at a sensitive time when their relationship with their child was breaking down in acrimonious accusations. These parents felt alienated from the unit and exposed. Over the course of the interview, the researcher developed an empathic understanding of them. The memo made in the fieldnotes at the time of the interview is quoted here to show a distressing aspect of the participant observer role.

"[The parents] felt their family was falling apart, their difficulties were being made public by Tom out of malice and for his own gain. They felt helpless in the process. My empathy for them grew as the interview developed. They seemed to be cornered and exhausted. They could see some of the difficulties Tom was up against... They didn't see how they could help him more than they'd tried to do. They felt rejected by him because he was so hostile towards them. They thought he was manipulating the unit, but that the unit couldn't see it. They had no advocate or anyone to see it from their point of view. At the end, they offered me a cup of tea, which, in the circumstances, I accepted. We chatted about their forthcoming holiday... My position as a researcher committed to confidentiality is somewhat difficult in that I have been given a privileged position with these parents which I can't use to help them" (Rannoch, week 3, p. 14).

A clinical meeting about this family took place the next day and was recorded in a memo:

... "X [a member of staff] went to call the Child Protection Unit...I stayed behind, a bit shell-shocked. I was taken aback by this course of events... If that had to be done, I would have wanted to tell the parents I was going to do it and why. I felt very sorry for them in anticipation. I stayed in the room on my own for about ten minutes, regretting what was happening and feeling that, somehow, I had been party to letting these people down. But I also felt sure that my role as researcher, my commitment to confidentiality, meant that I could do nothing, and say very little" (Rannoch, week 3, p. 17).

There are also significant differences between counselling and research interviews. Although both aim to understand the interviewee's experience, research interviews do not attempt to provide therapy. In research interviews, the respondents' views must be as uncontaminated as possible by the researcher. This means that the researcher's contributions must guard against the possibility of guiding or influencing the interviewee, or at least to minimise that possibility. Lofland and Lofland (1995) drew attention to

questions: they must be open, admitting any kind of answer, rather than leading, suggesting a particular answer ('do you feel that...?' is a leading question. 'What do you feel about...?' is preferable). In this study, which was the researcher's first experience of research, interview style improved with experience.

Morse and Field (1996) wished to see less transfer of skills than Clifford (1997) and sounded more warning bells than Lofland and Lofland (1995). For instance, they ruled out certain counselling interventions like reflecting back the interviewee's response, which they claimed risked putting words into the interviewee's mouth, or summarising it because it made interviewees' self-conscious. This may be over-cautious. Vulnerable interviewees need encouragement, and reflecting or summarising can be useful if they are kept discreet.

3.3.3.3 Documents

The documents made available to the researcher were information handouts for professionals about the referral protocol and the treatment programme, guidelines for the young people to introduce the unit and explain unit rules and expectations. They were few and mainly factual, compiled to meet their readers' expectations. By comparison with the interview content, they were bland. This material was analysed in the same way as the rest of the data and used to enrich or contrast the picture emerging from interviews and fieldnotes.

3.4 The Analytic Process

The process of analysis has been divided into stages in order to describe the complexity involved (Morse and Field 1996, Clifford 1997). The five stages adopted here are a combination of those mentioned in the research literature. The analysis of the data collected for this study extended over four years, the data collection itself having taken place in three stages, one in 1998, one in 1999 and one in 2000. To ensure continuity in the analytic process and quality, a diary was kept and analytic memos were attached to fieldnotes, interviews, categories and sub-categories as recommended by Morse and Field (1996) and Lofland and Lofland (1997). The total data amounted to just under 400,000 words.

3.4.1 Data Display

Voluminous data needs to be prepared for analysis in a systematic way to simplify the handling of such large amounts of text (Morse and Field 1996). Fieldnotes were managed first: they were written during the period of participant observation, usually in the evening of the same day, from notes made unobtrusively during the day. In total, 21 weeks of observation produced 93,000 words.

Interviews were guided by themes which were deliberately kept broad and neutral in order to let the young people speak for themselves (see interview section p. 78). As a result more data was collected than was necessary: some interview sections which had fostered a better understanding of the young people (for instance the circumstances of their admission), but did not help to answer the research questions, were set aside early on.

Interviews lasted on average 45 minutes - from 30 minutes to over an hour. Each tape took the researcher approximately six hours to transcribe, which made it necessary for the transcription of tapes to go on for several weeks after the period of data collection. Out of 55 interviews, or 285,000 words, 18 tapes were transcribed by a secretary. In this case, the researcher checked the transcripts against the tapes for accuracy.

Once a data filing system has been organised, the data can be easily retrieved (Morse and Field 1996). After each of the three data collection periods, the typed fieldnotes and interview transcripts were imported into the software package QSR NUD*IST version 4, which aims to assist researchers in the management and exploration of large qualitative data sets (Buston 1997, Gahan and Hannibal 1998, Benton 2000). This made it possible to retrieve the data with ease in spite of their volume.

3.4.2 Data Management and Reduction

Once organised, the texts must be coded and segmented into simple broad categories that do not overlap with each other (Morse and Field 1996). The raw data was initially managed by site and, within each site, by interview groups. Each group of data was coded into a small number of categories (see Table 3.2 for an example of three data groups: young

people interviews, parent interviews, and unit data which were drawn from field notes and staff interviews).

Site 1	Site 2	Site 3	Site 4
Young People 'Treatment' 'Involvement in treatment' 'Miscellaneous'	Same as site 1	Same as site 1 & 2	Same as other sites
Parents 'The problems' 'Treatment' 'Involvement in treatment' Miscellaneous'	"	"	"
The Unit (Fieldnotes and parts of staff intrw.) 'Culture' 'Current treatments' 'Parents' 'YP Involvement in decisions' 'The staff' Miscellaneous'	"	"	"

Table 3.2: Example of First Level Coding

Once coded, each category could be retrieved and analysed. The data analysis technique used in the study was content analysis.

3.4.3 Analysis

3.4.3.1 Content Analysis

The analytic method adopted was content analysis, which Cavanagh (1997) described as *"the distillation, through analysis, of words into fewer content-related categories"* (p. 5). The categories can be meaning-related or numerical, so that content analysis has been used across a spectrum of methods, from questionnaires to ethnographies. In content analysis, much emphasis is laid on creating and defining categories: they can come from the literature, from existing theory or emerge from the data (Cavanagh 1997). Importantly, however, the categories must be mutually exclusive (Morse and Field 1996).

In the study, the content of groups of data was segmented into a few broad categories as displayed in Table 3.2. The categories had been chosen because of their importance as topics across a group of interviews or a set of fieldnotes. The magnitude of a topic and the frequency with which it occurred across a set of data gave an indication of its importance (Lofland and Lofland 1995). These topics often reflected themes from the interview guides, revised and enriched by the interviewees. For instance the young people's interviews were initially broken down into two main categories: 'treatment' and 'involvement in decision-making', both themes from the interview guide. 'Treatment' was a large category that became subdivided into four subcategories: 'talking to people', 'being in the unit', 'groups and meetings' and 'medication'. These four subcategories emerged from the interview data, not from the interview guide. A category called 'miscellaneous' was always allocated to make room for unexpected or 'rogue' data (Hickey and Kipping 1996).

The quantitative potential of content analysis was exploited in two ways. Facts about the participants were extracted and logged in tables as base data: for example the age, gender and diagnosis of the young people in the sample. Interviewees' views were also recorded in tabular form to facilitate a grasp of complex findings: the young people's favourite and least liked treatment, their positive, negative and mixed responses to collaboration in decision-making... The same approach was adopted with each group of interviewees.

Before being sorted according to their content, fieldnotes had contributed to the evolution of themes and categories. Each day they were scrutinised for analytic themes so that current fieldnotes influenced the course of future observation (Lofland and Lofland 1995). This is how the category 'unit culture' developed. During the first period of data collection, the influence of the culture of that particular unit on everything that took place in it struck the researcher as significant. Questions regarding the history of the units, their values and their treatment philosophies guided further observation as well as being put to the staff during their interviews. Over the course of the study, the category 'unit culture' evolved from one data site to the next until it became a key category in the overall findings, on an equal par with the views of young people, parents and staff. The initial fourth research question, which had been *'What is the structure and functioning of the specialist treatment settings*

which are the context of the young people's experience?' became 'What do the unit cultures contribute to the young people and parents' experience of treatment and participation?'

3.4.3.2 Making Sense of the Data

As the data is transcribed, checked and coded, the researcher begins to make sense of it. Comprehension has taken place when the researcher is able to provide a detailed and coherent description of the respondents' actions and thoughts with specific stories as examples (Morse and Field 1996).

In this study, the content of the first-level categories described in Table 3.2 was printed out and second-level coding was done by hand. As the material was carefully read, sub-categories became identifiable which enhanced the meaning of the main category. Some small and irrelevant sub-categories were discarded at this stage, for instance how the young people anticipated the future, which was a theme of the interview guide but which did not add anything to the subject of unit life, treatment and participation.

As this analytic process progressed, it became clear that the hierarchy of categories obtained for each group of interviews in site 1 worked across sites, with only a few site-specific extras in the 'miscellaneous' sections. Once all of the young people interviews across sites had been coded together, the main messages of the young people emerged: their appreciation of relationships in the units, their mixed feelings about participation in treatment, their confident involvement in non-treatment unit life. The unit-specific categories helped to understand how therapeutic relationships and participation were enhanced or hindered in each unit. At this point, the robust new category 'unit culture' offered possible interpretations as to the contributions of the culture.

So far, the staff interviews had mainly been used to contribute to an understanding of the units. What was left of these staff interviews concerned the interviewees' views regarding the young people's involvement and the parents' inclusion in the life of the unit. This was gathered under two broad categories and analysed by hand. The findings came to complete the picture that had started to build of how young people and their parents experienced treatment in the four units.

At the end of this stage of analysis, documents were written on the young people's views, the parents' views, the staff's views and the unit cultures. These were three-part documents that included base data, a summary of the message of each category under their heading and a reflective piece that anticipated the next analytic stage: theorising.

3.4.3.3 Theorising

Analysis of the data allows the researcher to see it in a new way: the knowledge produced is something different, yet faithful to the data (Sandelowski 1995). Morse and Field (1996) complained that theorising was too rarely mentioned in relation to qualitative enquiry in spite of the fact that it is a critical component of it. A theory provides the structure that will allow the findings to be connected to the wider body of knowledge and applied to social settings beyond the study (Morse and Field 1996). There are different levels of theory, with greater or lesser explanatory powers. The theories that arise from the analysis of qualitative data are based on concepts less abstract than those of grand theories and have limited scope for generalisation. Merton (1968) called them middle-range theories. Nevertheless, these emerging theories should lend themselves to re-contextualisation, both in the settings under study and in other such settings, bearing in mind that any generalisation ought to be tested by further research (Morse and Field 1996).

There are several ways of developing an explanatory theory of the findings. One of them is the well-known systematic and incremental induction of theory from data called grounded theory (Glaser and Strauss 1967). Another way is to turn to adjacent literature and to look for similar concepts which can show the data in a new light. Morse and Field (1996, p. 106) called it '*lateral thinking*'. This is the method that was used in this study.

The findings regarding the young people, the parents, the staff and the units offered an interesting and complex picture. Some surprising messages emerged and resulted in a shift of emphasis: the young people's main message regarding relationships and the significance of participation partially matched the literature about adult service users, and in this sense was not unexpected. However, the parents' message about their longing for involvement was stronger than anticipated and surprising in the context of adolescent mental health services traditionally committed to working with families. The staff's message was nuanced

and suggested that the implementation of participation held difficulties for them. The unit cultures emerged as rich descriptions of complex social settings, clearly influential to the success of young people and parent involvement.

The literature review of a neighbouring academic field, that of pastoral theology, had yielded powerful concepts about user participation. Three of them were used to organise the findings into a coherent whole because of their fit with significant aspects of the findings. This theoretical explanation of the findings of the study brought together three levels of interaction in the settings linked to participation. Firstly that of one-to-one empowering relationships, secondly that of all relationships in a unit to form a participative community and finally that of the units with the outside world, both at local and national level. This theoretical model could then be re-contextualised, as it suggested reasons why some units were more successful than others at involving young people and parents. Further discussion of this is found in chapter 8. The trustworthiness of the analytic process is now addressed.

3.4.4 Fulfilling Criteria of Trustworthiness

Any researcher who adopts a position of critical realism expects the findings of ethnographic studies to be judged against certain criteria. The most important index of trustworthiness in qualitative research is its validity, but its reliability and relevance are also important (Hammersley 1992). As the researcher explains in detail how the research has proceeded, other researchers can decide whether the conclusions are likely to be accurate, consistent and useful. In a thesis such as this, it is the aim of the chapter on methods to provide enough transparency about the study to allow the reader to assess the findings. This section bears specifically on the validity and reliability of the data analysis.

3.4.4.1 Internal Validity

“An account is valid or true if it represents accurately those features of the phenomena that it is intended to describe, explain or theorise” (Hammersley 1992, p. 67). Since there is no way of proving that a knowledge claim is true, the plausibility and credibility of the claim must suffice, says Hammersley (1992).

Triangulation is mentioned as a key method of ensuring the validity of qualitative analysis (Porter 2000). Triangulation is the use of different methods of data collection to build a picture of the same phenomena. It results in a richer, truer picture (Clifford 1997). Triangulation is also achieved when different data sets analysed separately but focusing on the same event are used to corroborate each other (Porter 2000). Triangulation between different data groups was used to verify findings: the young people's perspective on their participation in decision-making was checked against the staff's view regarding the same topic. Both groups named obstacles to the young people's participation, several of which overlapped, such as the presence or absence of individual good will, power differentials and the young people's need to distance themselves from adults. Triangulation was also used between the findings emerging from staff interviews and those emerging from fieldnotes to explore the concept of unit culture. Silverman (2000) however, does not rate triangulation highly as a form of validation because it assumes that each method or data source has caught an accurate picture of reality that will offer valid corroboration, whereas each will only have a constructed version of reality to offer. Instead, Silverman (2000) recommends to begin analysis on a small set of data and to check the emerging categories on new data, perhaps even keeping some data back exclusively for this purpose. While no data was kept back in this study, site 1 young people interview transcripts were analysed, then tested on the site 2 set of young people transcripts, then on the site 3 set and so on. The same was done for parent interview transcripts, staff interview transcripts and fieldnotes. Comparisons between analytic results across similar data sets from different sites were performed regularly, helping to understand what the data sets had in common and what differences marked each site.

The plausibility of the theory proposed at the conclusion of a study must also be assessed and the likelihood of its generalisability to other situations. The theory conveyed in the findings of this study concerns a social framework focused around a certain type of empowering relationships. The theory, which had first been an abstract set of inter-related concepts generated from the findings, was tested by re-contextualising it, that is, by trying

it out for fit in the settings of the study. If it works in the context of the study, it is one step closer to being generalisable to other, similar context (Morse and Field 1996).

Some researchers recommend that qualitative findings be read by the respondents to test their credibility (McIver 1991, Clifford 1997). Other researchers argue that research findings cannot be amended to please the respondents (Hammersley 1992, Silverman 2000). The findings of this study were shared with one staff respondent a year after he had left his job in one of the units. The researcher felt that this person's views regarding the credibility of her findings and their acceptability would help her appreciate how the staff of the units might perceive them. Subsections of the findings were also presented to the staff in three of the four services. All were received with interest, which is not to say that ambivalent feelings might not have been present. Unfortunately, by the time the data were analysed and written up, the young people and their parents had long moved on and it was not possible to share the findings with them.

3.4.4.2 Reliability

“Reliability refers to the degree of consistency with which instances are assigned to the same category by different observers or by the same observer on different occasions” (Hammersley 1992, p. 67).

In the context of qualitative research, the veracity of the findings relies on the reliability of the researcher as the main research tool. The researcher must be able to demonstrate, to both herself and others, that the way she allocates pieces of data to certain categories and not others is consistent (Morse and Field 1996). In the study, the researcher coded and checked the same texts twice at different times to test the reliability of her coding and that of her categories. Weber (1994) describes this method as a weak form of reliability and prefers that another researcher do the checking. This was not possible because no other researcher was involved. However, categories were kept simple and mutually exclusive, such as the treatment modes available to the young people, and the different types of help required by the parents, so that the researcher rarely hesitated as to which category a sentence or paragraph belonged. The avoidance of ambiguous categories in this way supports the reliability of the coding (Cavanagh 1997). A few contrasting categories were

also used, such as positive, negative and mixed views regarding forms of treatment and participation.

In qualitative studies, the reliability of the data is difficult to demonstrate in other ways than by making them available to other researchers. One interview transcript and one set of fieldnotes are included in Appendices 1 and 2.

The openness of researchers about themselves as research instruments also helps to evaluate a piece of ethnographic research. This is the focus of the next section.

3.5 Reflexivity: the Place of the Researcher in the Research

In qualitative research, researchers inevitably shape the way their projects develop; their background and culture affect both data collection and data interpretation (King 1996). This has been called the reflexive aspect of this kind of inquiry (see epistemological section p. 65-66). If researchers are open about themselves, however, the extent to which their subjectivity may have influenced the data is easier for other researchers to assess (Trochim 2000). This strategy enhances the credibility of the research.

In this section the relationship between the researcher and the data is addressed (see also Claveirole 2004 in Appendix 3). Important personal characteristics through which the researcher inevitably perceived her data are her value positions, her roles in life, and the feeling states she experienced during and about the research (Morse and Field 1996). An analysis of how these have been taken into account helps to confirm the trustworthiness of the study as a whole (Gomm et al. 2000).

3.5.1 Values

Why was the topic of this study chosen? A recent emphasis on the negative evaluation of NHS mental health services by the service users' movement inspired the researcher's desire to investigate young people's views of their mental health care. The hypothesis was not value-free: if adults are so dissatisfied, it was sensible and tempting to assume that young

people would be too. Here could be a piece of research on behalf of adolescents with mental health problems, giving a voice to the voiceless and denouncing the injustices of the health care system. This fitted well with a number of the researcher's values: a feminist interest in advocating for silent and powerless human groups, liberal politics and a Christian concern for social justice. Indeed, support for these perspectives are found in this thesis, both in the literature review (Chapter 2) and in the discussion (Chapter 8). Furthermore, concepts have been borrowed from liberation theology (a Latin American way of doing theology which rests on the premise of a 'preferential option for the poor') to suggest possible ways of empowering young people in adolescent units.

Giving a voice to young users of the mental health services also suited the researcher's professional commitment as a lecturer in mental health nursing. Initiatives to discover more about service users' experience have been led by the users themselves (Barker and Peck 1987), the independent sector (Mental Health Foundation 1994, Beeforth et al. 1994) and by idealistic health care professionals dissatisfied with the imperfections of clinical practice. Several of them have been lecturers in nursing (Rudman 1996, Barker et al. 1999, Forrest et al 2000) frustrated by an educational system apparently impotent to bring about changes aspired to by critics. However, did this amount to taking the young people's side against the professionals?

New paradigms in qualitative design have developed which adopt a liberating agenda: feminist, ethnic and Marxist studies located within post-structuralist and post-modernist philosophical discourses. Their methods deliberately take up the experiences of particular groups of respondents with social critique in mind and distance themselves from the traditional methods of science, however adjusted (Denzin and Lincoln, 1994). Why wasn't such a paradigm adopted in this study to speak on behalf of vulnerable, distressed young people? Several reasons are invoked, both ethical and pragmatic. Experienced researchers like Lofland and Lofland (1995) or Hammersley and Atkinson (1995) have made what appears to be a valid critique of the use of social research for the purpose of advocating on behalf of particular groups. They find that the results are biased and one-sided. Instead, they support "*the broader values of enquiry, knowledge and demystification*" (Lofland and

Lofland 1995, p 174). Gomm et al (2000) make the additional point that it is impossible to evaluate partisan research because the results are linked to the ideological position of the researcher. These are important issues.

The fact that the context of health care research in Britain is a traditional one, with a tendency to positivist values, has also been taken into account. In such a context, a piece of ideological research, in rebellion against the scientific ethos, might have been difficult to use for the benefit of either the young people or the services. With this concern in mind, it was decided to go beyond the agenda of the young people, attractive as this may have been, and to take opportunities to understand the context of their experience. The observation of four clinical settings in action and interviews with three categories of informants made clear the soundness of Hammersley's (1995) view that taking sides is simplistic. The only possible position then became one of explaining what appeared to be happening and exploring how the young people's perspective compared with that of their parents and the staff. Dingwall (1992) rates an ethic of 'fair dealing' with all the respondents, privileged or underprivileged, powerful or powerless, villain or hero, as a significant index of good qualitative research. To others though, this preoccupation with neutrality makes the researcher a supporter of the political status quo (Habermas 1971, Allen 1985).

Efforts to deal fairly with all respondents, irrespective of the researcher's preferred values, is not to say that the latter's own values, roles and feelings do not play a part in the generation of the data. What is important is not to eliminate this kind of subjectivity but to monitor it and, as far as possible, bring it under control (Hammersley and Atkinson, 1995).

3.5.2 Roles

Most people have many roles in life and researchers often wear several hats. This was the case in this study (Claveirole 2004). The researcher went to investigate four adolescent mental health services. As has already been explained, she had connections with these units. She was, therefore, both an insider and an outsider to the research settings, and each position had advantages and disadvantages (Bonner and Tolhurst 2002). One insider issue

was that the researcher was known to some of the staff, but in a different role. Those who had been the researcher's students worried that their practice might be under scrutiny and said so. In response the researcher stressed the goals of the research which implied that, this time, she was the student. Melia (1987) relates how, when she first met the student nurses she was hoping to interview, their teacher, who was a colleague, had introduced her as Miss Melia. But in order to play down her teacher role in favour of her researcher role, she had taken care to dress informally and she had re-introduced herself as Kath once the teacher had left. A similar approach was used here. A friendly, informal and helpful approach on the part of the researcher seemed to help younger colleagues relax after a few days.

The researcher also knew the nurse managers of all the units with whom she was on an equal footing. Whilst this facilitated her access to the field, it might also have made it more difficult for them to let her see their units 'warts and all'. Another insider issue was the familiarity of such specialist units to the researcher: it was a useful aid to understanding but it could make it more difficult to notice and question aspects of practice which appeared obvious (Bonner and Tolhurst 2002). Monitoring these factors was the best policy since they could not be eliminated (Schwartz and Schwartz, 1955).

The adolescents quickly realised that the researcher was a nurse, albeit one from outside the unit. The way they responded to her gave an indication of what adults, nurses and outsiders meant to them. They might see her as someone who could help them, because nurses do, or as someone to whom they could say things about the unit, because she was not from the unit, or as someone not to be trusted. All these attitudes were displayed by young people at some time and contributed to the data.

The researcher spent most of her time with the young people in the first two or three weeks of each period of observation in order to experience the life of the unit from their perspective. This was to avoid giving priority to the professionals' over the young people's experience, the latter being less familiar and possibly less congenial.

Parents assumed that, being a nurse, the researcher understood how mental health care went. Some seemed to hope that what they said to the researcher would, somehow, get back to the unit staff, in spite of assurances of confidentiality. They had to be reminded that this

was not the case. They were then encouraged to think that what they had said to the researcher was worth saying to others.

Nurses doing home visits come against their own personal and professional value system. Evaluations of home decoration, family relationships, hygiene, smoking and drinking and daily routines are inevitable. One evolves a way of filtering these reactions or ignoring them as recommended by codes of professional ethics (Nursing and Midwifery Council 2002) and therapeutic guidelines (Bloch et al. 1994). The same process can operate in research, although such reactions had to be recorded in the fieldnotes.

Age and gender, sometimes called 'ascribed roles', play a part. Here the age difference had inevitable consequences. The possibility of a middle-aged researcher 'going native' with adolescent informants was limited by developmental differences. It offered a better chance of objectivity, but also a greater risk of ethnocentrism (in this case, of evaluating adolescent experiences with adult eyes). It was impossible to be an inconspicuous member of the group, which made certain locations, like bedrooms and young people's sitting rooms, out of bounds for observations (Schwartz and Schwartz, 1955).

Hammersley and Atkinson (1995) reminded researchers that a position of gender neutrality cannot be achieved in qualitative research. Gender is also treated as a significant personal trait in therapeutic settings where people's woundedness is not gender-neutral. Some adolescents have had abusive experiences with one gender more than with the other. A researcher inevitably becomes part of this reality and must learn to read the signs. Physical stature is relevant. A small adult woman is less threatening to young people still in the process of growing. Indeed, in adolescent units, large (often male) nurses sometimes feel that they have to be particularly careful not to appear overbearing.

Being French, therefore on foreign ground and speaking with a foreign accent, must have had an impact (which may not have been perceived by the researcher), on the parents in particular who had no other knowledge of her. There might have been some advantages in being a foreigner in that it could convey a status of "*acceptable incompetence*" (Lofland

and Lofland 1995, p. 57). It could mean needing a little more explanations than most people do. In this situation, it was helpful.

3.5.3 Relationships, Feelings and Emotions

To get on in the field, relationships must be established and maintained (Hammersley and Atkinson, 1995). It is a normal fact of human life that people strike relationships with each other when they come into social contact for any length of time. How can a researcher best manage the impact of developing relationships between herself and her respondents? More generally, how does she handle her own affective states, feelings and emotions - what McCall and Simmons (1969, p. 88) call "*the non-rational determinants of the observer's perceptions and interpretations*"? These subjective components contribute to the researcher's understanding of the situation and the best policy is again to monitor them by incorporating them into the data. Such monitoring requires a good standard of self knowledge and a habit of self-analysis in order to detect one's feelings, acknowledge them honestly and note what has given rise to them.

Feelings can originate from three sources and it is important to differentiate between them. Firstly, events, people or relationships in the field can trigger them off. In this case, they can be a cue to what is happening in the setting, and to how others might also feel (but perhaps not say). Personal feelings can give information about subtle and otherwise difficult to detect affective states in individuals and groups. Their potential interest can be noted in fieldnotes and checked out with respondents at suitable times. Secondly, feelings can originate in the personal life of the researcher, past or present. It is important to acknowledge such feelings and to note them too as they can lead to a distortion in the way the data is perceived and collected (Schwartz and Schwartz 1955). Thirdly, feelings can relate to the position of the researcher as researcher. Observing a setting as a known observer can lead to feelings of anxiety, isolation, loneliness, boredom and frustration. Such feelings may distort the data (Lofland and Lofland 1995, Hammersley and Atkinson 1995). Noting them, handling them and understanding them can allow the researcher to convert them into what Schwartz and Schwartz (1955) call 'partial assets', such as indicators of the

relationship of the observer with the setting. Of course the three sets of feelings analysed above are often felt concurrently in practice. It is not always easy to detect the origin of feelings, but it is important to keep up an effort of self-analysis in order to separate what rightly belongs to the researcher, from what belongs to the field.

Finally, an affective attitude based on respect for the observed and “*sympathetic identification*” with them (Schwartz and Schwartz 1955, p. 99) facilitates the collection of meaningful data because such an attitude brings greater trust and better communication. Therefore it minimises the disruption the researcher causes to the setting. Such a stable emotional state depends to a large extent on the researcher’s personality and maturity, but also on the unique interaction of these with the particular social setting. If for any reason the researcher experiences intense and fluctuating feeling states, since she cannot control her affective reactions and their effect on her observations, her only choice is to record them as part of her data. This will increase her awareness and understanding of the feelings, and will help counteract their distorting influence (Schwartz and Schwartz 1955). Lofland and Lofland (1995) warn, however, that researchers must be prepared to meet people they will not like and anticipate mixed, ambivalent and complex emotions.

3.6 Ethical Issues

A qualitative design implies closeness between researchers and respondents, which brings with it the need to protect the respondents’ right to privacy, confidentiality and honesty and to moderate the researcher’s use of status and power (Clifford 1997). In this study, specific attention had to be given to the young people because of their age: children and young people are presumed less mature than adults and therefore more vulnerable. Researchers must strike a balance between responsibility for their welfare and respect for their competence (Claveirole 2004). The young people’s status as patients of the National Health Service, and their mental state, added to their potential vulnerability.

Scientific research on and with human subjects is regulated by national and international ethical guidelines, none so much as medical research. The declaration of Helsinki was

adopted by the World Medical Association in 1964 and amended several times. It has been used as a model for other professional groups' guidelines on research (National Children's Bureau 1993, British Sociological Association 2002). It aims to protect research subjects from any form of harm the research might cause them. It stresses the importance of following rigorous scientific methods and weighing the risks and benefits of all studies. With regard to the engagement of research participants, they must be given adequate information, participate voluntarily - with the possibility of withdrawal at any time, their integrity and privacy must be protected and their consent sought, preferably in writing. Researchers working with children and young people were expected to seek parental consent until, in 1989, a section was added to state that children who were able should give their own consent as well as their parents (World Medical Association 1989).

3.6.1 Confidentiality

All research subjects are entitled to confidentiality (Clifford et al 1996, Nursing and Midwifery Council 2002). Children are entitled to confidentiality to the same extent as adults are, but if their welfare is at stake their parents or other relevant adults may need to be brought into the confidence (National Children's Bureau 1993, British Medical Association 1994, Blackie and Patrick 2001). The young people in the study were over twelve years of age.

Three information sheets were written, one for each group of respondents, in professional language for the staff, everyday language for the parents and simpler language for the young people (copies of the information sheets are available in Appendix 4). They were given out during a first meeting in each unit and each time a new young person was admitted to a unit during the study. They were always consolidated with verbal explanations. On a second visit, consent to the researcher being present in the unit was obtained. Each person approached by the researcher about a possible interview was offered another information sheet and further explanations. All were given at least twenty-four hours before consenting to be interviewed so that they could think about it and discuss it with others (Coyne 1998, Balen et al 2000). They were promised that the content of their interviews would be kept confidential from all but the researcher and that it would be

anonymised in the final report. The young people were also told, however, that should the researcher suspect them of being in danger, their confidence might have to be breached, although this would not be done without discussing it with them before hand. The kind of danger envisaged was a suicide plan or an abusive relationship, which might come to light through disclosure during an interview (Claveirole 2004).

3.6.2 Informed Consent

Adults gave consent in the usual way and signed a consent form. The Children (Scotland) Act 1995 considers children and young people under 16 to be capable of giving consent to decisions concerning them as long as they understand what is involved (Sutherland and Cleland 2001). Therefore young people gave their consent in the same way as the adults did but certain guarantees were put in place to protect them (copies of the consent forms are available in Appendix 5). Three local research ethics committees agreed to this on the basis of the Children (Scotland) Act 1995 section 15(5). The benefits and risks of the research were explained to young people in the information sheets. In order to ensure that the young people under 16 who consented to take part in the study had the capacity to understand what the research entailed, the researcher consulted the medical officer in charge of the young people's treatment and their key worker to confirm that their opinion about each young person's capacity concurred with the researcher's. It was agreed that, if in doubt, the parent's consent would also be sought but this eventuality did not arise.

3.6.3 Mental State

All the young people in the study had serious mental health difficulties; therefore their mental state was an important component of their overall mental capacity. It was agreed with the three local research ethics committees that young people who had the maturity to consent would not be excluded from the sample on grounds of impaired mental state alone but that they would not be interviewed for the duration of the impairment. This made it possible for young people who had a psychotic illness to give their views at a time when they could think clearly and when their welfare would not be endangered by an interview.

Decisions regarding the young people's mental state were made in collaboration with the medical officer and the key worker. Consent from these young people was sought in the way described above, but only when their mental state did not show sign of delusion or overwhelming distress. No young person being treated under the Mental Health (Scotland) Act 1984 was interviewed, however, because their mental capacity would have been difficult to determine and their involuntary treatment status would have made voluntary participation in health care research impossible to ensure (Blackie and Patrick 2001).

3.6.4 Causing Distress

Interviews can be intrusive when they explore personal stories because their content may stir up distressing feelings (King 1996, Laws 1998). Therefore provision must be made for support to be available should this happen (National Children's Bureau 1993, British Sociological Association 2002). However, since this study was taking place in mental health units, the young people had on-site support in the event of them becoming distressed. They were also assured, both in writing through the information sheet and verbally at the time of the interview, that they could withdraw from the study at any stage without jeopardising their treatment. Two young people were asked if they wanted to stop during their interview because of the personal and distressing nature of the topic they were addressing but both chose to finish the interview.

3.6.5 Use of Power

Disparities of power and status between researcher and participants is characteristic of sociological research, which obliges researchers to be scrupulously aware of the many ways in which they can abuse their position (British Sociological Association 2002). When the research takes place with children, the inherent power imbalance between children and adults requires careful monitoring (Balen et al 2000). A researcher's previous experience with the group on which the research focuses can help establish relationships of trust and is an important dimension of success. Knowledge of children's world, language and the differences brought about by development and gender will significantly affect both the

quality of the data and the ethical integrity of the relationship with the participants (Coyne 1998, Greig and Taylor 1999). In the study reported here, the researcher's experience as a nurse in similar settings to those studied gave her a knowledge of young people whose mental health is seriously compromised. It allowed her to understand their mental state and to find empathic, non-patronising ways of communicating with them (Balen et al. 2000).

The ethical standards of this study had to be monitored by the National Health Service (NHS) and its representatives because of the young people's status as patients of NHS Trusts. How this was done and how access to the sites was gained is the object of the next section.

3.7 Gaining Ethical Approval and Negotiating Access

3.7.1 Ethical Approval

Research on NHS patients and employees necessitates approval from a NHS research ethics committee designated to cover the health board where the research is planned. Since 2003, a new research governance framework for health care research has put new procedures in place but this study started in 1998 and its applications for ethical approval took place under the previous regime.

The study was based on the collection of data from four adolescent mental health units, two of which were in the same health board; therefore three applications to three local research ethics committees were necessary. Each approval process took approximately three months to complete. A long and detailed application form, the questions of which were more suited to experimental than qualitative research, was filled and sent to the secretary of the committee in advance of a meeting. Issues of interest to the committee were:

- Details of the scientific rationale and research design
- Details of how the respondents' right to confidentiality, anonymity, informed consent, and protection from harm would be ensured
- Copies of information sheets and consent forms

- The name of the director of study and that of an independent university representative
- The existence and origin of financial support for the research
- Copies of the university's and the researcher's insurance policy

Each region made specific demands: one asked for the information sheet and the consent form to bear the name of the NHS Trust in which the data would be collected, not that of the university. One asked for an independent person to sign the consent form in addition to the respondent and the researcher, and two asked for the young people's general practitioners to be notified that one of their patients was taking part in the study. All three committees accepted to let the young people give their own consent provided their mental capacity to do so was discussed with the health care team. The decision of the committee was communicated to the researcher after the meeting (copies of the letters of approval from the three committees are in Appendix 6). Negotiation for access to the unit took place in parallel.

3.7.2 Access

Application for access was started at the same time as application for ethical approval. It started with a telephone call to the nurse manager to explain the researcher's interest. A formal letter followed, addressed to the person in charge of the service as recommended by the nurse manager, usually a consultant psychiatrist working in the unit. A summary of the research proposal and a suggestion of suitable dates accompanied the letter. One head of service responded that being observed would make the junior staff anxious and asked the researcher to visit the unit and explain her study at a staff meeting before granting access and negotiating dates for the data collection. The other services accepted to take part in the study before an information meeting was held with the unit staff. At these meetings it was clear that the staff had been consulted about the researcher's request. Consent from the young people to be observed and interviewed could not be sought in advance because they might have been discharged before the start of the study. Until the young people who would be available during the data collection had been admitted, there was always a possibility

that they might refuse to take part in the research, even though access had been granted by the staff. Copies of access approval letters from NHS Trusts are in Appendix 7.

3.8 Limitations of the Research

Several of the limitations of the study, some of which were inherent to the design and methods, have been discussed earlier in this chapter. Two further limitations must be mentioned. The aim and four research questions with which the study started were ambitious. The investigation of three groups of stakeholders in four social settings by means of 55 interviews, during 21 weeks of observation yielded a large amount of data (nearly 400,000 words). Its organisation and analysis took a longer time than was desirable. This research was undertaken part-time, with only three months of full-time study, although during the data collection lecturing tasks were kept to a minimum. Had more time been available, the data might have been more thoroughly explored and more use made of the potential for comparison between data from different groups of stakeholders and different sites. When the study started, its topic – user participation applied to young people in mental health care – was new. It has now become accepted as important in policy and practice, even though its application remains challenging. The findings offer new and relevant knowledge however, because of the use the study makes of two academic fields and the light pastoral theology helps to shed on health care practice. The interface between several stakeholders' views in the context of four social settings also offers new insights. Space has limited the reporting of the findings and in chapter 7, which relates the cultures of the units, evidence from the data has had to be summarised and referenced rather than directly quoted.

Another limitation lies in the risk that the researcher's existing knowledge of the settings and staff would influence the study negatively by introducing a biased understanding of some of the respondents and units. Efforts have been made to declare the researcher's possible conflicts of interest. In reality however, knowledge of the field seems to have been mainly an asset: it facilitated access and allowed the researcher to connect quickly with the respondents on the basis of existing positive feelings for the staff and continuing

satisfaction in working with vulnerable young people. While the parents were strangers, their stories were moving and a current of mutual sympathy was almost always struck. As a result, the danger of a biased appreciation of the perspective of one group of respondents did not appear to materialise. There is no doubt however that the same study carried out by a stranger to the field would have been different in both positive and negative ways.

CONCLUSION

This chapter has focused on the research design and methods of the study. Epistemological issues relevant to the context of health care research have been summarised and the ethnographic methods chosen to carry out this investigation has been described and justified. The design has been explained and details have been given of the data collection and analytic methods to allow other researchers to assess the trustworthiness of the findings. Finally, ethical issues have been discussed, including the way they are monitored in the case of research on NHS service users and employees. The next four chapters report the findings.

CHAPTER 4: YOUNG PEOPLE'S PERSPECTIVE

INTRODUCTION

The first objective of the study (see Chapter 3, p. 70) was to explore a sample of young people's experience of their treatment in four adolescent mental health units. This objective was broken down into two main questions, one about the young people's perspective regarding their treatment, the other about their perspective regarding their participation in treatment. In this chapter, findings culled from interviews with all the young people in the sample (n = 18) present their answers to these questions. In the first section, the main relevant facts about the sample of young people (age, gender, status as inpatient or day-patient and diagnosis) are laid out in tabular form. In the second, the young people's views regarding the helpfulness or otherwise of particular treatment components are explored. In the third section, their views about their participation in treatment planning and decision-making are presented. Finally unit-specific aspects of the findings are highlighted.

Anonymity and the Use of Pseudonyms

Throughout this and the following three chapters, names have been changed and many details which might have identified the units have been disguised to preserve the anonymity of the research participants.

Most of the staff respondents were nurses. They are called by their first (fictitious) names. The psychiatrists are 'Dr X' to allow the reader to make a rapid distinction between the disciplines. In the units, these psychiatrists would have been called by their first names.

The parents are named after the initial of their child's first name. Helen's mother, for instance, was Mrs H. When two first names started with the same letter, for the second interviewee's parent the second letter of their child's name was added (Dean was interviewed before Diane. His mother was Mrs D. and Diane's mother was Mrs Di.).

1. BASE DATA

Eighteen young people who had known the researcher throughout her period of observation in their unit were interviewed (inclusion and exclusion criteria are discussed in Chapter 3, p. 73-74). All the young people were of white British origin (as were all the units' patients at the time of the study). Fourteen lived in urban areas, thirteen were still at school, four were unemployed and one in work. Further detail about the age, gender and diagnosis of the sample is given below.

Age (Table 4.1): The mean age of the sample was sixteen. Units in Scotland at the time of the study drew varied age boundaries around adolescence. The lowest age was usually fourteen, but younger adolescents were occasionally admitted if there was no children's unit nearby, if the young person was post-pubertal or if the mental health problem was typical of adolescence, such as anorexia nervosa. The upper age limit was also blurred: for instance Arisaig did not admit young people whose school days were over. For some young people this meant sixteen, for others eighteen. Knoydart, on the other hand, went up to twenty. Fisherfield upper limit was twenty-two in order to accommodate young people whose first psychotic episode needed prolonged treatment.

	<i>Sample YP</i>	<i>12 – 13</i>	<i>14 - 16</i>	<i>17 - 21</i>
<i>Knoydart</i>	5	0	4	1
<i>Arisaig</i>	5	1	3	1
<i>Rannoch</i>	5	1	3	1
<i>Fisherfield</i>	3	0	0	3
TOTAL	18	2	10	6

Table 4.1: Age Range of Young People in the Sample

Gender (Tables 4.2 and 4.4): children with mental health problems include more boys than girls (see Chapter 2, section 2.6). The proportions are reversed at puberty and remain so during adulthood. This was reflected in the units' populations at the time of the study (see Chapter 7) and demonstrated in the sample which comprised more girls than boys by a ratio of two to one. Exceptions to this statistic are young people with a schizophrenia of adolescent onset, the majority of whom are boys. Three out of the six boys in the sample had a diagnosis of psychosis or schizophrenia (see Table 4.4).

Treatment status (Table 4.2): Fisherfield and Knoydart offered day-patient and Arisaig inpatient care only. Rannoch offered both. Inpatient status was required when young people's problems put their lives at risk through suicide or self-damage. The mental health problems of the inpatients in the sample were acute, whether they consisted of depression with self-harming or suicidal ideas, psychosis with active delusions and hallucinations or anorexia nervosa. The day-patients' problems were not necessarily less serious – although some were – but they were more manageable at that particular stage.

	<i>Female</i>	<i>Male</i>	<i>Day-Patient</i>	<i>Inpatient</i>
<i>Knoydart</i>	4	1	5	0
<i>Arisaig</i>	4	1	0	5
<i>Rannoch</i>	2	3	3	2
<i>Fisherfield</i>	2	1	3	0
TOTAL	12	6	11	7

Table 4.2: Gender and Treatment Status of Young People in the Sample

Diagnostic Categories (Table 4.3): the young people's mental health problems were usually many, complex and enduring but it was possible to identify a primary diagnosis which corresponded to the most disruptive symptoms or the most accessible to treatment. Depression was often accompanied by anxiety. Several young people used self-harm: two of them had a psychotic illness, two were depressed, one was highly anxious and the other was in the process of being diagnosed as having a borderline personality disorder (BPD). Serious sexual abuse had come to light for a number of young people but they had been referred because they were depressed, suicidal or psychotic, not because of the abuse.

	<i>Psychosis (+ Psychotic Depression)</i>	<i>Non- psychotic Depression</i>	<i>Anorexia Nervosa</i>	<i>Anxiety</i>	<i>Borderline Personality Disorder</i>
<i>Knoydart</i>	0	2	1	2	0
<i>Arisaig</i>	2	0	2	0	1
<i>Rannoch</i>	2	2	0	1	0
<i>Fisherfield</i>	3	0	0	0	0
TOTAL	7	4	3	3	1

Table 4.3: Range of Primary Diagnoses of Young People in the Sample

	<i>Female</i>	<i>Male</i>	<i>Day-Patient</i>	<i>Inpatient</i>
<i>Psychosis</i>	4	3	4	3
<i>Depression</i>	3	1	3	1
<i>Anorexia</i>	2	1	1	2
<i>Anxiety</i>	2	1	3	0
<i>BPD</i>	1	0	0	1
TOTAL	12	6	11	7

Table 4.4: Range of Primary Diagnoses According to Gender and Treatment Status

Overall the sample was fairly typical of patient populations in young people's units in Scotland at the time of the study (Green and Jacobs 1998, O'Herlihy et al. 2001).

2. YOUNG PEOPLE'S VIEWS REGARDING THEIR TREATMENT

In their interviews young people discussed their experience of treatment, its helpful, unhelpful and mixed elements. Some treatments, although unpleasant, were recognised to be helpful. This section gives details of these views regarding the six most frequently mentioned treatment ingredients. Table 4.5 indicates the quantitative balance of positive, negative and mixed or ambivalent comments the young people made about each approach. All the young people's interviews were then scrutinised for variations in the categories. These variations are identified in the separate sub-sections that follow. Quotations taken

from the young people's interviews aim to illustrate each variation encountered but do not represent the proportion of young people who spoke on behalf of each variation.

	<i>Valued</i>	<i>Mixed</i>	<i>Not Valued</i>
<i>1 - Being with other people / talking to YP & staff informally</i>	14	3	1
<i>2 - Admission to a specialist unit</i>	8	3	2
<i>3 - Formal one-to-one therapy</i>	10	0	0
<i>4 - Meetings and groups</i>	6	3	1
<i>5 - Medication</i>	3	5	2
<i>6 - Nursing observation</i>	0	3	3
<i>Miscellaneous</i>	1 (food)	1 (ECT)	1 (Section MHA)

Table 4.5: Young People's Views about Six Treatment Approaches

2.1 Being with Other People

Valued: being with others, either young people or staff, being able to speak to them informally about the difficulties of their current lives, being listened to, understood and supported was the dimension of being in a mental health units young people found the most helpful.

“When I walked in the unit everyone seemed just like me and everyone was having the same problems. And the staff understood more and they were all experienced in psychotic illnesses and it just seemed like more of a natural place to be because people there understood” (Int. 3C, p. 13).

Some particularly mentioned the nurses' presence and support and for a few, the kindness of the staff was a surprise:

“For about a month or something I was getting sedated practically every day and I don't know, they were really nice to me, I was just, like, surprised that they were, like, listening to me, talking to me and everything, it just felt really nice, I think that can help” (Int. 2A, p 4).

Others stressed the companionship and understanding of other young people who seemed able to convey a great deal of care for each other:

“Sometimes I just wanted to stay in my room and they would just tug me out and say ‘come and watch a video’ and things like that... It was good because I felt bad by myself and eventually I would feel a lot better just ‘cause they’d made an effort to include me and that...” (Int. 1B, p 2).

The young people could give each other vital help, as when Brid encouraged Mary to disclose her history of sexual abuse to a nurse:

“Brid had kind of guessed too, ‘cause, like, me and Brid had talked about things; Like Brid had persuaded me to tell Madge” (Int. 1B, p 6).

Mixed: the company of the other young people sometimes felt depressing because of the problems they had:

“A lot of the time it is a bit depressing because you see everyone with their difficulties and everything, that can drag you down a little bit” (Int. 2A, p 6).

Each admission and discharge meant loss and change:

“It is hard when other patients leave because you have got used to them and there are new patients coming”... “And you’ve got to try to get used to new strangers, folk you’ve never met” (Int. 7A, p. 6).

Helen found the company of other young people helpful but she was suspicious of the staff. She would have liked more time without the staff whom she experienced as an intrusive, controlling, policing presence:

“Sometimes they just like to keep an eye on you to see what you are getting up to and that you are not getting into any trouble. There’s no privacy” (Int. 7A, p 8).

Not valued: Rosie was the only young person who did not value the presence of either young people or staff. Her home was a long distance from the unit, she missed her family and she felt intruded upon:

"It feels like there are people surrounding me all the time. It just feels like I've got no space of my own" (Int. 7B p 6).

Overall, comments about the benefits of being with people who knew about mental health problems and cared far outweighed negative comments. Most young people valued the presence of the staff whom they found kind and helpful, although two interviews highlighted suspicion of the staff's intentions and stressed their intrusiveness. The presence of other young people with mental health problems was appreciated by all but one young person who was too homesick to care.

2.2 Admission to a Specialist Unit

In their interviews, young people reflected upon their experience of receiving treatment in specialist day or inpatient services.

Valued: young people often had a negative anticipation of what the unit, the staff and the young people would be like. Several young people were surprised by the appearance of **the unit** and the way it worked:

"I thought it was just going to be like a ward in a hospital, like in a general hospital, I didn't think it would be the way it is with a lounge and a kitchen and a TV and things like that" (Int. 1B, p 3).

The staff:

"I imagined it to feel clinical with white uniforms and all that. It was much better. The nurses were all nice. I thought they would be horrible [laughter]" (Int. 16A, p 3).

The young people:

"I was very reluctant to come to any kind of inpatient day programme style thing because I just thought, 'oh, it will just be a lot of wee psycho people running around screaming and shouting and things', and I thought, 'Nah!'" (Int. 3C, p 7).

Often regular attendance at a day-unit was not a chore:

"It is quite easy to be here. I mean it isn't something you think, 'oh God, I don't want to go'... Something you would want to skive like school" (Int. 1, p. 5).

The unit felt safe, respectful of young people's feelings and there was a sense of purpose in going there:

"When I come up here I know that I am going somewhere that I'll be safe in... I think that you appreciate that others, you know, when they're speaking and that, nobody should make fun of them" (Int. 3, p. 13). "I suppose by coming up here I am learning to like myself better" (Int. 3, p. 17).

Mixed: some young people knew they did not have a choice regarding their admission.

Some gave in under the pressure applied by parents and staff:

"I never fought it off too much. I was fighting the very first few days I was here I was fighting, trying to escape... But then I thought there is no point because they'll just bring me back. So there is no point in trying...It's nice but I still want to get away" (Int. 1A, p 4).

Others came in under a section of the Mental Health (Scotland) Act 1984. The presence of other young people helped Diane who had been sectioned resign herself to being in the unit:

"At first it was really bad because I was trying to run away all the time and, er... for a month, I tried to run away practically every day, but, like, after that it got a lot better. After, like, I got to know everybody in here, all the other patients and all that and I got some good friends, I think" (Int. 2A, p 2).

Not valued: dislike of a unit and its treatment could also inspire a young person to cooperate with treatment in order to be discharged:

"I want to be with my family and friends and have a more normal life than sitting in a hospital to get told when to sit down and what to eat and how long I can go out for. Sometimes it's not much of a life and it's not a very nice place to be when other people are ill, you know" ... (Int. 7A, p 5).

Inpatient unit experience: being an inpatient seven days a week for months was more difficult than attending a day-unit three, four or five times a week:

"Sometimes I think being an inpatient is just all too much because you're here everyday. You're watched all the time...I'd prefer something like being here four days a week" (Int. 1A, p. 5).

In inpatient units, young people focused on activities as a way of relieving boredom. Jill enjoyed being in the unit: *"It is different, it's really different, quite good"*. She particularly enjoyed outings organised by the staff:

"I like going out of the unit and I like it when some members of staff come, because it's more fun" (Int. 16A, p 9).

But Jill found the evenings dull and difficult because people did not spend them together and the nurses stayed in the office. Then she would start brooding and thinking about her problems. Weekends were also long and boring: *"weekends are terrible" (p 10)*. To compensate, Jill's grandmother would visit her twice a day and Jill might phone her four or five times over and above that.

Helen also found that there was not enough to do in the unit. The weekends were particularly bad; she suggested the young people might be allowed to go home more at the weekends:

"I mean quite a lot of people are away at the weekend and you are left sitting yourself and it's dead quiet and there is nothing to do and you feel

quite depressed”... “If you are not well enough to go home, well maybe go out with staff, doing stuff...” (Int. 7A, p 10).

For some young people, being an inpatient was tolerable for a short time only:

“At first I thought it was ok. But now I wish I could go home and just go back to just seeing a psychiatrist twice a week, just go back to that, because I hate having to stay in here all the time” (Int. 7B, p 6).

Although the balance of comments about admission to a specialist unit was more positive than negative, it was clear that being a day-patient was easier than being an inpatient. Kindness, respect and mutual support went a long way towards making an unwelcome experience bearable but boredom in the evening and at weekends represented a big problem. Adults had a part to play in organising company and activities for young people stuck in psychiatric services at unsociable times. Being admitted a long distance from home, and therefore not having access to family members on a daily basis, was often painful for young people aged between fourteen and eighteen who had never lived away from home before. Long admissions, lasting several months and more, compounded the problem.

2.3 One-to-One Therapy

This section refers to scheduled appointments made for young people to receive some form of individual therapy from a member of staff. The practice varied from unit to unit. Rannoch offered it systematically to all young people from their key-workers and called it counselling. So did Fisherfield, where the organisation of it was informal and meetings were initiated by either staff or young people. In Arisaig, one-to-one therapy was only organised when a young person was thought to need a particular form of one-to-one intervention like psychotherapy. In Knoydart, the primary treatment intervention was group therapy and one-to-one appointments were not the norm, although young people and their key-workers met on an ad hoc basis when necessary.

In their interviews, a number of young people spoke highly of one-to-one therapy because it was supportive, easier than group work and they expected it to help them understand the

root of their problems. Some of these young people were receiving a form of one-to-one therapy, others were not but would have liked to. One young person did not appear to value the regular appointments she had with her key-worker and expressed a wish for one-to-one therapy. No young person was dismissive of this approach.

Young people who had experience of one-to-one therapy: Sarah had therapeutic conversations with her key-worker, her psychiatrist and a psychologist. She valued all highly and explained what she found therapeutic in these encounters:

“You need someone you can relate to easily, and that takes a bit of time, and you need support and encouragement. But you also need to look quite hard at where the problem is coming from” (Int. 1C, p. 5).

Having appointments with more than one person was better:

“I think it’s good if you have a lot of people to talk to because if you don’t feel comfortable about speaking to one person about something you can speak to somebody else. Which means there’s usually always somebody who you can talk to if you need to” (Int. 2A, p 11).

The gender of the therapist could be significant:

*“I talk to Liam ‘cause he’s a male, he’s a male nurse, he’s my male nurse... It’s the male one that I get on with more, because he is a male.
Res.: how do you like that? Is it helpful to talk to Liam?
Alan: yeah. I tell him everything that I do” (Int. 4B, p 9).*

Young people who would have liked one-to-one therapy: Mairi was in group therapy and found it hard to talk in front of other people. She would have liked one-to-one therapy to help her understand the root of her problems and because she thought that speaking to one person first would make it easier to express herself in the groups. She meant formal scheduled appointments, not ad hoc meetings with key-workers. In any case, she felt she couldn’t speak to the nurses:

“If you go to talk to one of the nurses you can’t be completely sure they’re not going to tell other people like parents, other staff. They don’t promise that they won’t so that’s fair, but it makes it difficult to trust them” (Int. 1, p. 3).

Approaching a key-worker to speak to them was felt to be difficult. Fran thought the nurses were good at noticing how she might be feeling and encouraging her to discuss it. She would not have been able to approach a nurse, even her key-worker, to confide in, so it was important that the nurses took the initiative. This explains why young people preferred appointments to be set up in advance.

Rosie was at Rannoch and therefore received regular counselling from her key-worker, Christine, who explained how this worked in her own interview:

“I do individual work with her [Rosie] and to start with it was extremely difficult because she just wasn’t able to say what was going on inside her... I would try to see her twice a week. Usually we allocate an hour” (Int. 11B, p 6).

In her interview, Rosie complained that she was not getting one-to-one therapy, which she felt would have helped her. When asked further about that, it became clear that Rosie disregarded the meetings she had with Christine. To her, one-to-one therapy seemed to mean seeing a doctor, although she was unclear about it:

“I would rather talk to a doctor... talking to a doctor they can... it is doctors that can prescribe medication and... I don’t know...” (Int. 7B, p 8).

Confusion regarding who was qualified to give individual therapy, and a tendency to discount time spent with nurses, was not limited to Rosie. Amanda, who had had experience of formal out-patient appointments with a psychiatrist before her admission, missed having a time and a place set aside for her in advance and appeared to think it was the characteristic of doctors to deliver this kind of service:

“A doctor has more time and you’re on your own with them” (Int. 2, p 7).

In summary, one-to-one therapy seemed to be a valued intervention by those who received it and a desirable one by some who didn't. The young people's comments suggested that they hoped to understand what was causing them problems in their lives and that it was easier to explore this with someone special, with whom they developed a trusting, supportive relationship and met at a time and place carefully set aside. There seemed to be a tendency to devalue time spent with nurses and to expect doctors to be automatically more competent.

2.4 Meetings and Groups

This category includes a variety of groups which took place across the units: community meetings, group psychotherapy, art therapy, action therapy, anxiety management, activity groups and discussion groups were the most common.

Valued: some young people found the groups helpful and enjoyable:

"The groups are really good. I think they're really helpful. They bring us all together and working as a team. Even if you're in a bad mood you end up laughing about it." (Int. 1B, p. 7).

Community meetings were often selected for positive comments:

"They're all right. I used to be shy to speak but now, you ken, I bring up what I think and that" (Int. 6B, p. 6).

Being with ten other people in a room was a new and scary experience at first, but help was available and you got used to it. Fran found all the groups helpful in different ways but particularly the art group:

"That's when you've got to draw, like, instead of writing. And I mean that's quite good. Because they'll tell you to draw when you're angry and then, you ken, you can just let your feelings out on the paper and it's quite good" (Int. 3, p. 8).

Unlike Fran, Michael did not like groups that used drawing or games as a means of communicating feelings. But he valued talking groups like the community meeting where people had to speak about their feelings:

“Just listening to the other people’s problems, just... gives you a chance to know how other people are feeling and they ask you how you’re feeling” (Int. 12, p. 8).

Mixed: Mairi was not convinced all groups were helpful and she disapproved of them being the main therapeutic option:

“Sometimes I think groups can’t really help you with your personal issues. I don’t know. Some groups just don’t help... I don’t see how they can help... Either you work through your personal issues through the groups, or you don’t work on them at all: you don’t concentrate on the individual” (Int. 1, p. 4).

She did not include the community meetings in this criticism, even though she found sharing her feelings in them difficult:

“In the groups [community meetings] you have to say how you feel. That’s hard. But it’s good, it helps. It’s just hard. So if you’re not feeling good, you don’t want to come” (Int. 1, p. 5).

Not valued: Alan found the groups boring:

“I don’t like the groups. I don’t know, it’s just pointless... Every day, it’s always the same thing. Aye: ‘place is a mess’, ‘place is a mess’, ‘place is a mess’... And two a day: there’s two a day, ken! It breaks up the tele, ken. You try and watch a film and they break it up with all these stupid meetings” (Int. 4B, p. 7).

Wanting groups that were not there: some young people were in units where there was little group work, or where some particular types of groups did not take place. This was the case of Sarah and Helen.

At Fisherfield there was no psychotherapy group because such groups were considered too stressful for people who had had a psychotic episode. But Sarah would have liked one:

"I think it would be quite good to hear that other people go through the same sort of thing as me" (Int. 1C, p. 6).

Helen was not part of a group yet she thought a group with only young people in it might be helpful:

"to see how other people feel, so that you can understand them a bit better, know how to react to them, not upset them". [These groups should be without staff because] "It's easier when you know they're not writing it all down...When staff are about they don't like to talk" (Int. 7A, p. 8).

Groups, when available, were on the whole valued, although specific ones were not. Community meetings were the staple therapeutic fare of both Knoydart and Rannoch. The nurses who ran them were experienced and skilled (see Chapter 7). Even young people otherwise critical of group therapy seemed to understand the point of community meetings and value them (except Alan who preferred to watch television). It was interesting to hear two young people suggest a form of group therapy of which they had no experience.

2.5 Medication

Medication here refers to any type of medication the young people mentioned as having been prescribed to them for their mental health problems. Several young people interviewed referred to it.

Valued: a young woman who had been on several anti-depressants thought the current one helped her, although the depression was still there:

"I am on the maximum dose.

Res.: do you think it helps?

Carol: It keeps my mood a bit up. But I still don't think I'm right" (Int. 5, p 3).

Several young people were aware that their anti-psychotic medication dealt with the worst of their psychotic symptoms...

"Sometimes they [the voices] are quiet but at other time they're extra loud, then I have to ask the staff for extra medicine (Int. 16A, p 5).

...although the side-effects were not welcome:

"If I take it, it makes me sleepy, and if I don't take it, I am quite ill" (Int. 16A, p. 6).

Mixed: some young people had responded badly to some anti-psychotic drugs. Consequently they held ambivalent views about them. Sinead had put on weight with a traditional anti-psychotic and had not been able to shed it since. She was sixteen and could not wear fashionable clothes because of her large size. She had not been oversized before taking that medication. Furthermore, it had had no lasting therapeutic effect. She was now on a new medication which helped her and the side-effects of which (dry mouth, sweating and stiff joints) were manageable.

Diane also had bad memories and it was not clear whether her current prescription was helpful or not:

"Res.: does it help?

"I'm not really sure. Some of the staff said they thought it did but... I am supposed to come off it now or something, I think, because they don't know if it's helping. That's what I got told yesterday, but, er... I used to be on a different medication when I first came in, and one of them was really nice and made me feel really calm and there is one I hated – Droperidol or something" (Int. 2A, p 11).

Isaac did not like the medication he had been prescribed, so he had weaned himself off it:

"The last thing I was on er... made me feel worse so I just stopped it. I just came off it gradually" (Int. 2C, p. 8).

Not valued: Mairi was still angry that the first approach to her depression in the out-patient department had been medication:

"Being given drugs at the beginning and nothing else for three weeks, that didn't really help. I don't think it should have happened like that.

Res.: what would you have liked?

Mairi: er... somebody to try and understand what the problem was, where it was coming from" (Int. 1, p. 4).

Medication was not liked by any of the young people who took it but several of them thought they were better with it, at least some of the time. Occasionally, negative side-effects outweighed the therapeutic benefits. A number of young people had had bad experiences with some medications. It was no replacement for a therapeutic relationship and some form of counselling.

2.6 Nursing Observation

Nursing Observation of people at risk is assumed to be taking place in all mental health services. There are three levels of observation, the most intensive being called 'special observation' (for more information refer to the literature review p. 53). It is the level referred to here. Some young people's comments on special observation reflected their ambivalence about this type of help. It is worth noting that most young people for whom special observations were prescribed accepted them, however grudgingly, so that the Mental Health Act was not invoked.

Mixed: Mary, who made determined attempts to harm, or 'punish' herself as she put it, experienced it as both frustrating and supportive:

"It's just kind of irritating if you want to talk to a friend or something, or sometime you want to be by yourself and cry and you can't do that. You just can't be by yourself and have time to think for yourself. In fact sometimes it's ok, if you're scared, or you want to do something stupid, then... At the moment I have someone next to my bed every night. So that's kind of annoying as well. It's especially annoying if you really feel that you want to cut yourself and you never get a chance" (Int. 1B, p. 10).

Young people who were anorexic and therefore did not want to eat normal quantities of food were on special observation, at least during and after meals, and sometimes

throughout the day. This was never welcome although Michael could see retrospectively that he would not have eaten normally without being supervised. Sometimes, being observed had an unplanned effect: the young people turned it into a game which they had to win:

“The more they pushed, the more I wanted to defeat them. I wanted to lose more weight” (Int. 12, p. 4).

Only special observation together with bed-rest and “*somebody on your back all the time*” (Int. 12, p. 7) helped, although it didn’t feel helpful at the time.

Not valued: Kate was on special observation for a short time after her admission because she was making herself sick and losing further weight:

“It’s horrible because somebody is always watching you, there’s no privacy (Int. 5A, p. 5).

This stimulated her to try harder and she managed to keep her food down. As a result, the nurses trusted her more and she began to take more responsibility for her food intake. Kate thought special observation was a necessary evil: had she not been supervised, she wasn’t sure she would have been able to stop vomiting. When on special observation, Kate preferred to be ignored by the nurse rather than have conversation forced on her.

For Helen, losing control over her eating was an unpleasant experience so she started to eat in order to be discharged although, privately, she did not agree that she had an eating disorder:

“I had no control over my body, so I decided to get a wee bit of control back and started eating” ... “It’s what you have to do to get out” (Int. 7A, p. 5).

Some young people found special observation hard to bear:

“You can’t ever be on your own. If you go and sit in your room for a little while, there’s all these people knocking on the door, coming in. I don’t like that at all” (Int. 7B, p. 6).

For some, to have a nurse shadowing you in front of other young people and visitors was an embarrassment:

“It’s horrible. It’s like you should have no privacy and er...I just stayed in the TV room most of the time. It’s embarrassing, like, if you go up to your room, you have a member of staff outside the door. And it’s awful if you get a visitor and you’re on [special observation], because they hear every word you say” ... (Int. 2A, p. 10).

Special observation was never popular although it was occasionally perceived as support or at least as a necessary evil. Occasionally it appeared to spur a young person to pretend they were better than they were, or to conform superficially to treatment requirements in order to get the staff off their backs.

2.7 Miscellaneous

This section focuses on three components of treatment, each mentioned by a young person. Two were selected because they are well-known interventions (ECT and detainment under the Mental Health Act), and the other because it highlights a less common but nonetheless real social care role NHS services sometimes play in people’s lives.

2.7.1 ECT

Rosie was the only person in the sample whose treatment had included ECT. She was receiving ECT because, in the opinion of the treatment team, she had responded neither to a variety of anti-depressants nor to counselling.

“Res.: What has it been like to have ECT?”

Rosie: Well I don't mind. It has been helping. The only one thing I don't like about it is how confused I am afterwards, I really hate that so much.

Res.: Confused...?

Rosie: Yes, when I try to remember things that happened earlier on, I just can't remember, it's horrible.

Res.: Does it come back?

Rosie: It does after a while... Some things...

Res.: Do some things not come back?

Rosie: Yeah” (Int. 7B, p. 7).

2.7.2 Detainment under a section of the Mental Health (Scotland) Act (1984)

None of the young people interviewed were in this category and only one had experienced it recently. It had left her with an overwhelming sense of powerlessness:

“It was horrible. It's like it makes the staff think they own you. They can restrain you, they can stop you using the phone, like, give you medication against your will. It's horrible. I didn't like it at all”... “I knew I could appeal and everything, but I just thought, well, like, they would probably agree with the staff, so I didn't” (Int. 2A, p. 9).

2.7.3 Eating and Washing

Alan was a young man who had lived alone since the age of fourteen because of family breakdown. His education had been cut short and he spent what little money he had on alcohol and drugs. He liked his flat where he was free to do what he wanted but he missed company and other aspects of a normal teenage life. When interviewed, he was nearly eighteen and had a diagnosis of schizophrenia. A major role of the unit, as he saw it, was to provide him with basic elements of health and social care (including soap):

“Yes, that was helpful [being admitted], getting fed, getting healthy and feeling healthy ‘cause taking medication was making my skin all nice and my eyes and my teeth... I’ve been cleaning my teeth twice a day. At home I wasn’t taking any soap” (Int. 4B, p. 9).

Overall the sample of young people interviewed showed a preference for treatment methods mediated by people: staff and young people’s company and understanding, the support provided by informal services where safety and respect were the norm, interventions based on relationships, like individual and group therapy. A number of young people also received more intrusive and controlling interventions, like medication, special nursing observation, seven-day inpatient care, ECT and legal detainment under the Mental Health Act. They found these more difficult to tolerate, or even to see as helpful, although some did mainly with hindsight. One or two young people experienced them with powerlessness and resentment.

3. YOUNG PEOPLE’S VIEWS REGARDING THEIR PARTICIPATION

The young people were asked if they contributed to decisions regarding their treatment and regarding day-to-day life in the unit. In this section, their responses to these questions are analysed in two corresponding sub-sections, followed by a summary of how their views applied to each unit.

The numbers of young people who answered positively, negatively and ambivalently to each question are displayed in Table 4.6. They demonstrate a strong contrast between participation in decisions regarding treatment, to which fewer young people felt they contributed, and participation in decisions regarding everyday living, in which the majority of young people felt they had a say. Nuances and contradictions in the answers were explored and are detailed in each relevant sub-section.

Table 4.7 shows young people’s views of their involvement in each unit. It demonstrates that the units were better at involving young people in decisions regarding day-to-day living than regarding treatment. It also shows that some units were better at involving young people than others. The units in Table 4.7 are presented in order of ascending young people involvement. A detailed analysis of these results can be found in section 4.

	<i>Yes</i>	<i>Mixed</i>	<i>No</i>
<i>Decisions –re Treatment</i>	8	3	7
<i>Decisions –re Day-to-day Living</i>	12	5	1

Table 4.6: Young People’s Views of their Participation in Decisions

<i>Young People Involvement</i>	<i>In Treatment</i>			<i>In Day-to-Day Living</i>		
	<i>Yes</i>	<i>Mixed</i>	<i>No</i>	<i>Yes</i>	<i>Mixed</i>	<i>No</i>
<i>Arisaig</i>	1	1	3	0	5	0
<i>Knoydart</i>	1	0	4	5	0	0
<i>Rannoch</i>	3	2	0	4	0	1
<i>Fisherfield</i>	3	0	0	3	0	0
TOTAL	8	3	7	12	5	1

Table 4.7: Young People’s Views of their Participation by Individual Units

3.1 Involvement in Decisions about Treatment

3.1.1 Clear Statements of Participation

Some young people felt that they contributed to decisions and gave a clear, unambiguous answer:

“They always ask you if you’re happy with things and if you’re no, ken, it’s really up to you... You get a lot of responsibility, ken. They make the choices up to you. It’s good because you don’t feel like you’re pushed into anything (Int. 6B, p. 7).

“Meeting the doctors to get your say across... about how you feel about your treatment and how you feel about your problems and all that: you actually feel that you’re being listened to by somebody”.

“Res.: Do they decide your treatment or do you help them decide about your treatment?”

Jill: I help them decide

Res.: They listen to you?

Jill: Yes they do” (Int. 7A, p. 7).

The two excerpts above came from interviews with young people from different units. One was a 12-year old day-patient who struggled with very high levels of anxiety, the other was a 16-year old inpatient recovering from a psychotic episode. At least one such simple and clear message was found in each unit. Most young people, however, made more nuanced statements regarding their involvement and described obstacles they had encountered.

3.1.2 Obstacles to Participation Named by Young People

Some of these obstacles came from the staff or from the setting, and some came from the young people themselves. Some responses indicated that obstacles made involvement in decisions difficult but not impossible. According to others, obstacles could make participation impossible. Yet others described obstacles in order to explain why it was not possible for them to be involved in decision-making. In other words, young people varied in their assessment of the possibility of involvement. A pattern was nevertheless discernible in each unit’s ability to involve young people, some units being more successful than others (see section 4). Two young people were angry about their powerlessness but most did not seem to expect involvement in decision-making, as much as an ongoing discussion of the issues with staff, and respect for their views – about treatment decisions in particular. Some explained that they did not have the confidence to put their point of view across.

3.1.2.1 Obstacles Originating in the Staff or the Setting

3.1.2.1.1 *Adults and young people disagreeing about the young people's best interests.* This disagreement could focus on the nature of the problem itself, as in the case of Helen's diagnosis of eating disorder. Helen did not think there was much wrong with her eating and therefore disagreed with her admission to a specialist unit. She resented the unit. All treatment options were imposed by adults and experienced by Helen as an intrusion and a breach of her right to be involved in decisions about her own life, although she had yielded to the imposition:

"I just didn't want to be here. I couldn't get home and I did not like that. I couldn't get out and people were telling me when to sit down and when to stand up and I didn't understand why because I didn't think I had a problem" (Int. 7A, p. 4).

The spectre of coercive treatment and legal detainment could prevent young people from asserting their preferences.

*"I cannae stop my medication. If I stop my medication I have to move back here. They'll grab me and inject me, stuff like that. To stop taking my medication is a bad move...
The nurses have a lot of power they can just section me. I've already been sectioned in here because I tried to discharge myself. I'll just keep getting lifted..." (Int. 4B, p. 11).*

Some young people accepted such interventions philosophically if they helped them, particularly if they knew they had a choice once outside the danger zone:

*"Res.: How do you feel about that?
Alan: Er... ok as long as it helps me" (Int. 4B, p. 11).*

Others resented them:

"I was not involved in decisions about going into hospital or coming out of hospital, and when I was in hospital decisions about bed-rest, special observations..." (Int. 12, p. 9).

This young person perceived coercion to have taken place throughout his treatment and, like Helen, he was angry.

Some young people gave instances when they had not been listened to but explained that it was unusual.

“I would say I’ve had quite a good run at saying... the only thing is what is happening now... which I am not sure is going to be helpful...” “I don’t think they’ve listened to me” (Int. 2C, p. 7-8).

3.1.2.1.2 *Staff or the unit overlooking young people when making decisions about them.*

One young person found that she had had her say overall, but that it was sometimes necessary to repeat what you wanted several times before someone listened to you.

“Sometimes you have to say it quite a few times before it sinks in...” (Int. 2A, p. 10).

To Kate who was thirteen, being listened to was a bonus, not an expectation. Her doctor made decisions about her treatment but *“sometimes when you have a point she considers it”* (Int. 5A, p. 9).

One or two young people were angry and rebellious at the hold the unit and its treatment team had on them and felt that any attempt to consult them was cosmetic:

“They ask you what you would like to happen before you have a case review, but I don’t think what I say goes... it just never happens, they always make their decisions and I don’t get anything” (Int. 7A, p. 11).

One area of decision-making about which all the young people in Arisaig complained they had no say, and about which they expressed a clear wish to see change, was the issue of time out of the unit during the week and at weekends:

“One thing you don’t really get to discuss that much is people’s time out, like I think you should be more able to discuss that. I think you should be

able to discuss with the doctors what time out you get every week. That doesn't bother me now because mine is pretty free but it bothers quite a lot of other people. And used to be very annoying... I think you should have a chance to discuss it and come to an agreement with somebody about it, rather than being told 'right, this is your time out' (Int. 2A, p. 12).

The issue of time out crosses the boundary between treatment and day-to-day living. It is a good example of young people feeling overlooked when decisions were made about their treatment because decisions about time out were made in a clinical meeting, hence its presence in this section. The number of young people who mentioned it is entered in the 'day-to-day living' column of Table 4.7 (p. 127) because it affected the young people's experience of evenings and weekends.

3.1.2.1.3 Feelings of powerlessness in the face of the unit and the staff perceived as powerful.

One young person knew what she wanted but she did not always dare to say what it was:

"Sometimes I feel I can say what I want and sometimes I just keep it in, 'cause I feel I don't have the right to tell them what's better" (Int. 3, p. 10).

The presence of a strong treatment regime in the unit, where certain options were prominent and others not, could make young people feel powerless to influence their own treatment. Some young people expressed frustration that they had to go to group therapy sessions they disliked and felt they did not use well, while they were not offered individual therapy. These same young people did not, nevertheless, think that the treatment regime should be changed because they valued many of its other aspects.

3.1.2.2 Obstacles Originating in the Young People

3.1.2.2.1 Having difficult decisions to make

Being involved in decisions regarding treatment meant sharing in the staff's knowledge of your problem and its likely future course. This could be difficult and frightening to hear, especially in the case of schizophrenia:

“I really have been involved in a lot – in fact in most of the decisions about my life. Even though I might not have liked some of the things that have been said... But in the end I know everyone was just trying to prepare me...And I have been involved quite a lot” (Int. 3C, p. 18-9).

3.1.2.2.2. Ambivalence about collaborating with adults

Young people who broke the unit’s rules and expectations knew decisions about the consequences would not come from them. Each unit made certain demands on young people, usually connected with safety and the welfare of the community. Respect and regard for peers and unit property, not bringing drugs, solvents or alcohol into the unit and not being under the influence of these substances, letting people know when you are leaving the building, are all examples of the expectations Rannoch clearly stated in writing to young people before admission. Young people who were not used to rules were expected to learn some self-control. Allowances were made for those whose mental state made self-control difficult.

“I didn’t want to become a day-attender, but I was forced to because I ran away from the unit” (Int. 3B, p. 6).

3.1.2.2.3 Feelings of hopelessness and disinterest brought about by mental distress

Sometimes it was difficult for a young person to know what they wanted:

“I never really know what to do for the best though, so I usually make the wrong decision, or sometimes I just go along with things anyway but I would say I have quite a big choice sometimes, like I can choose things...” (Int. 1B, p. 9).

3.1.3 Confusion about Participation

Two young people appeared confused about the input they had had. They contradicted themselves and the evidence provided by other data.

Rosie did not think she had had a say in the decisions regarding her admission and her course of ECT. She did not know who had made those decisions. Yet, the field notes mentioned an interview between Rosie and Dr Grey which took place in week one, the objective of which had been to find whether she was competent to give informed consent to another course of ECT:

“Dr Grey came to report what he had found, that [Rosie] was really depressed underneath the superficial features of flatness and lack of affect. She still had thoughts of suicide / serious self-injury. But she was able to give informed consent” (Rannoch, week 1, p. 7).

Rosie herself, earlier in the interview, had implied that she had contributed to the decision of being admitted:

“I wasn’t that keen on coming in but I thought I had to because I wasn’t going to get better any other way” (Int. 7B, p. 5).

Dean stated that he had contributed to his treatment decisions but went on to complain that no one listened to him.

Overall, almost as many young people seemed to feel involved in decisions regarding their treatment as didn’t, with a few expressing ambivalence. The majority of young people gave nuanced responses, demonstrating an awareness of the complexity of the decision-making process. In the next section, the young people’s views about their say in day-to-day decisions around the unit is analysed.

3.2 Involvement in Decisions About Everyday Matters

Practically all the young people thought they contributed to decisions about everyday living in the unit.

“All the young people, like, if you want to go out, ye ken, you could say you want to do that or no, ken...” (Int. 6B, p. 12).

“Like we plan the activity group, planning for what we’re doing in the next few weeks, like swimming ... It’s all down to young people” (Int. 5, p. 10).

A young person who thought the staff made decisions about everything was in Rannoch and his understanding of the situation was different from everyone else. Alan had been his own master since he had started living alone at the age of fourteen. He thought giving up his freedom to the unit was part of a deal in return for being provided for his health and social care needs:

“We go to beaches... Just take us in the cars. Like we went to X a couple of weeks ago, a big fair ground with roller coasters and that. Went there for a trip out. You get videos as well.

Res.: So who decides all that?

Alan: Er... the nurses.

Res.: Do the young people have a say?

Alan: No. But sure enough, they get well fed, they get bedded, clothed, bed, breakfast. And it keeps you out of mischief this place. It’s a safe place to be in” (Int. 4B, p. 12).

None of the other young people at Rannoch thought the nurses made these decisions:

“Young people have all of the say in doing that. And the staff, like, confirm it, or tell you that it’s not suitable, or help you arrange it, and things like that, but really it’s up to us what we organise” (Int. 1B, p. 11).

Dean also had an idiosyncratic understanding of the situation at Arisaig. He thought young people could make decisions about day-to-day living in the unit but he was reluctant to get involved in case he said something that upset one of the young people and somebody did something bad to him in return.

Some young people explained that there were restrictions to the decisions they could make about everyday activities:

- Other young people's wishes had to be taken into consideration:

"It's always the majority – so sometime if the majority want to go somewhere, you just agree..." (Int. 1B, p. 11).

This might mean choosing a film to go to, the certificate of which included the youngest person in the group. Several young people mentioned this.

- Basic rules laid down by the unit for the behaviour of all young people had to be observed.

"You just do whatever you want to do. When you're breaking the rules, like say you were playing with a ball and you smashed a window or that, or getting into fights, things like that, but otherwise you can watch TV, and do pretty much what you want..." (Int. 3B, p. 6).

One young person felt that young people's participation had a certain arbitrariness about it. It was limited by criteria she could not fathom. The result was that, although most of the time the staff would help young people to organise an activity that appealed to them, there were occasions when young people did not feel heard because the decision was already as good as made:

"The staff are usually quite good about organising, like if you want to go to the cinema, like, check how many staff are on and there's enough staff we'll go. If there aren't enough then we'll get a video out instead, you know, like, to make up for it"... But, er... sometimes you're not really ... like you talk to the staff and they listen to you, but they've already made up their minds, like the answer is no to everything (Int. 2A, p. 6).

Or part of the decision was negotiated but not the other:

“Sometimes like if you want to go out a walk after tea, it is your choice, if the staff are okay with it, but sometimes you get a choice whether you go out but you don’t have a choice in how long you go out for” (Int. 7A, p. 11).

In summary, the large majority of young people thought they could contribute to decisions about the life of the unit. Two had their own interpretation of the situation which differed significantly from that of other young people in the same unit or overall.

Restrictions were mainly related to the needs of the community as a whole. Decisions were the result of compromise between the needs and wishes of young people of different ages, with different problems. They had to follow unit guidelines aimed at safeguarding the interests of all.

Some young people thought there was an element of unnecessary control in the way the staff sometimes responded to requests and suggestions from young people. While some aspects of decision-making were negotiated and transparent, others were not. The young people’s comments about decision-making will now be addressed unit by unit.

4. ISSUES SPECIFIC TO INDIVIDUAL UNITS

Table 4.7 (p. 127) shows that the young people’s participation in decision-making varied from unit to unit as well as between treatment and day-to-day matters. Fisherfield and Rannoch had a strong and explicit policy of young people involvement. These units succeeded well at involving young people. Knoydart offered a strong contrast between involvement in treatment and involvement in everyday matters. Arisaig offered a mixed picture in both areas. The units are discussed in order of ascending young people involvement.

4.1 Arisaig

Arisaig was a seven-day inpatient unit with ten beds for which there was a waiting list. Its client group had long standing, serious mental health problems and often stayed for many months. Five young people aged thirteen to seventeen were interviewed. One thought she

was involved in decisions regarding her treatment, one had mixed views according to different forms of treatment and different events, and three thought they did not have a say in their treatment, one of whom was angry and resentful about it.

Since the treatment regime consisted more of coercive interventions than of other kinds of interventions, one might have expected control to be an issue, and although it was, there were instances when some young people had experienced negotiations in decisions about these interventions:

“I was on [special nursing observation] for ages but they, like, they discussed with me a plan, like, to get off [special observation] gradually and everything, so like, that’s quite good. Because I got a say in what I wanted and everything” ... (Int. 2A, p. 9).

So did Jill, even though she was receiving treatment which included medication and special observation:

*“Res.: Do they decide your treatment or do you help them decide about your treatment?
Jill: I help them decide
Res.: They listen to you?
Jill: Yes they do” (Int. 7A, p. 7).*

This indicates that it was possible to negotiate certain aspects of coercive interventions and to involve young people in their management but it did not happen in every case, either in Arisaig or in other units.

All the young people thought that decisions regarding everyday living were shared with them most of the time, although occasions were mentioned when staff had already made all or part of the decision. There was one exception to this, however, which all the young people mentioned: their lack of participation regarding decisions about their time out of the unit. Although they were invited to make suggestions about time out, they felt the staff did not take these suggestions seriously and the time they were given bore no resemblance to them. This was a seven-day unit where young people often spent evenings and weekends. They found the time long and boring. Some complained of being homesick.

4.2 Knoydart

In this day-unit, five young people were interviewed whose age ranged from fourteen to seventeen. They were treated for non-psychotic problems. The young people's views regarding their contribution to decision-making conveyed a strong contrast between decisions about treatment and decisions about other aspects of daily living. Four out of the five young people in the sample felt they had no choice in their treatment. Attendance at therapy groups and community meetings was a staple requirement of treatment, although there were individual ingredients in each treatment package. Two young people complained that, although the community meetings were helpful, other groups were not. They would have preferred a one-to-one form of therapy.

The strong treatment culture of Knoydart, evolved over many years (see Chapter 7), may have made it difficult to involve young people in decisions about their treatment. It is interesting to note, however, that the treatment culture at Rannoch, which was also group based, seemed to leave young people feeling that they could choose whether or not to attend particular groups for their treatment:

"I was told all about them, groups, and I decided which ones I wanted to go to. I thought they all sounded quite good and that. I thought they would help me as well to socialise more and that" (Int. 3B, p. 6).

Knoydart could make young people feel involved in decision-making regarding treatment because one young person thought she had had a choice. Unlike the others, however, she was over the age of sixteen and she had left school, both of which may have been significant.

All the young people thought they contributed to decisions about the daily activities of the unit and the staff made this a high priority.

4.3 Rannoch

This unit provided both day and inpatient care. Five young people aged between twelve and eighteen were interviewed: two inpatients and three day-attenders who had also been inpatients. Rannoch had an explicit policy of involving young people in decisions regarding every aspect of their life in the unit, as this statement from the nurse manager witnessed:

“Working in partnership [with young people] is really important and we’ve been working quite hard on promoting that” (Int. 8B, p. 9).

All the young people interviewed thought they had made some contribution to decisions regarding their treatment: two thought they had taken part in all decisions, two thought that they had overall, except when it came to medication and nursing observations. One conveyed a confused picture and contradicted herself about whether or not she had made any decision. Other data suggested she had.

All the young people thought they were involved in decisions regarding activities around the unit except Alan who felt he had to take part in whatever was going on in exchange for the health and social care he received from the unit.

4.4 Fisherfield

In this day-unit from which three young people were interviewed, the clients were slightly older (over sixteen) and recovering from a serious psychotic episode. Several had a diagnosis of schizophrenia. The young people interviewed had felt involved in decisions regarding both their treatment and the daily life of the unit, although one of them was about to be discharged under protest. Giving young people a choice was an important priority of the unit, as was made clear by Paul, the nurse manager:

“ We make sure that anything we do with them is collaborative, and that we’re not in anyway kind of coercing them” (Int. 4C, p. 7).

All the data collected at Fisherfield supported this statement.

CONCLUSION

The young people interviewed in this study explained that they preferred treatment interventions based on relationships and mutual trust. On this basis, they valued admission, one-to-one and group forms of therapy but found coercive interventions like special nursing observation and the use of the Mental Health Act difficult, although potentially helpful. Medication aroused ambivalence.

Their views about their involvement in decisions regarding their treatment were nuanced and highlighted difficulties but fewer young people felt satisfied with their level of involvement in treatment than with their contribution to every day decisions in the unit. The units varied in their ability to involve young people but on the whole found it easier to encourage participation in day-to-day matters than in treatment.

CHAPTER 5: PARENTS' PERSPECTIVE

INTRODUCTION

The second objective of the study was to explore in interviews with parents their perspective on their child's treatment and their own contribution to the context of care. Two themes from these interviews are explored in this chapter after a section introducing the base data: the parents' views, firstly about the units and their treatment programmes, secondly about their own involvement. In a final section, unit-specific aspects of the findings are discussed.

1. BASE DATA

The parents of all but two young people in the sample were interviewed: sixteen in total. In the case of one young person, it was her grandparents who were her guardians. Eight couples chose to be interviewed together and eight mothers alone. Nine interviews took place in the parents' home, seven in the units. One single mother in Knoydart made several appointments for an interview but did not keep them. One couple with a daughter in Rannoch were not approached because a legal action was taking place between them and their daughter.

	<i>Parents/Young People Interviewed</i>	<i>Couple /Mother</i>	<i>At Home/In Unit</i>
<i>Knoydart</i>	4/5	0/4	3/1
<i>Arisaig</i>	5/5	2/3	1/4
<i>Rannoch</i>	4/5	4/0	3/1
<i>Fisherfield</i>	3/3	2/1	2/1
TOTAL	16/18	8/8	9/7

Table 5.1: Number, Type and Location of Parents' Interviews

2. TREATMENT ISSUES

Parents' perspective on their child's care and treatment differed in some ways from the young people's. Admission itself and the relief of not being the front line carer any longer came first in their evaluation of therapeutic help. Other interventions were seldom discriminated from each other and were poorly understood, except those best known to the lay public like medication and one-to-one therapy. A shortage of therapeutic resources was noted and treatment in an adult ward was severely criticised.

Table 5.2 gives an idea of what parents understood and valued about the therapeutic interventions offered to their children. The same categories have been selected for this table as for Table 4.5 on p. 110 of Chapter 4 to allow comparison.

Unlike their children, parents most valued the admission itself (see Table 5.2, category: 'Admission to a specialist unit') although they criticised specific aspects of the unit. This is discussed in section 2.1. In contrast, the young people had commented most favourably on having young people and staff to talk to. Their parents mentioned it as the second most therapeutic element of treatment, but less than half of them did so.

A key aspect of parents' comments in their interviews was that many of them were unable to be specific about what the unit offered by way of treatment or what was helping their child. They thought the unit and the treatment were simply either helpful or unhelpful. A few therapeutic interventions some parents commented on individually will be explored in section 2.2.

Therapeutic Approaches	Helpful	Don't know	Unhelpful
<i>1 - Being with other people / talking to YP & staff informally</i>	7	2	
<i>2 - Admission to a specialist unit</i>	14		1
<i>3 - Medication</i>	3	1	4
<i>4 - Meetings and groups</i>	3	3	
<i>5 - Formal one-to-one therapy</i>	6		
<i>Treatment in general</i>	2	1	3

Table 5.2: Value of Specific Treatment Interventions as Perceived by Parents

What the parents were most voluble and detailed about in their interviews, however, was their own involvement in the unit and the help they received from the staff in understanding their children's mental health and in caring for them. This will be analysed in section 3.

2.1 Admission to a Specialist Unit

For all but one family, admission was assessed as helpful: it relieved parents of the anxiety of caring for their child 24 hours a day and it offered them respite so that they could attend to their own lives and to the rest of the family. They found the unit helpful because the environment was suited to someone with a serious mental health problem, it boosted the young person's confidence and the staff was genuinely caring – which surprised some parents.

The units were also criticised: the treatment was not working, some young people learnt bad habits from others and witnessed disturbing events. In inpatient units they were bored in the evening and at weekends and in day-units, help at those times was difficult to access. For some, the unit was a long way from home and not as comfortable or well-appointed as home.

2.1.1 Helpful Aspects

Relief: all parents experienced the admission of their child, whether to a day-unit or as an inpatient, as welcome relief at a time of crisis:

*“The unit, I mean, is a God-send for kids, ken. I am glad the unit is there”
(Int. 9, p 15).*

Respite: in addition to relief, admission and regular attendance provided respite from a caring situation at home that had become very difficult:

*“We're struggling... They [staff] know what they're doing but we're lost...”
(Int. 6A, p 4).*

A suitable environment: it was easier for a unit to create the stress-free environment so necessary for a young person after a psychotic episode, yet so difficult to implement at home. The way the staff organised the environment and behaved with the young people encouraged their confidence:

“Well I feel it has really built her confidence up and her self esteem. She is definitely quite a changed girl since she came here with a lot more confidence in herself and she seems to like herself a lot better”. (Int. 1A, p 5).

Genuine care: some parents were impressed by the genuine care their child was receiving at the hands of committed and skilled members of staff:

“The great thing about the unit and Ruth particularly is that you have the feeling that she really cares about Sarah” (Int. 8C, p 20).

2.1.2 Unhelpful Aspects

Disappointment: although the majority of parents found relief in the units and said they received invaluable help from them, a number of problems were highlighted and disappointments were voiced. These were often specific to the organisation of inpatient care, although day-units could also disappoint.

“My hope, the only good thing about here is that she’s going to get better. I am not seeing that happening [little laugh]. And you sort of... lose a bit of hope because you’re not seeing... But I’ve seen her: she’s got a lot worse. She’s on a downhill slope” (Int. 5B, p 19).

Contagion: some parents worried that their child had picked up destructive ideas from other young people, often to do with suicide and self-harm:

“Dean picks up ideas and worries from people” (Int. 3A, p 3).

Rosie's self-harm had increased greatly since she was in the unit. John was behaving badly, running away with another young person and getting himself suspended. Some young people had started to smoke.

Boredom: there were repeated complaints that the young people did not have enough to do in the evening and at weekends:

"I think they could do with some stuff to keep them occupied... they must get bored, some of them are in here twenty four hours a day, it's not very pleasant first of all to be here, but make it a little better if you can. Especially when they can't get out" (Int. 6A, p 14).

Distance: it was even more difficult if the unit was a long distance from home. One family drove 150 miles each way to collect their daughter for the weekend on Friday evening and take her back on Sunday night.

"The hardest thing to take is the fact that we are so far away so we rely on phone calls to help when she's down. You know? You can get half a dozen to a dozen phone calls a night: 'if you don't come and get me, I'm going to kill myself', you know?" (Int. 5B, p 11).

Out-of-hours on-call facilities: the day-units were closed in the evenings and at weekends. Several parents were dissatisfied with the out-of-hours facilities available when they found themselves alone to deal with worrying situations. Michael had tried to hang himself one night and his mother wanted advice from the unit staff who knew him. Carole who was depressed often felt suicidal in the evening. She had phoned the hospital emergency line on two occasions but had not been put through to a mental health professional and the unit had not been informed the next morning. Her family had organised a twenty-four hour rota to make sure she was never left alone.

"Somebody to be there who you can talk to, ken, you can phone up maybe at twelve o'clock at night when things are bad and say 'well I've got a problem, can you help me?' (Int. 9, p 16).

Shabby-looking buildings: the adolescent units in the study didn't look attractive or well-appointed buildings:

"The building is of poor quality. Not good enough for young people to have a good quality of life"... (Int. 3A, p 4).

Diet: the food coming from the hospital kitchens was stodgy and the diet was not healthy.

Parents experienced having their child admitted to a specialist unit after months of family struggle and crisis as the most helpful therapeutic intervention, although specific aspects of hospital care were criticised. They were vaguer about the treatment the young people received once in a unit.

2.2 Therapeutic Interventions

Parents' knowledge about therapeutic interventions in mental health care came over as limited. They mentioned and seemed to understand the importance of therapeutic relationships between staff and patients, whether carried out formally on a one-to-one basis or informally, in everyday interactions, and medication. They found group therapy difficult to understand. No one made reference to milieu therapy.

One-to-one therapy: this category refers to both formal and scheduled one-to-one sessions and to therapeutic relationships with staff.

Because they had heard or read about counselling and psychotherapy as a way of helping mental distress, parents were pleased when the unit staff had managed to gain the trust of their child and engage them in a therapeutic relationship:

"She has got somebody to talk to here, to let know how she is feeling because she can't actually... she doesn't tell us very much" (Int. 6A, p 8).

Conversely, they felt let down if that process was hindered in any way:

“They’ve changed Fran’s doctor. Sometimes you think, well she’s started to trust someone, and then to change to someone else... I feel sometimes they dinnae ken what they’re doing, ken?” (Int. 9, p 9).

Therapeutic relationships can be supportive and companionable, or they can be used to explore a young person’s inner world. Some parents did not make the distinction: they expected a therapeutic relationship to explore the causes of problems to get to their roots. The fact that this might not be possible, particularly in the case of psychosis, did not appear clear to these parents.

“I thought there would have been a lot more counselling, a lot more talking, trying to get her to talk about her problems... like what was her childhood like, you know, what was her relationship with her parents, trying to get a picture...” (Int. 5B, p 13).

The parents in interview 5B found it hard to accept, or even to hear, that their daughter was psychotically depressed because it would have meant that the problem was more serious and difficult to understand than they could cope with. They disagreed with the staff that their daughter’s depression would not be helped by exploration of her earlier life. Although they authorised Electro-Convulsive Treatment (ECT), they were also seeking psychotherapy.

Medication: parents knew about medication. To them, it was a major ingredient of treatment. Carole had been in the unit for a few weeks and had just been prescribed an anti-depressant. Her mother spoke of it as ‘the’ treatment, even though Carole had been in group therapy for her depression since admission:

“They’ve just started treating her, actually, for the depression. This is only the second week of a new tablet. Last week she had a terrible week, but this week she’s not too bad” (Int. 10, p 8).

Parents who commented on medication, however, made it clear that they expected it to be used with caution because of its side-effects and that they did not think of it as a panacea. They disapproved of it replacing regular personal contact with a doctor.

"I mean he didn't know her and straight away he was prescribing Prozac"
(Int. 5B, p 3).

Parents whose children had been on anti-psychotic medication for some time understood that it was an important part of treatment:

"Well the pills have helped her actually if she would just keep on them" (Int. 6A, p 8).

Although they found them problematic because of their potency:

"There has never been a dead right one, actually – she has never really been free from illness for a sustained period of time... She had bad reactions, side effects, intolerance" (Int. 8C, p 4).

While parents accepted medication as an important element of treatment because they knew of it outwith the personal context of their child's admission, they did not accept it blindly. They were aware of controversies regarding side-effects and they did not want it to replace therapeutic relationships.

Group therapy: most parents did not understand the role of therapeutic groups. In the two units where treatment was group-based, they were more likely to say that they did not know what the treatment was or how it worked.

"I know they have, like, say quite a few meetings, and I think they have certain days for certain things. I know there's a mental health group meeting, I cannae remember them all but I know they have, ken, quite a bit"
(Int. 10, p 12).

They also tended to feel more alienated from their child's treatment:

"Nae idea what the treatment is, what treatment she's getting... I've never really seen anything, or heard anything, treatment-wise" (Int. 9, p 12).

The parents' level of education probably made a difference. A mother from a professional background had eventually worked out what the groups consisted of, and she could begin to explain how they were helping her daughter:

"Perhaps through some of the groups that they have whereby they express in other ways [art group, games...] the emotions that she perhaps hadn't realised she'd got – but maybe that's what she is feeling – identified 'I feel like that' and then, having decided that, being able to deal with it. If you don't know you are feeling something, you can't deal with it" (Int. 22, p 5).

But she felt the unit had been slow at explaining what the therapeutic philosophy was:

"I remember the first time we went along, I soon said 'what do you do?' and it wasn't actually explained. And I feel as a parent – I mean Mairi is only 15 – I really feel I would really like it to be made clearer; I mean she told us a little bit, but the actual philosophy behind it, I would have liked to know" (Int. 22, p 8).

No parent explained clearly what group therapy was about. Not understanding the substance of the child's treatment was met with trust by some parents, frustration and a sense of alienation by others. Some tried to make good their lack of understanding by guesswork, questioning the young person and their own reading.

2.3 Resources

A number of parents expressed concern that the units lacked resources, human and material: day-units as well as residential ones were needed, more nurses, better buildings, recreation equipment and opportunities...

Diane had been treated in the inpatient unit the previous year for anorexia nervosa. Some weeks after her discharge she had started to lose weight again but there had been no room in the inpatient unit. It was not until she had lost a lot of weight that she could be re-admitted as an emergency. Had the service had a day-unit, more inpatient beds and more nurses, Diane's mother thought Diane's needs would have been attended to more quickly.

"The nurses and that they're overworked actually. I think actually they're short-staffed as well. They're doing a lot of overtime and things like that" (Int. 6A, p 14).

A selection of games to occupy the young people should have been available:

"The pool table they got for them is kind of falling apart. Maybe if they spent a wee bit more money, sort of style, they could get some games for them" (Int. 6A, p 14).

Parents would have liked the health boards to spend more money on the mental health of children and young people.

2.4 Treatment in an Adult Psychiatric Ward

Had more resources been available for children and young people in the mental health services, young people would not have had to be admitted to adult acute admission wards. Three young people in the study had spent a few weeks each in one of these wards because there was no adolescent bed available for them. In the process, they had had to relinquish the care of their adolescent psychiatrist to become patients of the ward's consultant. Their parents made devastating and incriminating criticisms of the treatment these children had received. The ward was chaotic; the young people were distressed; they had built no therapeutic relationships with anyone, nurse or doctor.

"It seemed to us that there was very little therapeutic content to what went on in the ward. It really seemed to be about custody and providing medication, not even very well controlled or monitored medication" (Father, Int. 8C, p 7).

Meetings between staff and parents had not been planned and parents' views had not been sought:

"I also felt that as parents we were not really welcome, and our ideas and views were very unwelcome" (Mother, Int. 8C, p 7).

At the time this research took place, the issues revealed in this section had been attended to by a group of parents, the NHS Trust and the health board. Therefore it was not the pressing ethical matter it would have been for the researcher had it come to light in the study for the first time.

Conclusion

In their interviews, parents commented on their child's care and treatment. All except one appreciated the help provided by admission to a specialist unit. This intervention relieved them at a time when they were finding it difficult to cope with their child's serious mental health problems. Few parents, however, appeared to understand the exact nature of the help that was provided, with the exception of well-known interventions such as medication and one-to-one therapeutic sessions. Several parents would have liked to know more. A number of parents commented on the shortage of resources they had noticed in the units. They thought more should be available. Three families had experienced treatment in an adult psychiatric ward and made severe criticisms of what was provided for young people in that setting.

In the next section the parents' description of their experience of involvement with the treatment units is analysed.

3. INVOLVEMENT IN THE UNIT

In this section, parents' comments about their own involvement in the treatment of their child are shown. If parents' grasp of the specific kind of help their children received was vague (see previous section), they had much to say about their own relationships with the various units. They conveyed a clear message regarding needs of their own, which were linked to, but different from the needs of the young people. They expected the units to fulfil some of these needs. In the first subsection, emerging areas of conflict between the needs of the young people and the needs of the parents are highlighted. In the second subsection, the parents' needs as they described them are explored.

Table 5.3 shows parents' views about the staff's availability and their own involvement in each unit. In the same unit, some parents felt adequately involved and others not, showing that families' individual characteristics played a part in engagement. Some units, however, appeared more successful at engaging parents than others. The units are presented in ascending order of parent satisfaction.

Staff availability / Parent involvement	Good	Mixed	Poor
<i>Rannoch</i> (4 parents)		1	3
<i>Knoydart</i> (4 parents)	3		1
<i>Arisaig</i> (5 parents)	4		1
<i>Fisherfield</i> (3 parents)	3		
Total (16 parents)	10	1	5

Table 5.3: Parents' Views of their Involvement in the Unit

All parents said they wanted to be involved in their children's treatment but in practice some made more efforts than others. Transport, distance, home demands, levels of social inclusion all contributed to parents' ability to go to the unit, meet the staff and understand issues related to mental health and treatment. Some parents highlighted a time consuming element to being involved: time spent taking young people back and forth or visiting them, going to scheduled meetings, talking to members of staff on the telephone etc. A few mothers had given up their jobs in order to be available.

Some parents who had had a difficult time looking after their child in the weeks preceding admission welcomed the respite and preferred not to be too involved so that they could get on with neglected aspects of their own lives.

Definition of the family: the researcher met parental couples and mothers on their own. Of the latter, some lived alone, some lived with a partner or husband who might or might not be the father of the young person in treatment. In some cases there were siblings or half-siblings at home, in others not. In their interviews, parents referred to other family members' needs as well as to their own. For the sake of simplicity, the word 'family' has

been used here to refer to the people who lived in the same premises as the parent and the young person interviewed.

3.1 The Young Person and the Family: a Conflict of Needs?

Both young people and parents had expectations of the units and the units had a sense of obligation to both young people and parents but, strictly speaking, it was the young person who was the identified client of the hospital. This ambiguity seemed to generate a number of potentially conflictual issues which varied from family to family and unit to unit. Three were identified in the data of this study.

3.1.1 Who Was the Unit for?

When parents and young people were in conflict, it seemed difficult for the unit to remain neutral. In the case of Helen, the parents were in no doubt that the unit was for them:

“They’re no there for Helen, they’re there for the family, and it is very noticeable” (Int. 14 A, p 13)

said Helen’s mother. Helen and her mother did not agree about the extent of Helen’s eating disorder or about the treatment. While Mrs H felt heard and supported by the unit staff, Helen did not.

In Tom’s case, it was Tom who felt supported by the unit. Tom was in conflict with his parents and his father thought it was difficult for the staff to listen to both sides: they were not well placed to understand parents because they heard the young people’s point of view. As a parent, he felt at a disadvantage.

3.1.2 Behaviour at Home versus Behaviour in the Unit

Some young people’s behaviour had caused problems at home before admission and, in the parents’ view, continued to do so, although they were doing well in the unit. Such parents

felt they were not being heard and they were not being given the advice and support they needed to manage at home:

“They agree with me: ‘he should be at home, he shouldn’t be doing this, he shouldn’t be doing that’ ... but they’ve never come up with any suggestion about what else I can do” (Int. 2B, p 9).

This mother had doubt about the effectiveness of her son’s treatment.

3.1.3 Confidentiality

The staff’s duty of confidentiality towards young people, of which they were highly aware, could, if a young person requested it, prevent them from informing parents about their child’s life in the unit, their state of health and their treatment - even if that parent was looking after that young person at home every weekend. One young person in the sample was in this position. Her mother had found it painful. And it was difficult when her daughter went home on pass. She felt she had no rights:

“We don’t seem to have any [rights] in a situation like that. We’re at the mercy of our children” (Int. 4A, p 8).

The staff had gone on welcoming this mother, however, and had tried to negotiate information on her behalf:

“Quite often I have phoned up when I have been worried about something or another and they really do their best to tell you what they can, you know?” ... “Dr. White has meetings with me and with Diane to try and get some information out into the open. They really have done everything they could have done” (Int. 4A, p 6, 10).

Another mother thought information was being withheld from her because of confidentiality, even though this had not been openly stated:

“He is under 16 yet I feel sometimes things are held back from me because of patient confidentiality” (Int. 3A, p 2).

In this case, the concept of confidentiality had eroded this mother's trust in the unit because her son was 14 and psychotic and she felt unsure that she was given all the necessary information.

Parents, by contrast, were not entitled to confidentiality because they were not official patients of the hospital and did not have a confidential file. Whatever information they gave went into their child's file. One young person in the sample who had requested to read her medical file had stumbled across information given by her parents in this way and had been angered and distressed by it.

Supporting both parents and young people was clearly a difficult challenge for the staff. Different units and different families tended to give rise to different solutions.

3.2 The Needs of the Family

"With Sarah, I still find if she is not well, if she is depressed and she is talking self-harm, it has an immense effect on how I feel. I find it very hard to sleep and I find myself very tired. And your whole life, I mean, day after day after day when I find we have talked about very little other than how Sarah is" (Int. 8C, p 18).

This comment, made by Sarah's father about the effect of his daughter's illness upon him, was representative of how all parents felt. Parents also stressed that it affected the whole family, not only themselves.

Guilt was a prominent feeling: parents frequently felt guilty that the problems were, somehow, due to their failure as parents. One couple even feared the breakdown of their family and public shame.

Parents' needs as expressed in their interviews have been grouped into five categories. They are listed here and used to present the findings in the subsections that follow.

- Help and support
- Communication
- Advice
- Explanations
- Involvement in decision-making

3.2.1 Help and Support

Help and support was necessary to cope with the young person's problems, the treatment and the general disruption to lives and relationships. The units' support also replaced the social support the family had lacked when relatives and friends had not been able to provide it because they did not understand.

Because they were so intimately associated with the young person's distress and difficulties, parents, siblings and families wanted to get involved in the young person's treatment:

"I think when something happens like this, a child of yours takes an overdose, you feels very vulnerable and you feel very guilty and all this, and it took me a wee bit to say 'oh come on, I can do something here, I can take part'..." (Int. 22, p 8).

And they needed help and support in their own right:

"Me and my husband have been meeting Susan and Jan [key-workers]. First of all it was once a week before he was getting out of hospital, just for support for us, and then it was once a fortnight and it has been a help" (Int. 21, p 16).

Many parents reported receiving such support from the units:

“They’ve been brilliant. We can’t really say anything against them because when we have had it bad with this. We would walk out crying and they would come running after us, saying ‘come on back in and talk’. They were here to help us as well. They have been really brilliant, haven’t they? Told us to phone anytime, it didn’t matter when” (Int. 8A, p 13).

But not all:

“I don’t feel they give the parents the support” (Int. 2B, p 16).

Some siblings had been helped:

“Jim was included as well [Sinead’s little brother]. Callum [key-worker] did a lot of sessions with Jim on his own because Jim found it very difficult to accept Sinead’s illness” (Int. 7C, p 23).

But others had not:

“It’s upset everyone’s life, really, it really has, even Jerry [younger brother] ... There hasn’t been enough support available for him...” (Int. 5B, p 16).

Several parents reported having become socially isolated both because of the time and energy they spent dealing with their family problems and because of the difficulty they had explaining what was going on with their child. They feared, and often encountered, misunderstanding from relatives and friends. Their social network failed them when they needed it most. The unit’s support was the more important because of it.

3.2.2 Communication

Parents wanted to be able to share information with the unit staff. They found it easier if they had one or two special members of staff to relate to and to trust. They wanted to meet them flexibly, in the unit and at home, with the young person and without. But they were easily put off because they felt vulnerable and lacked confidence.

Exchange of information

Parents relied on the units for information about their child's progress and behaviour in the unit and about the treatment team's thinking. Some parents experienced good communication:

"I think anything I'd need to know they would tell me, you know. There're no secrets or anything, they just have these discussions all the time. If anything crops up they'd tell me like, they would tell me" (Int. 10, p 14).

But not all:

"I think I would like to maybe be informed a wee bit more" (Int. 9, p 13).
"I feel the family should be told more so that we can understand. There is a lot I'd like to know... Not much is discussed. Some days I go in and Dean is upset but I am never told what's happened" (Int. 3A, p 2).

The communication should be two-way: parents also wanted the staff in the units to be available to listen to their own changing views and worries, their questions and their comments when something was wrong. Some found:

"If you had any worries and you would phone them up, they always got in touch again. They don't ignore you or anything. They always got in touch to inform you what was happening and things" (Int. 6A, p 14).

But this was not always the case:

"If I speak I feel scrutinised. I have tried to say when something's happened or what I think but I feel I am being kept out of it. It's like he's been kidnapped" (Int. 3A, p 2).

Relationships with the staff

A member of staff specially allocated to the family seemed to help. It was usually their child's nurse (i.e. key-worker) or psychiatrist. As they got to know this person, parents became less anxious about broaching difficult or painful issues regarding themselves and

their families. This 'advocate' was often the person who had met them most frequently, phoned them at home and perhaps visited them.

For example Mrs J. found it difficult to communicate important issues to nurses she did not know well. She preferred to meet John's key-workers when she came into the unit:

"I don't know the rest of the people very well... But Christine and Olivia are inclined to come and speak to me and they ask me how I am and how John's been, and how I think he's doing and whatever... But if they're not there..."
(Int. 2B, p 15).

If they were not there Mrs J. confined herself to superficialities and went back home with her worries. Although the review meetings were meant to be the best opportunity for young people and parents to discuss treatment with the staff, Mrs J. found them intimidating because of the presence in them of staff she did not know well.

The unit staff appeared to underestimate their own importance in their relationships with parents. If they went on holiday or on night duty, they trusted that another member of the team would fill in their place with the family. This, however, did not always happen: another member of staff might not have the same commitment to the family, or the family might not open up in the same way, waiting for their own doctor or nurse to re-appear. The family was not always told why this link had been severed and they sometimes misunderstood the significance of it.

Mrs R. had a good connection with Rosie's key-worker, Christine. When Christine went on holiday, Mrs R did not appear to know. Her communication with the team diminished and she did not understand the cause:

"I really miss Christine, you know, because we'd meet and approach these issues with her... I haven't really seen Christine" (Int. 5B, p 19).

Christine had been an important link between the unit and the R family. Dr Grey had tried to help by holding occasional meetings with Rosie's parents and they mentioned these gratefully. But they did not understand why they had not seen Christine.

Meetings

Whether or not families had meetings with the unit staff, and the form these meetings took, varied from unit to unit and from family to family. The most standard type of meeting was the regular review of treatment that took place in every unit but even this was not standard since in Arisaig it did not involve parents and there was no system to report to them what had been decided. Some families had family therapy meetings, some had support and information meetings. Some needed to request a meeting while others had them offered to them. Some only met the staff on an ad hoc basis when they came into the unit. In some units the medical staff always met the family at least once, in others not. Key-workers, who were mostly nurses with the exception of an occupational therapist, were the only workers to work with the family as a matter of course. In their interviews parents asked for meetings and set parameters about what was and was not helpful.

Family therapy meetings were used to see if the family could change certain intrafamilial patterns of relating which were causing stress and difficulties. Parents acknowledged their usefulness but they found them hard:

*“Why should we have to change our attitude in the way we deal with things?
It's not us that's ill (Int. 8A, p 14).*

Little by little they realised that they needed to listen and they became willing to change. It was painful:

“I suppose it's not very nice for a parent to be told that your thought processes are maybe too rigid and you can't afford to have a rigid thought process, especially with someone that's coming back from a mental illness. We have got to be able to give and take. So, me probably in particular, have had to take a lot on board that way to change my attitude towards things” (Father, Int. 8A, p 14).

Several parents came to realise that they had to make the meetings work:

“My family (partner and daughter) should learn to use them [meetings] better: they go home and moan about them and I tell them to speak in the meetings” (Int. 3A, p 3).

Some parents would have liked occasional meetings in their own homes because it would have made it easier for the whole family to get involved: some family members, usually siblings and fathers, refused to come to family meetings in the unit because they found them daunting. Those who had had meetings at home found it helpful because they felt more confident to say what they thought.

Several parents mentioned a need to meet the unit staff without their son or daughter. One reason given was that parents wanted to tell the staff about anxieties regarding their child, or about difficulties they experienced at home. Young people's behaviour at home often created tension: what they ate or what they refused to eat, what they said and aggressive or destructive behaviour. In these cases parents worried that if they said this to the staff in front of the young person, they would aggravate the situation. Yet they wanted to tell the staff to obtain reassurance, support and advice.

Dean was slowly emerging from a psychotic episode and his family needed help to discriminate between psychotic and non-psychotic behaviour:

"We should have regular meetings with a key-worker every week, but without Dean so that we can express our worries about Dean" (Int. 3A, p 3).

John was verbally, and sometimes physically, aggressive towards his mother while his father worked abroad. In meetings with staff, Mrs J felt vulnerable if she mentioned this behaviour in front of John because she knew she was likely to cry and she thought it would increase John's feeling of power over her.

"It's because I usually end up getting myself in tears, I really get myself into a state. And he sits and sees all that. And he seems to enjoy it" (Int. 2B, p 15).

Mrs J. did not feel she had opportunities to speak about this behaviour to a trusted member of staff without John. Therefore the aggressive behaviour went on without the unit's knowledge. In the research interview, Mrs J. spoke disparagingly of the unit at first and complained that John had not improved. It was only at the end of a long interview in her

home, with her husband's support, that Mrs J finally gave the researcher a glimpse of this continuing difficulty. The unit, on the other hand, thought that John was doing well.

What the parents requested was a flexible approach to the place, time and mix of people who met:

"We have meetings sometimes individually, sometimes Sarah, my wife and myself will meet with her key worker – that's Ruth – and that has happened quite often at home here" (int. 8C, p 20).

Parents' lack of confidence

A number of parents said they felt at a disadvantage in their communication with the units. They felt unimportant or struggled to uphold their confidence in the face of a professional setting that sounded high-powered, articulate and distant:

"The actual philosophy behind it, I would have liked to know...It makes you feel a little bit... I can't think of what the word would be but – you know, as if you don't matter, you're sort of not important in this" (Int. 22, p 8).

The staff appeared incomparably more knowledgeable than the parents about the latter's problems. The parents were often emotional and hypersensitive about their difficulties: they felt vulnerable.

Some parents felt socially and educationally inferior to the unit staff. Therefore going to the unit was intimidating and expressing themselves even more so:

"When I go up to the unit, I feel very very small 'cause I feel they're all way above me. It's just a feeling I've got. I feel sometimes like a stupid wee lassie myself when I'm trying to tell them things. And it's horrible, and I hate it, sometimes ken, if I go up there. I feel as though they're talking down to me and I'm trying to explain things, so they understand, and it's frustrating. It really is frustrating. It really is... (Int. 9, p 15).

In order to cope better, this mother tried to prepare herself in advance:

“If I’ve got an appointment up there, I’ll be maybe in the house and I’ll say, right, I’ll ask them this, I’ll ask them that, or I’ll tell them this. And you get up there and it doesnae work like that. You go in. They mention something, so your mind’s away on something else and you come out and you think but I never asked them this, and I should have said that” (Int. 9, p 15).

Rightly or wrongly, some parents felt that they and their information were unwelcome.

“It’s just an attitude from some staff, like you’re too nosy. If I notice something about Dean I go and say but I feel they’ll think ‘oh here’s the pest again’, or ‘you don’t give up do you’ (little laugh)” (Int. 2A, p 3).

“I’ve got to admit that I sometimes felt when I did go up to the hospital... it was almost like they didn’t... you know, ‘Alan’s here now, he’s our responsibility’ and anything I said it was like they didn’t want to know, ‘cause I was interfering if you like” (Int. 13B, p 18).

The standard of communication parents expected of the units made sense: two-way information sharing, availability, consideration for their vulnerability and inexperience. But it did not seem to be a remit all units and staff were able to meet.

3.2.3 Advice

Another need parents experienced was a need for advice. How should they behave to be helpful to their child: should they challenge a depressed young person who did nothing in the house, or should they leave her alone? Should they discuss menus with an adolescent who was anorexic and how controlling should they be? Was it better to let a son recovering from a psychotic episode lie in bed or to insist that he got up?

For instance Michael’s mother explained that the unit had told them how to manage their son’s meals:

“ ‘You are still the adults, you take care of him, you take control’... Because sometimes you don’t know if it is the right thing to do, if it will make him more ill or... so it is good they help and support us to do right. And we feel we can help them look after Michael” (Int. 21, p 17).

Like Mrs M., many parents felt they were receiving advice and were grateful for it:

“If I’ve got a problem, or I’m no sure of something, I can ask them up there, and they’ll tell me how to deal with the situation” (Int. 9, p 9).

But not all: Tom’s parents, whose relationship with their son was breaking down, thought Tom had hoodwinked the unit staff while their own side of the story had gone unheard. Tom’s behaviour at home was as difficult as ever and his parents did not feel they were addressing the problem jointly with the unit. Although Tom was improving in the unit, his progress was not being transferred to the home situation and it was at risk of being undermined there. Tom’s parents remained distressed and vulnerable, feeling that their child was doing well with strangers but not with them.

3.2.4 Explanations

Parents wanted to understand both problems and treatment but mental disorders can be difficult to explain and to understand. Some parents interviewed did not appear to do so, sometimes in spite of explanations given by the staff, sometimes because explanations, according to them, had been lacking.

Parents expressed a need to understand their children’s problems:

“I joined the Eating Disorders Association to try and understand better but it’s hard to understand. I don’t think I’ll ever understand. My husband doesn’t understand either (Int. 21, p 16).

They also wanted to understand the treatment, and how it worked:

“I’d like to know what they’re doing and why they’re doing it. Why are they doing, like, the games; what are the games for? To me it’s for trust and things like that, but is it? Because, as I say, I dinnae know, ken (Int. 9, p 13)?

Psychosis, schizophrenia in particular, was difficult to understand because it is not well known. Parents tended to be surprised by the low-key treatment (designed to cut down stress), the absence of psychotherapeutic dwelling into the past, the aggressive medication. They wanted to push their children on to resume their schooling quickly. Yet it was difficult for them to hear members of staff's efforts to explain. Emotionally, it was a difficult message to assimilate and imparting it was a form of therapy. Consequently, a number of parents appeared to have understood and accepted the nature of their children's problems but others had not. Of the parents whose children had been psychotic, some thought they had been given enough information and all of these except one appeared to the researcher to have a realistic grasp of the situation.

"We had to learn from scratch. They told us and we had a lot of family meetings and discussions. The discussions obviously matched up what we were seeing... We were given a lot of written information about the illness. We were given at that time a tremendous amount of support" (Int. 7C, p 10).

Nevertheless, two mothers worried that their children were not receiving the right treatment. Both expressed the wish to see their children receive a form of counselling that would 'get to the root of the problem'.

"Because I do feel there's something deeply buried in Alan that he's just not got out yet... Something in there is wrong. And the hospital is giving drugs, they're feeding him, they're there to talk to him if he needs something but I don't think they're giving him the proper counselling, medical help at all" (Int. 13B, p 12).

The young people, however, had been diagnosed as having, respectively, a psychotic form of depression and schizophrenia, neither of which was likely to respond to psychotherapy, although both were receiving regular supportive counselling. Either these parents had not been given or they had not assimilated the psycho-educational message appropriate to their needs.

3.2.4 Involvement in Decision-Making

Parents wanted to be involved but they meant this in a general way: they wanted to be part of the treatment team through information and consultation. Several said that they did not understand the issues sufficiently to make informed decisions and that, as long as they had explanations and were given an opportunity to agree, they preferred to follow the staff's advice. This was particularly true with regard to medication.

"As far as the medicine side of things, you know, we just trust the doctor to prescribe the best thing and see how it's affecting her" (Int. 5B, p 19).

The majority of the parents interviewed felt they had been consulted:

"We were consulted every step of the way" (Int. 7C, 8).

Occasionally a parent complained of powerlessness: although they were involved, they felt the terms were the staff's:

"Well, I'd like to make a lot of decisions... Really we havenae got any say. We can go up and say to them 'well we think this, we think that' but it takes a wee while for things to start to move" (Int. 9, p 14).

Rosie's parents, who had agreed with forms of treatment they did not like, such as inpatient residence and ECT, felt that they did not have any real choice since there was nothing else on offer and they were desperate:

"With ECT we did have a say in it. They recommended she had the treatment as a last resort and obviously it takes a parent's signature to go on ECT treatment. I wasn't happy with it and I don't believe in her having it. It's something I don't believe in but er... she's desperate for help. So I did it for her, not for me" (Int. 5B, p 19).

The staff's power was keenly felt: during a discussion regarding Rosie's ECT, the Mental Health Act had been mentioned. Rosie's parents remembered this with resentment, as a

veiled threat that, should they withdraw their consent to ECT, the Mental Health Act would be invoked to override their decision.

“I voiced my concern and they talked about sectioning her. And I thought ‘well, I don’t think there’s any need for that!’ She’s still here and I am still prepared to put her here although I don’t like it, I mean... The only thing was I think maybe they felt that I was going to withdraw my consent for the ECT and I wondered perhaps was that the reason? We don’t know” (Int. 5B, p 21).

The power differential between them and the staff had led these parents to hold back their suspicions:

“It’s difficult to say to somebody ‘you’re just mentioning the section because we’re thinking about stopping this treatment’. That’s very difficult because you feel you’re accusing them of... having this big stick...” (Int. 5B, p 21).

Some parents involved during a long admission period stressed the need for decisions to be made in partnership between staff, young people and parents, all making the effort to compromise, acknowledge occasional mistakes and reach consensus as much as possible.

“We were involved, a partnership between ourselves, Sinead and them, it was group consensus. Normally we took counselling and discussion and the way forward became obvious to all parties, and there was no feeling of animosity” (Int. 7C, p 13).

One parent suggested that, apart from the skills of the staff, some parents also brought many life skills into the equation:

“Can I be big-headed there? I think as well we were quite good relatives” (Int. 7C, p 23).

Parents wanted to be informed and consulted even more than involved in the decision-making itself, although this varied from parent to parent and depended on several variables such as the nature of the problem, the length of the admission, the quality of the

relationships between stakeholders. But parents were sensitive to what felt to them like powerlessness, something which the staff seemed to underestimate.

In this section, the whole parent sample's need for involvement during a child's admission, and the multiple forms it takes have been presented. In two thirds of the cases, these needs were fulfilled while for a third they remained unfulfilled. The parents' involvement will now be considered unit by unit.

4. ISSUES SPECIFIC TO INDIVIDUAL UNITS

Table 5.3 (p. 152) suggests that one third of parents in the study felt their needs had not been fulfilled, but that almost two thirds had, with one parent remaining ambivalent. The parents who viewed their involvement in the unit negatively came primarily from Rannoch while Knoydart and Arisaig had one of the remaining two dissatisfied parents each. Fisherfield's parents (three sets) were all pleased with the service they had received. The units are discussed in ascending order of parent satisfaction.

4.1 Rannoch

Several possible variables could have played a part in making parents' involvement at Rannoch more difficult: the unit was in a rural area where distances between the unit and the parents' homes were long - in one instance 145 miles. Apart from this family who came from outside the region, the parents interviewed were in such a social position as plausibly to be intimidated by the status and knowledge of the unit staff. One family lived a chaotic life and would have needed focused effort on the part of the unit to be successfully engaged.

There were, however, additional unit-driven factors: on the one hand the unit's policy for involving parents was vague and it did not appear to be a priority (see Chapter 6, section 3). Several staff members had mentioned in their research interview that they had concerns about the unit's lack of parent involvement. On the other hand, the policy for involving

young people was detailed and carried out as a matter of priority. This may have made it difficult for the staff also to involve parents with a similar level of commitment. Especially if we take into consideration, firstly that three out five young people in the Rannoch sample were in conflict with their parents (so much so that one set of parents could not be interviewed) and that another family was partially estranged. Secondly, that, as outlined in section 3.1, there could be direct conflict between the needs of the young people and the needs of their parents. Involving both parents and young people seemed to be a challenge for all units.

4.2 Knoydart

Knoydart had had a policy of involving parents but, of its own admission, it had found it more difficult to keep up with parents since it had become a day centre. Most parents felt supported by the unit but a couple of parents mentioned being intimidated. Knoydart's complex treatment philosophy was not readily explained to parents and not easy for them to understand (group psychotherapy, modified therapeutic community). The consultant in-charge suggested in his research interview that a more successful engagement of parents would have required additional resources: hours of staff time for home visits, parent support groups and the specific attention and sensitivity that vulnerable chaotic families require:

"I think with the most sensitive parents we don't succeed and I think, you know, if we had more capacity and I doubt – I can't see us getting it – we could bring in the most sensitive, wounded, threatened parents in" (Int. 19, p 15).

Parents at Knoydart also found the out-of-hours on-call system unsatisfactory and unhelpful.

4.3 Arisaig

Arisaig did not appear to have a clear policy regarding the involvement of parents but family therapy was offered to some families and the staff tried to make themselves available when parents came in to visit their inpatient children. The consultant in charge also gave appointments to parents who asked for them and those who did seemed to find Dr White supportive and helpful. Some parents (the majority) were satisfied with the nurses' availability at visiting times and on the phone. One vulnerable mother, however, complained that she did not feel welcome and that the information she received was too limited.

4.4 Fisherfield

Fisherfield had a clear policy of involving parents and it was a priority. Being a day-centre did not hamper it. The staff put time and energy into meeting parents in the unit or at home, speaking to them on the phone, holding parent support groups, educating them about their children's psychosis and its possible meaning. The parents all appeared to feel welcome, informed, advised and generally supported. The study only interviewed three young people and their parents in that unit, which is a small sample. These were parents, however, whose experiences of the mental health services extended over several years and they all compared the unit favourably with their previous experiences.

CONCLUSION

The parents interviewed in the study made clear that they wanted to be involved and that they had needs of their own which they expected the units to attend to. The units were faced with the challenge of working with the young people in the unit and the parents outside it. Parents' and young people's needs could not always be addressed together; siblings had to be taken into consideration; distances, geographical and social, had to be transcended. All

this required commitment, skills and resources. According to the parents interviewed this was not always successful but two thirds felt satisfied with the help they had received.

CHAPTER 6: THE STAFF'S PERSPECTIVE

INTRODUCTION

Each member of staff interviewed was specifically asked how involved young people were in decisions taken in the unit concerning their lives there and how much work the unit did with parents. In this chapter, basic information about the staff sample is given in the first section, findings regarding the staff's perspective on young people's involvement in decisions in the second and regarding the units' involvement of parents in the third section.

1. BASE DATA

The units that participated in the study were similar in size except Fisherfield, which was small. Knoydart, Arisaig and Rannoch contributed six members of staff each to the sample and Fisherfield two, in all twenty. All the key-workers to the young people in the sample were interviewed to provide information and a context about the young people's treatment. In addition the consultant psychiatrist and the nurse manager of each unit were interviewed about the history of the unit, its role and its key policies. One occupational therapist and one teacher were added to the sample because of their central role in the staff team and to add another profession's perspective. One nursing assistant was interviewed at the suggestion of another interviewee (this is called 'snowball sampling', see Chapter 3, p. 74). All staff asked for an interview accepted it and all were interviewed in the unit.

	<i>Key Workers</i>	<i>Nurse Managers</i>	<i>Consultant Psychiatrists</i>	<i>Other</i>
<i>Rannoch</i>	3	1	1	1
<i>Knoydart</i>	4 (1C/N)	1	1	0
<i>Arisaig</i>	3	1	1	2
<i>Fisherfield</i>	2 (1C/N)	0	0	0
TOTAL	12	3	3	3

Table 6.1: Number, Type and Unit of Staff Interviewed

2. YOUNG PEOPLE'S INVOLVEMENT IN DECISION-MAKING

In their interviews, the staff members were asked about their views regarding young people's involvement in decision-making in their unit. All the interviewees made a distinction between decisions regarding treatment and decisions about everyday life (activities, house keeping, group dynamics etc.). The findings regarding these two aspects of the question are presented in two subsections.

2.1 Young People's Involvement in Decisions Regarding their Treatment

Treatment decisions aimed to address mental health problems, some of which were highly complex. Although the four units did not deal with exactly the same problems, there was much overlap, at least in terms of seriousness and length of manifestation. Some (Arisaig and Rannoch) treated young people at an acute stage of distress and took some of them in as emergencies. Others admitted young people with similarly serious problems but at a later stage, when the crisis had stabilised (Fisherfield). Knoydart treated young people whose problems were serious and long-standing but not psychotic such as depressions, eating or anxiety-based disorders. The treatment process for these problems, from admission to discharge, consisted of a series of smaller or larger decisions informed by several stakeholders, followed by implementation. While the overall goal was to resolve or reduce the young people's mental health problems, there were many sub-goals along the way

concerning safety, treatment and short-term life-management. These were the decisions in which the young people would participate, along with other stakeholders like their parents and a variety of professionals. The importance of the young people's contribution to this process varied from unit to unit. Analysis of the staff interviews highlighted variables which, according to the staff, affected the young people's contribution. These are explained in section 2.1.1. It also brought to light differences in the way each unit involved young people at each stage of the treatment process. This is presented in section 2.1.2.

2.1.1 Variables Affecting Young People's Participation in Treatment Decisions

One key-worker thought that it was more difficult to involve young people in decisions regarding their treatment than regarding day-to-day business and that the unit's success at this was variable:

"Probably to be honest it will be very variable... But probably things to do with the management of their illness, it's difficult." (Int. 5D, p. 7).

Most of the staff interviewed stated that decision-making regarding treatment was not straightforward because of the type of problems these decisions were trying to address, the age of the client group, the responsibility the staff had for their safety and other characteristics of this type of decision-making. Overall they brought to light a significant number of variables which they felt affected young people's participation in the decision-making process. Some of them originated in the nature of the problem, some in the staff, some in the young people and some in the unit cultures.

2.1.1.1 Variable Originating from the Seriousness of the Problem: Safety

Depending on a young person's state of health, a member of staff might take a more or less directive part in the discussion of a decision with that youngster. A referrer recommending emergency admission to a young person might feel there was no other option:

“Her physical state of health was very poor, she needed the support...and that was put to them [the family] as a... in a very directive way” (Int.19, p. 1).

Sometimes a form of treatment was recommended which the young person found repulsive yet the staff felt could not be bypassed:

“I think a lot of the time Sinead’s felt quite out of control, things like admission... She’s felt like, you know, she’s been saying ‘I don’t want to go to hospital’ and we’ve said ‘we really think you should’ and I know she’s felt hugely powerless, and not got a voice, and not listened to. I don’t know what we do about that...” (Int. 5C, p. 8).

On these occasions, a young person’s choice was between understanding and accepting, or resisting and fighting, adults’ firm direction, not between therapeutic options.

2.1.1.2 Variables Originating from the Staff

2.1.1.2.1. Use of professional expertise

In less dramatic circumstances, when safety was not at risk, some staff still had the conviction, born of their expertise, that some therapeutic options were more helpful than others. They would then try to persuade young people to make a certain choice or to persevere in a choice already made. If persuasion did not work, however, they would not move on to coercion.

[Medication and other treatment measures are] “ ...always discussed with them. Sometimes they’re not happy to go into groups. And I’d say with gentle persuasion most of them go into the groups, even to give them a try, even if it’s just for a few weeks. But there again you get the ones who point blank refuse: no interest in it, they don’t want to go. And there’s no point in forcing them because the work’s got to come from them” (Int. 10B, p. 18).

Here, where safety was not at risk, a young person had more freedom to choose between therapeutic options, but they received strong guidance as to which was the quality decision.

2.1.1.2.2. Skills for involvement

Some members of staff pointed out that to involve young people in decision-making new skills were involved. Maggie thought that, in order to be understood by young people and families, the staff had to learn to adapt their language:

“I think what we’ve learnt through the last few years is how to adapt our own language so that the young persons themselves should be able to understand” ... (Int. 8B, p. 12).

Christine, had had to adapt to a higher level of patient participation than she had been used to when she moved to the unit from an adult ward:

“I think when I first started it was very difficult to give the young people so much power I suppose and decision-making, because usually the nurses make all the decisions and discuss it with the patients and that’s it. But to actually be, you know, have them involved in absolutely everything that’s going on, that took a bit of getting used to” (Int. 11B, p. 23).

Consultant psychiatrist Dr White thought he was more likely to involve his young patients in decisions about their treatment than his junior doctors were. He had to teach them:

“It’s one of the struggles I have with my junior doctors. They’re much more likely to be autocratic with young people than I am. And I am much more likely to negotiate even with detained patients... even what medication, if there is a choice of equally effective treatments, what sort of things they’d like, trying to involve them in that” (Int. 13A, p. 13).

Involving young people in decisions regarding their treatment was easier and came more naturally when the staff were experienced and skilled at it. Knowing how to do it, for instance using words young people could understand, and knowing how far risks could be taken were two aspects of this.

2.1.1.2.3. Legal responsibility

Consideration of their legal responsibility for young people's safety was an inevitable part of the senior staff's thinking.

"Quite often we'll allow young people to make mistakes to help them learn, providing the mistakes aren't too disastrous. So we'll give them a bit of freedom about a diet plan when they are anorexic, and allow them to do it from week to week to allow them to see when they aren't managing a diet, let them try it out. But there's always the element of course that we've got legal responsibilities for their safety and well being, so we will be putting limits on what they're doing" (Int. 13A, p. 14).

When the Mental Health Act was involved, even ordinary day-to-day decisions were overshadowed by a psychiatric dimension. It was important but difficult to keep a balance between being responsible and abusing power.

"It's not about 'can I stay out until 11 p.m. tonight?' What it's about is 'Can I stay out until 11 p.m. tonight Dr White please and I've got schizophrenia and I am detained under section 18 of the Mental Health Act'. And then you're saying, 'oh right, well... How much choice do I give you in this? Because the law actually says you don't really have any choice in this... if you're detained... And what am I doing? If I say you can't go out, you can't'. That puts me in a powerful position. I have to be sure not to abuse that." (Int. 13A, p. 17).

The responsibility could weigh heavily in the balance:

"I am the responsible medical officer under law, for this group of patients and that puts quite a different onus on me. You know, if a detained patient commits suicide and I've written in their notes that they can have leave of absence, then that's a very clear um... focus of investigation for the fatal accident inquiry. That's around for me" (Int. 13A, p. 18).

The risk of litigation could make the staff in charge anxious. Some thought that young people's involvement in decisions ceased to be a right when they were detained under the Mental Health (Scotland) Act 1984, although they would make an effort to give some leeway.

2.1.1.2.4 Ability to acknowledge mistakes

Sometimes young people refused to conform to the professional advice given to them. Key-worker Mark thought this was more manageable than it might appear. The treatment recommendations were not always right and, although it was difficult to admit it, it was important to do so.

"[Some] young people will actually say themselves: 'I don't want to do this, and perhaps even vote with their feet... But ultimately obviously we can't force them. And we're not necessarily right... I think we also have to admit when we're wrong, because we are wrong at times..." (Int. 6, p. 3).

Young people might know better what was right for them sometimes and the staff had to be able to back down when necessary.

2.1.1.2.5 Individual good will

Some individual members of staff demonstrated in their interviews and through the field notes that they had a personal commitment to involving young people in their work, independently of the unit's own policy.

"In terms of what I do with them I always ask them and I always try and use their ideas. Say I have something planned and then they will ask to do something else, then I would always use what they wanted to do and try and organise that for them. Sort of assist them to organise it if that is appropriate... In the group work that we do, and also in individual sessions, definitely..." (Int. 15A, p. 15).

This difference in approach to young people involvement between unit policy and individual staff members could cause friction:

:

"Sean: At the moment the only kind of decisions that I can see that young people and their families are involved in are passes to home, and that is about it really. They should have more.

Res.: What else could they be involved in do you think?

Sean: Treatment regimes and really be filled in an awful lot more and asked their opinion an awful lot more" (Int. 12A, p. 15).

This key-worker's views about his unit's commitment to young people participation were shared by two other junior staff members and reflected by comments in the field notes.

2.1.1.2.6 Power differentials

The staff were more powerful than the young people. This put young people at a disadvantage in negotiations about treatment decisions. Key-worker Maeve felt Sinead was overpowered when they wrote a care plan together. So Maeve changed her approach:

"[Sinead] went away with [the care-plan] and she came back and she said 'I've thought about it and it's too difficult' ... I think that was really helpful because she actually felt that when she was planning with me she wasn't able to really get her point across. So I've been doing this much more. Saying 'go away, bring me back what you want' and I think that feels more empowering" (Int. 5C, p. 8).

The negotiations about treatment decisions took place in context of uneven power. This member of staff felt she found a way of empowering the young person.

2.1.1.3 Variables Originating in the Young People

2.1.1.3.1 Maturity

Some key-workers wondered how allowances might be made for the young people's lack of developmental maturity. More immature young people needed more guidance in their decision-making. Key-worker Christine was happy with the balance of participation and control her unit had established.

"I think some of them might be fifteen, sixteen but some of them are quite immature for their age. I think some of these young people might need a bit of a hand and need us to maybe take the lead... I do think that if it was left entirely up to the young people, then it would be a riot and staff need to be there to control things. So I think we do that quite well. I don't think they control the unit, but they participate" (Int. 11B, 24).

It was difficult to treat young people successfully against their will. They were expected to reflect upon themselves and their lives and to bring changes. Some young people did not

perceive a need to do this and working in partnership with them was not possible. Unless their need for treatment was acute, they were best to postpone it until they could face their need of it.

“Sometimes I think they don’t agree with us because they’re not ready for change and that can put blockers on you being able to work with them in partnership if they’re not ready to admit that that’s a problem or they need to make a change there and that can make a difficulty...” (Int. 15B, p. 16).

The consultant, Dr White, was concerned about developmental immaturity affecting decision-making:

[How can we involve them] ... “...without falling into the trap of seeing them as more developmentally advanced than they are? And recognising that you can’t make the same proper decisions, whoever you are, aged 14, about your life, as you can when you’re 34. And how do we involve them, without making them feel on one hand patronised, on another hand them thinking it’s a pen and paper exercise so that they’re seen to be involved, and also without allowing them to make decisions that are too big for them yet to make” (Int. 13A, p. 16).

This was not a concern shared explicitly by other senior staff.

2.1.1.3.2 Mental state

Sometimes adults had to make unpopular decisions with the best interest of a young person at heart because illness stood in the way of young people being able to make a good decision.

“What the young people sometimes feel is that the adults, parents and the staff, come to decisions that the young person is not satisfied with, and there’re certainly one or two at the moment who feel the adults are thwarting them...It’s not adults saying they know best, but trying to work in the young person’s best interest when their decision-making skills are impaired by illness” (Int. 13A, p. 14).

Often, the young people did not agree with this assessment. The thwarted young people referred to in this account were two fifteen year-old girls who were anorexic. Their views

regarding diet and exercise were significantly different from those of the staff or of their parents. Anorexia Nervosa makes a logical assessment of such issues impossible.

2.1.1.3.3 Adolescent strivings for autonomy

It has been considered a normal aspect of development for adolescents to take their distance from adults in order to find their own way (Evans 1982). They may need to test out the adults' ability to set them limits. Key-worker Susan expressed concern that treatment could become a battleground between young people and key-workers in the process. Even treatment targets agreed earlier might be turned into a fight. How could you respect a young person's autonomy, yet serve her best treatment interests at the same time?

"I push [X] all the time because she can't get out on her own, so I am pushing her and she feels that she has no say in what's happening and I try to give her a say, but at the same time I am always having to push her, otherwise she wouldn't go out at all" (Int. 11, p. 7).

Another key-worker, Mark, put this in another way:

"I think aims of therapy often get mixed up with limit testing or limit setting. I don't think I've met a young person yet who doesn't test the limits in some way. There are two things here and there's a tension between the two things" (Int. 6, p. 3).

Key-worker Ruth described Isaac's inability to agree to anything positive proposed by an authority figure:

"What happens is if I pin him down to say 'you'll have to tell me yes or no', he will be compelled to say no. So I just say 'I hope you're going to say yes' ... and you know, as much as we can, without completely lying down and being complete doormats, we try and do that" (Int. 4C, p. 9).

To manage not to become trapped into a fight about treatment by rebellious young people required ingenuity on the part of the staff.

2.1.1.4 Variables Originating from the Unit Culture

2.1.1.4.1 Limited flexibility in the existing treatment programme

Each unit was limited in the amount of choice it could offer a young person by the variety and flexibility of its treatment programme. Units which, like Knoydart, had developed a strong culture over many years and offered a social form of therapy through a collective programme of activities, were less willing to let an individual make decisions which did not fit in the 'framework' as key-worker Susan called it.

"I think they can make decisions, but I think the framework [of the unit] is quite firm - and I think we are talking here about years and years - I'm not saying that's wrong because it's probably a tried and tested way, I mean I do think things around here work, so I think they have decision-making within a framework" (Int. 11, p. 6).

Sometimes young people expected something different from what the unit offered. Key-worker Mark thought conflict between them and the treatment team regarding the main goals of therapy was not sustainable.

"I guess, we do come into conflict sometime, between what we expect, what we aim for and what the young person would like to aim for. Sometimes that means we can't actually work with a young person" (Int. 6, p. 3).

Negotiations and empowerment did not always lead to partnership. They could also end in separation.

2.1.1.4.2 Unit policy regarding young people participation

In all four units the senior staff professed that they involved young people in treatment decisions, yet there were variations. The key-workers gave more nuanced views and divergence between the opinions of the senior staff (consultant psychiatrist and nurse manager) and the key-workers was an indication that the participation of young people was problematic. This was the case in Arisaig and comments from that staff team are contrasted below with comments from the Rannoch team which were homogeneous. Findings from the interviews were also compared with the field notes. These units were chosen for this

section because they were both inpatient units working with young people impaired by serious and long-standing mental health problems, including psychosis, thus showing how different participation policies could be in similar units.

In Arisaig, the nurse manager described the participation process as one by which young people told their key-worker or doctor what they wanted. These professionals then took these views to decision-making arenas only attended by staff where the decision would be made informed by the views of the young people. The process was explained to the young people and they were frequently reminded of it. The emphasis was on them actively managing their dissatisfactions, needs and wants.

“I like to think that actually, that is part of the culture to speak up either for yourself or to be represented and there are a lot of kids make comments and are unhappy about something. And, you know, what you are going to do about it? Who will you speak to about that? ...And there’s a lot of encouragement for the kids to do that...” (Int. 10A, p. 16).

The consultant explained that the young people were expected to ask questions.

“From the outset, from the very first interview, we’re saying ‘ask questions’ from the word go. ‘If you don’t know, if I’m not making myself clear, ask questions’. So we hope we evoke in young people a curiosity to ask about the programme” (Int. 13A, p. 13).

The onus of participation was on the young people. However, other staff from the same unit did not think this policy of having young people ask questions and lobby representatives with their wishes and complaints worked. They thought it did not replace the young people’s attendance at treatment planning occasions, which did not happen.

The community meeting, which could have been an opportunity for young people to give their points of view, was not used in that way:

“I think a lot of it [the community meeting] is to give the young people information from staff. And at the same time I suppose give the young people an opportunity to voice their opinions, but I don’t think they often do” (Int. 9A, p 14).

It became clear that participation at Arisaig was not followed through and that there was no decision-making structure to support it, although several staff members, senior and junior, wished it to happen.

In Rannoch, by contrast, a strong policy was in place. It had increased slowly in line with national policy, as the consultant explained:

“I think it has been a gradual process over the last years with the new Children Act legislation and people being much more aware of consent and issues of consent. I think it’s been more a gradual process than a sudden one... I think it’s been the right process...I think you have to [consult the young people] for the unit to be a success. People have to be here because they want to be” (Int. 14B, p. 11).

A key-worker in the same unit offered a similar perspective:

“I don’t think nurses should make all the decisions. We can recommend and hope that our recommendations are taken up” (Int. 11B, p. 24).

One member of staff worried that this policy had gone too far and was concerned that young people had too much say, particularly over and against their parents. This issue will be pursued further in the next section.

“I don’t know if the kids have too many rights... but the kids have definitely a lot of weight here. I am not against that, but we just don’t seem to see it from other people’s point of view at times, which is worrying... It’s worrying me that a wee bit” (Int. 12B, p. 6).

Although working with a similar client group, these two units involved young people in their treatment in a different way and to a different degree. The most accurate reports about the effectiveness of the unit’s participation structures came from the key-workers.

2.1.1.4.3 Lack of resources

Sometimes an issue of resources prevented the staff from carrying out a young person's preference regarding her treatment. This was the case when Sinead had asked for a member of staff to accompany her every day of her first week back at her own school. She felt strongly that anything less would be too stressful. But a member of staff could not be spared.

2.1.2 The Treatment Process and its Stages: Young People's Involvement

In all units a standard treatment process was used that involved three main stages at which decision-making was called for: at the time when admission was considered, at approximately six-weekly treatment reviews when the young people's mental health problems were assessed, treatment implemented and reviewed, and at discharge. Two of these three major stages will be presented in the first section. There was no data about the third stage, discharge.

In addition to these major treatment stages, there were two minor ones: weekly clinical discussions took place among the multi-disciplinary team to update the treatment plans, and care plans were written by the nurses to guide the everyday care of the young people. These two minor stages will be presented in the second section.

Two units, Rannoch and Fisherfield, had an explicit policy of young people participation. Their contribution was carefully scripted into the treatment process at every stage. One unit, Knoydart, run its day-centre along therapeutic community values (see Chapter 2, p. 40). Young people were involved in most aspects of the unit's life because they were members of the community. Arisaig had no coherent policy or structure of involvement. In their interviews, members of staff conveyed some of the challenges of each stage.

2.1.1.5 Major Stages

2.1.1.5.1 Admission

When treatment was desirable but not critical to the safety of a young person, which was the case of most young people admitted as day-patients, the willingness of the young person to be referred and admitted was indispensable, as the consultant of a day-unit pointed out:

“They obviously first get involved because we are discussing the possibility of their referral to [the unit] and you would not make a referral if they didn’t agree” (Int. 19, p. 1).

The nurse manager stressed that they did not expect young people to want admission to a psychiatric unit, although they did not expect them to come against their will either:

“There’s bound to be some persuasion in getting young people into the programme but we don’t accept young people who are kind of coerced into the programme by somebody else. They’ve got to have some volition themselves so they would be able to say no, if they felt that strongly about it. Most people don’t want to come - it would be something strange if they did” (Int. 7, p. 2).

At this stage, the staff saw it as their job to make the unit attractive to the young people, to allay their fears and to facilitate an informed assent to admission.

“...Talking about it and the arguments for it, listening to what their fears are... And then having a look around the unit and be shown around... And then they can come for coffee and meet other young people, their key worker...” (Int. 19, p. 1).

This nurse-manager thought the nurses in his unit were good at encouraging young people to see treatment as something worthwhile because very few young people dropped out at this stage.

“I think most of the time we are reasonably good at engaging young people. Good in that when they’re referred here there’s very few people reject the

treatment, there're very few people who don't come along. So in that sense, and at that stage, most young people can vote with their feet" (Int. 7, 2).

The consultant of an inpatient unit, dealing with a young man in an acute psychotic state who might have warranted an emergency admission under the Mental Health Act, thought that even then there was room to help this young man make his own decision.

"I think it would have been very easy on Tuesday when we saw this boy to have got into an immediate confrontation with him there and then, and then to end up sectioning him. Whereas, because I'd seen him the day before and I was fairly confident that it had been going on for a few weeks... It involved probably a little bit of risk taking but we'd been very clear with him and the mother that they could phone any time and say 'he's on the way' and hopefully by doing that we might have avoided the use of the Mental Health Act... We won't know until we see him this morning" (Int. 14B, p. 12).

These interviewees thought choice was essential in the case of non-emergency admissions. Interestingly, an experienced psychiatrist thought she could also introduce choice in an emergency one and she tried to.

2.1.1.5.2 The Treatment review

Treatment reviews were regular meetings held every six to eight weeks to review a young person's progress. The first review usually dealt with a multi-faceted assessment of the problem, those that followed with treatment. In three of the four units, the young people attended the treatment review, often with their parents. Their presence allowed them to contribute their own information about the problem and the treatment and to be involved in the planning of the next stage.

The treatment review replaced what a few years earlier had been called the case conference. This only involved the multi-disciplinary team and decisions were communicated to young people and parents afterwards. Arisaig still operated in this way but the staff talked of including the young people soon. The comments of its staff are presented first. The comments of staff from Knoyart and Rannoch, who invited young people into their treatment reviews, are given second. All highlight similar staff anxieties raised by reviews

but a contrast of solutions. The units which involved young people in their reviews were proud of doing so.

In Arisaig, the consultant was keen to involve young people in their treatment review and hoped that a decision to that effect would be made soon but he expected the professionals to want time without young people and parents before the review in order to discuss them. So he anticipated a need for a two-tier meeting: a first part reserved for the professionals and a second to be shared with the young person and the family.

“I think [the review] is a very appropriate time for professionals to get their heads together because when we’re uncertain about diagnosis, that sort of wrangle shouldn’t take place in front of the young person. I think it’s distressing and anxiety provoking. But I think when it’s feedback, and it’s a discussion about planning, then I do think the young person herself should be involved. I’d like to have a two-phase case-conference, half an hour for professionals, half an hour with young people and their families in, I’d quite like to do it that way” (Int. 13A, p. 15).

In Knoydart, by contrast, the case-conference had been done away with for two years and had not been replaced. There was a treatment review that young people attended throughout.

“Now we don’t have a case-conference. The review is what used to be the case-conference. So we actually say how it is, we make our decisions in the presence of the kid and, if the kids want it, if it’s appropriate, their parents. So we don’t have separate case conferences anymore” (Int. 19, p. 13).

The staff did not spend time on their own prior to the review but they were expected to have informed themselves about other people’s points of view.

“Instead of everybody involved being in the case conference we drop out half the people. So it’s relatively small... but there is an expectation of consultation. People wouldn’t go in disarmed, without knowing what other people think. They have a pretty good idea”... (Int. 19 p. 13).

In Arisaig, where young people did not go into the review, there was an expectation on them and their key-workers to inform each other about their respective positions. The key-workers could then take the young person's perspective into the review. Once made, decisions were passed on to the young people but they were then beyond discussion. Several key-workers expressed frustration about this.

"I feel a bit disappointed that they and their families aren't at the reviews actually. I think that is quite odd as well... I think that would be a good learning experience for all of us. It would mean that they were more involved" (Int. 15A, p. 16).

The nurse manager of Knoydart, where young people had been going to their review for the last two years, thought the treatment review was the main arena for young people's involvement in their treatment.

"They're involved in the process of decision-making by basically giving them a chance to talk. We make the reviews as small as possible. The review's gone over with them beforehand and they'll also have a sheet about family history and stuff on which they'll be able to comment"... (Int. 7, p. 11).

Other Knoydart nurses thought the young people's participation in their review was a challenge because it was difficult for them to make use of it:

"I think the platform of a review can be quite difficult for a young person... they are given different mediums to help bring their thoughts to it so we don't expect them to come and talk... We try and make the meeting as small as possible for them but we don't expect them to come and say this is what we want. They can write it down, either they can read it out, or their Mum..." (Int. 8, p. 8).

One of the key-workers could offer their services as advocate:

"You also work with a co-worker. And you can try, like, Susan is my co-worker and if I'm the young person's main key-worker I've often asked Susan to meet with them before a review, or something. To actually say 'I'm in this review as well, can I help? If there's something that you want to say that might be helpful, can I take it for you? Will you be able to say

something?' I suppose to try and help them feel that they have an ally. But I think that it can be hard, it can be an issue" (Int. 8, p. 9).

In Rannoch, where young people also went into their reviews, the professionals only stayed in the meeting for as long as they had business there. Teachers, social workers and others left once the decisions that concerned them had been made while the young person and the family stayed throughout. This, said the nurse manager, was to convey the message that the review was for the young person, not for the professionals. In that unit they were aware of having adapted their language to fit the needs of young people and families. One member of staff also discussed the potentially upsetting nature of what young people heard in the review but thought it was preferable to keeping them in the dark and to incite suspicion of what was being said behind their backs.

"Sometimes young people do get upset in reviews...Our sense is that if young people are there they have no sense of things happening without their... you know, involvement and so suspicions and things are, you know... dampened, because they're opened to all. And yeah, they can be very painful, very difficult; sometimes families get upset in it as well. But we've found that in the long run the openness actually in some ways helps support the relationship between staff and families" (Int. 8B, p. 12).

All the staff interviewed wished to involve young people in their reviews but in Arisaig, this had not yet happened. One staff anxiety was about the need to make time for the professionals to inform each other without the family being present. In Knoydart and Rannoch, the professionals were expected to gather information informally before the review. No special meeting was provided.

When young people were not in their review, as in Arisaig, someone had to represent their point of view. But even when they were in the review, it was clear that speaking on their own behalf was intimidating. Knoydart provided a nurse-advocate. Rannoch kept the meeting small and taught the staff to speak in simple language.

Discussions taking place in the review could distress young people. Rannoch staff thought this could be dealt with and that honesty bred better relationships between young people and staff.

2.1.1.6 Minor Stages

2.1.1.6.1 Weekly clinical discussions

Between the major stages of the treatment process that took place every six weeks, there were weekly gatherings of the multi-disciplinary team to share information about all the young people's progress and make any necessary decisions. The young people were not involved in this meeting in any of the study's units at the time of the research. In Rannoch, however, it was stated that young people would have been welcome had they wished to be there and had they been free at the time (this meeting was held in the morning while the young people were at school).

In Arisaig, an inpatient unit, evening and weekend time-out was decided in the weekly clinical meeting and the decision was communicated to the young people in the community meeting that followed. The young people sent their requests to the meeting through a staff-representative and waited eagerly for 'feedback' to hear how their wishes had fared. They were particularly keen to know if they would be allowed to go out that weekend. The general feeling was that they never got what they wanted.

"Moira [a young person], explained what feedback from [the clinical meeting] was. She said that young people put in their wish but it was a waste of time and they never got what they wanted. At that point Helen arrived and confirmed that" (Field notes A, week 5, p. 4).

2.1.1.6.2 Care planning

Care-planning was a nursing task which allowed the nurses to apply the treatment decisions made in multi-disciplinary meetings to day-to-day care in the unit. Traditionally care plans were decided by the nurses, then shared with the young people. In Rannoch, joint care planning between young people and key-workers had been recently implemented. The nurses had struggled with it initially.

"Working in partnership is really important and we've been working quite hard on promoting that in terms of the care plan... They are actually done together with the key-worker and the young person so they actually sign them to show that they have taken ownership of the care plan with the key-worker" (Int. 8B, p. 9).

In Knoydart and Fisherfield, shared care planning took place most of the time although the young people did not sign their care plan. In Arisaig, two key-workers mentioned but they felt powerless to bring about changes.

“I feel in some ways it could be better in terms of would you want to show people their care plans and things like that when they [care plans] are very locked away. For some it might be worth drawing them up with them. It wouldn't work with everybody, but I think you know, the likes of Kate now, I think she should be seeing what we are thinking and working towards discharge together” (Int. 9A, p. 8).

A process of shared care-planning was explicitly implemented in one unit. In two others care plans were discussed with young people. In one unit the care plans remained the nurses' task.

Overall, partnership with young people regarding their treatment was seen to be desirable but difficult and a number of variables in the possibility of young people's involvement were identified. The treatment process itself involved several stages at which decision-making was required. Each stage brought certain challenges and each unit dealt with these in their own way. Rannoch had a clear policy of young people involvement. Its staff offered a coherent account of how it was carried out. Fisherfield and Knoydart also involved young people. The message from Knoydart staff was interesting and nuanced, although less cohesive than the message from the Rannoch team. Arisaig betrayed conflict among the staff regarding young people's involvement. There was no clear policy and partnership was limited.

2.2 Young People's Involvement in Decisions Regarding Everyday Activities

The young people were more involved with decisions regarding their daily life in the unit than in their treatment. A large proportion of the staff interviewed said this, and the field notes testified to it too.

In Knoydart, Jan thought that involving young people in the life of the unit at every level was a strong part of the unit's philosophy:

"I'd like to think they have as much input into the day to day running of things as they possibly can. One of the aims of here is that they're involved in what we do" (Int. 8, p. 8).

The physical environment of the unit, the house itself, was partly entrusted to the young people's care through what were called 'duties', like watering the plants, putting the dinner in the oven, keeping the lounge tidy. The young people made decisions about outings and camp.

"Camp was discussed. Daph [staff-nurse] wants the young people to decide what kind of food they want to order from the kitchens and Susan [staff-nurse] wants them to think about activities they'd like to do while there" (Field notes, week 5, p. 5).

At Fisherfield, Meave thought that it was more difficult to involve young people in decisions regarding their treatment than regarding day-to-day business.

"I think that sometimes we are very good at involving them in what we are going to do like... practical things, positive things. I think we're good at organising camp, you know, deciding what young people want to do and things like that" (Int. 5C, p. 7).

Everyone interviewed in Rannoch thought the young people participated actively in decisions regarding the life of the unit, although at times, some of them might be too preoccupied to pay much attention.

"If it's something that's going to involve the young people, they're asked, questions are put to them, discussions are made, they might not always want to participate and, you know, let you know how they feel but they're usually given the options to put their point across" (Int. 10B, p. 17).

According to the staff in all the units, young people were more involved in decisions regarding ordinary aspects of life than in treatment decisions. All the units seemed to manage a high level of involvement.

Conclusion

The staff interviewed perceived the involvement of young people in the life of their units, particularly in treatment decisions, as a complex endeavour and they quoted many variables that influenced its success. Although all the staff in the study asserted an interest in involving young people, they varied from each other in their ability to implement it. The type of mental health problems they dealt with in treatment was invoked by some as making a difference in the possible level of involvement. While the young people's mental states and their legal status under the Mental Health Act appeared to make a difference, units dealing with young people with serious problems like Rannoch and Fisherfield still managed to achieved a high level of young people participation.

3. PARENTS' INVOLVEMENT

In their interviews all the staff members were asked how the units involved parents or carers and the family in the young person's treatment. The young people's carers at the time of the study were all parents except one set of grandparents, therefore the term carer will not be used further in this chapter.

Introduction

A careful read of the staff interviews revealed that a basic level of parent involvement was taken for granted. Parents or their substitutes were always part of a young person's admission.

For young people under sixteen, the minimum required of parents seemed to be their acceptance of the young person's admission and treatment, a minimum of communication

with the unit staff and a willingness to provide the young person with a reasonable level of care outside the unit. If parents refused treatment, which was rare, alternatives had to be found, either to the parenting or to the admission. An example of the former was seen in the study: the relationship between a fifteen-year-old girl in the sample and her parents broke down as a result of her admission. Because treatment was strongly recommended and she was keen to co-operate with it, substitute care was sought from the social work department through the Children's Panel. If pathways to treatment other than admission existed, a young person might not be admitted.

"Sometimes we won't be able to work with parents... I think ultimately if you're offering treatment on quite a lot of experience and based on a process of negotiations, and at the end of that negotiation we were still at the other end of the scale then er... I guess we would have to say, well... That doesn't happen very often. In fact it happens extremely rarely..." (Int. 7, p. 13).

Older young people, like adults, needed a 'next of kin': a relative, a friend or a statutory agency.

Occasionally, some parents did not wish to get involved but to make the most of the respite offered to them by the admission of their son or daughter to the unit. This could be a problem for the unit:

"There's a sense of sometimes when families and young people come here, that their responsibilities are then diminished and there is an expectation that the nursing staff and the doctors will then be responsible for all their behaviours... So we have to do a lot of work on that, and not get caught up into a vacuum where we're expected to take on parental responsibilities" (Int. 8B, p. 16).

In other words, adolescent units did not shoulder responsibility for a young person's treatment without adult support external to the unit. Therefore the findings described here do not question the need to involve parents, they relate the staff's views about the way it was carried out.

Analysis of the staff interviewees' discussion of parent involvement yielded four themes. They are explored in the four sections that follow.

3.1 Young People's Priority over Parents

Several members of staff stated that young people were the unit's primary responsibility, not their parents. One of the three consultant psychiatrists interviewed reflected that she had seen a shift in her unit's work during the previous ten years towards young people and their rights. She was not sure of the origin of it. As a result, parents were less involved than they had been.

"I think we may have lost a bit of our cultural involvement with parents..."
(Int. 19, p. 2).

The second of the three psychiatrists was clear about whose views regarding the young people's treatment were more important:

"I think first and foremost are the views of the young people, second are the views of the parents..." (Int. 14, p. 12).

In two of the units, being sixteen gave young people extra rights to involvement and decision-making: from then on, their parents would not be approached without their consent (Int. 7, p. 12, Int. 11, p. 7, Int. 4C, p. 16).

These priorities meant that in the case of a disagreement between young people and their parents, the staff would be more likely to support the young person (Int. 6, p. 4).

"I think that's because we work with young people and we are for them much more although ultimately it is not about taking sides, but we do end up taking young people's side much more than parents" (Int. 6, p. 4).

This message, about the young people's priority over their parents, was not unanimous however. It came only from the staff of two out of the four units. Even in those two units,

only some staff took this view. This suggests that units, and staff members within one service, held diverging views regarding the importance of parents.

3.2 The Structure of Parental Involvement

In section 1, regarding young people's involvement in decision-making, the treatment process was described as having major stages. This structure is also used in this section. The major stages were admission, treatment reviews and discharge. Discharge was not discussed in the interviews but the two other major stages, admission and reviews, are considered in section 3.2.1. Contact between parents and staff that took place informally between the major treatment stages is the object of section 3.2.2. Some parents and families were involved in activities that were explicitly therapeutic. This is discussed in section 3.2.3.

3.2.1 Parents' Involvement in the Major Stages of the Treatment Process

3.2.1.1 Admission

Pre-admission visits, when parents and young people came to see the unit and meet the young people and staff, were a common procedure in all the units, unless the admission was an emergency, which, in the case of Arisaig, was the case 50% of the time (Int. 10A, p. 13). In some cases, the family was also visited at home before admission.

3.2.1.2 Treatment Reviews

Treatment reviews were regular formal opportunities all the units had to review a young person's treatment progress. Until recently, reviews, which used to be called case-conferences, only involved the multi-disciplinary team. Three of the four units in the study now involved the family. In Fisherfield and Rannoch this was done systematically:

"At the end of the three-week assessment we have a review to which families are invited. And that's very important – unless for some reason parents might select not to come. And then, after that, we have the six weekly review to which parents are invited" (Int. 14B, p. 13).

Initially, Knoydart had only invited young people into the review, not their parents. Then one young person had expressed the wish to bring a parent and since then parents were always invited. Dr Black felt this was too rigid and parents should not be systematically expected into reviews because some young people might be more comfortable without their parents there. They shouldn't be made to feel offensive or rule-breaking for saying so. Therefore each review should be dealt with on its own merit (Int. 19, p. 12).

This was not Knoydart's nurse manager's point of view. Ruth wanted to have parents in reviews as a matter of course, unless the young people were over sixteen, in which case they could choose.

"We prefer to involve the young people's parents unless there is a really good reason not to involve them. So they would all be asked to attend the review... Because it's partly you want to work together with parents, help them to help the young person get better and stuff so you want the parents on your side..." (Int. 7, p. 16).

In Arisaig, neither the young person, not the parents were invited into the review. But while the young person would be met afterwards to hear about the decisions taken, no meeting was scheduled to take place with the family. Parents were simply encouraged to phone that evening to hear what had been discussed and decided. The nurses who answered the phone at that time of night however, were on a late shift. Therefore they had not been at the review, which took place in the morning. Hence the report was second hand. The nurse manager, and other members of staff interviewed, thought this unsatisfactory:

"I think a family meeting maybe [is needed] after the review so that it can be discussed...because what happens is, it is usually left to the nursing staff to feedback to the family that evening whatever, and maybe they weren't even in the review, and that is no good to anybody" (Int. 15A, p. 16).

It is interesting to note disagreements here again, between and within units. Three units involved parents in reviews and one unit did not. In one of the units that did, Knoydart, the senior staff interviewed had different opinions regarding the desirability of involving

parents. In the unit that did not, Arisaig, the staff interviewees also held different and conflicting opinions about what should be done.

3.2.2 Parents' Informal Involvement

In all the units, engaging parents in a relationship of trust was delegated largely to individual key-workers, as this consultant psychiatrist explained:

"I would expect, you know, that for any young person here, the nursing staff would be in telephone contact with their parents at least once or twice a week" (Int. 14B, p. 13).

Apart from telephone calls, there could be scheduled visits to meet a key-worker and informal contact when parents accompanied a young person to or collected them from the unit. This was more likely to occur in an inpatient than a day unit where the emphasis was on the young people turning up and participating. Therefore informal contacts were more successful in inpatient units (Int. 19, p. 2). Parents could also request to meet any member of the treatment team.

Two key-workers thought that relying on telephone calls between reviews was unsatisfactory. They suggested that weekly meetings, some of them in the family home because parents might talk more easily in their own home, would be more helpful, but this was not systematic practice (Int. 11B, p. 25, Int. 15B, p. 17).

The parents' ability to respond was a significant factor in the success of engagement, as this key-worker suggested:

"Looking at the parents I've been involved with, they've been involved, like, to completely varying degrees. I think you always make it an open invitation to parents. They can phone us as often as they want... I know I quite often invite young people's parents on a weekly basis, or else I would phone them... We always encourage parents to contact us, so we probably take the lead from them...(Susan, Int. 11, p. 8).

Working with parents lead key-workers to make decisions regarding the frequency and nature of the contact required. This was a responsibility for which some key-workers received help and guidance in clinical supervision (Int. 8B, p. 17), which was regular practice in all but one unit.

Generally, the form and frequency of parents' informal involvement varied within units and between units. The most common types of informal contacts were telephone calls and casual encounters at the unit. The parents' willingness and ability to initiate contact with the staff made a difference to the success of their informal involvement.

3.2.3 Parents' Involvement in Therapeutic Work

Therapeutic work was independent of the parent involvement activities described above. It was part of the treatment programme and only took place when felt to be necessary. Only qualified members of staff practised family therapy. In the four units involved in the study, none of these were nurses.

Fisherfield worked on a therapeutic model aimed at early intervention in the treatment of psychosis. This included a programme of support and psycho-education with the family.

"Ours is a teaching, information sharing model, skills training model. You know: 'we provide you with the information, we provide you with the evidence, we are not the experts, we just show you that this is the sort of things that work and help you to work out ways of doing this sort of thing yourself'..." (Int. 4C, p. 11).

For Sarah and Sinead's parents, the initial support had taken place in their home:

"Callum and I went out to the family, I think on a fortnightly basis for a few months. So we did home visits and became very involved with the family at that time" (Int. 5C, p.1).

Fisherfield checked with young people before inviting parents and remained available to parents after their son or daughter had been discharged.

“We invite all interested parents, and [check] that the young people are okay about us inviting. But we also allow, we also invite and continue to remain open to parents whose young people have moved on” (Int. 4C, p. 16).

Individual family work lasted for a few months and was followed by a relatives’ group. The individual work allowed to meet the family’s specific needs and the relatives’ groups offered parents an opportunity to encounter people in similar situations to their own, to give and receive support and to provide hope that things might improve.

“You have the kind of shared experience thing as well of people whose son or daughter has just broken down and they’re saying things and feeling things, and there are other parents in the group who are two years on and can say ‘I can remember feeling like this and a lot of the time, hopefully, it gets better’” (Int. 4C, p. 15).

Multiple family groups – groups gathering several families for mutual support – did not take place in other units but they had been suggested as desirable by members of staff in Knoydart who were thinking of establishing such a group (Int. 19, p. 14, Int. 11, p. 8).

In summary, therapeutic work with families varied: it took place systematically in Fisherfield in the form of psychoeducation regarding psychosis. In the other three units, it only took place when it was prescribed as a form of treatment, over and above the other transactions of parental involvement.

3.3 Staff Respondents’ Evaluations of Parental Involvement

The staff’s evaluations varied, demonstrating widely differing views within each unit about the success of the unit’s parental involvement. Positive evaluations are presented first, unit by unit. Negative evaluations follow in the same order.

3.3.1 Positive Evaluations

The view of some members of staff was that parent involvement was a straightforward business, as this statement from psychiatrist Dr White from Arisaig shows:

“Involvement in decision making... it tends to be collaborative. We give them information as we see it, they give us their information and hopefully we come to a mutual agreement” (Int. 13A, p. 13).

Dr White made himself available to parents who wanted to see him and asked for an appointment:

“I make it very clear to all staff that if parents want to meet me, then that message is to be passed on and I’ll send them an appointment, and I can do it soon providing they don’t make an appointment five times a day” (Int. 13A, p. 13).

He also relied on parents making use of the staff’s accessibility at visiting time:

“We encourage parents to come in and make coffee and meet staff and chat to staff. And staff are very relaxed and informal at six, sevenish in the evening when they’re hanging about and parents can approach them to talk” (Int. 13A, p. 13).

Mark, key-worker from Knoydart, thought that, in most cases, parents took part in decision-making:

“It depends what the family actually asks for... I think they do get a say, a definite say, in what they want to see happen, and what they’d like in term of support...” (Int. 6, p. 4).

Olivia, from Rannoch, found that parents became readily involved in the unit but preferred to leave decision-making to the staff:

“Most of the time... anybody that I’ve worked, you know, any young people, I’ve worked with the parents all along. Usually you find that the parents are quite co-operative...Parents are quite happy for you to try anything. I mean,

there are... we do occasionally get the ones that are unhappy, but usually you find that once you sit down, give them the reasons for it, explain everything to them, they're prepared to at least give it a try" (Int. 10B, p. 20).

These positive evaluations from three of the four units' staff interviewees were contradicted by the negative evaluations of interviewees from the same units, given in the next section.

3.3.2 Negative Evaluations

In Arisaig, parents did not go to treatment reviews, which meant that they had no formal structure for their involvement in treatment decisions regarding their child. All the staff interviewed except Dr White thought this was unsatisfactory, as shown by this statement from the nurse manager:

"Families I feel currently we let down a bit. I think we should probably be seeing them a bit more often, and again my personal plea is case review and family meeting after it" (Int. 10A, p. 17).

Arisaig parents, like their children, were expected to lobby the staff to have their opinions known and listened to. They had to make appointments and ask questions. Trish thought that this informal system invited a 'hit or miss' success rate:

*"Researcher: How involved do they [parents] get in decisions?
Trish: I think it depends on who it is, the kind of folk they are, how outspoken they are, how willing they are to sort of stand up. They don't get invited to reviews or anything like that, it's just the family meetings or speaking to somebody, you know, when they pick somebody up or leave, if they want, or querying something in family meetings..." (Int. 9A, p. 9).*

Other key-workers, like Sean, were also uneasy with this structure for parental involvement and did not approve of it (Int. 12A, p. 16).

In Knoydart, Dr Black thought that the unit did not manage to involve the more vulnerable parents in the way that they used to:

"I think we were able to woo somewhat the most suspicious and threatened of parents. I suppose we do that less well as a group" (Int. 19, p. 15).

In Rannoch, Madge, a senior key-worker, thought that contact with parents was often infrequent, unless they were involved in some form of family therapy. As a parent of teenagers herself, she knew she would want more communication with the unit and more involvement than most parents received.

"I would imagine a lot of parents feel sort of on the periphery in their child's care because it's very much them [the children] that we work with unless we do family work or organise to work with the parents... As a parent, I think I would probably feel quite left out, you know, people are coming in and working on my child but I don't know exactly..." (Int. 15B, p. 17).

Christine, another key-worker, also thought that relying on telephone calls between the pre-admission visit and the first review, and then between six-weekly reviews, was unsatisfactory, as did the nursing assistant (Int. 11B, p. 25, Int. 12B, p. 7).

It seems clear from these findings that Arisaig, Knoydart and Rannoch lacked a clear and explicit policy on parent involvement about which the staff could speak with one voice. Fisherfield stood out as different because the unit's policy on family work was articulated clearly and the two staff members interviewed spoke about it in similar terms.

Obstacles to the involvement of parents were discussed by several interviewees and are the object of the last section.

3.4 Obstacles to Parental Involvement

Four types of obstacles were mentioned: confidentiality, the parents' own ability to get involved, lack of resources and distances.

3.4.1 Confidentiality

Confidentiality was discussed in some interviews, particularly in Arisaig where it had been a problem. Key-worker, Trish, felt that it interfered with the unit's relationship with parents. Because young people could request their treatment to be kept from their parents, the staff could be prevented from sharing information freely with some parents.

"I think it is really difficult... because we get kind of caught up in the young people's confidentiality, which I think we have to. It can be quite difficult knowing how much they want parents to be involved, but you know, obviously, obviously they need to know at least some of what has been going on to be able to cope" (Int. 9A, p. 9).

Key-worker Kenneth, also from Arisaig, shared this view. He had been key-worker to Diane, a young woman in the sample who had requested that all information regarding her treatment in the unit be kept from her mother:

"I personally find it quite difficult to work with Diane's mum because of this. Because she is so desperately wanting to know how to help her daughter and we cannot disclose anything because of the confidentiality aspect so I find Diane's mum quite difficult to deal with" (Int. 11A, p. 5).

Mindful of the fact that young people could request confidentiality about their treatment, the researcher asked Rannoch's nurse manager, John, how confidentiality was managed in treatment reviews since families always attended with their son or daughter:

"We work with that. We say that these reviews have to be open and honest and we work with that. Occasionally things will come up but we will try and work with that... Unless there are issues of safety..." (Int. 8B, p. 13).

Although confidentiality was a potential problem then, it seems that an experienced member of staff like a nurse manager was less intimidated by it than two staff-nurses. These two contradictory viewpoints came from two different units, so it is also possible that unit policy and practice influenced the way confidentiality was managed.

3.4.2 Parents Themselves

Parents were expected to be available to support the young people and a complete withdrawal from contact with the unit was not possible, as seen in the introduction to this section (3). But the success of their engagement with the unit depended to a large extent on their ability to respond to the staff, and even to initiate contact. For instance, one consultant psychiatrist and three key-workers referred to parental involvement in terms of encouragement to contact the unit whenever they wished, the frequency of contact being left up to them (*"we probably take the lead from them"*, Int. 11, p. 8). Although one key-worker thought the success of this was variable (*"It depends on how outspoken they are, how willing they are to sort of stand up"*, Int. 9A, p. 9).

The problem was that some parents found it difficult or impossible to initiate links with the staff and ask for information or meetings, because of their own mistrust, vulnerability or chaotic life-style. This was suggested by another consultant: *"I think with the most sensitive, wounded, threatened parents we don't succeed"* (Int. 19, p. 3). Such parents might have been involved, had contact been adapted to their needs.

One father, who felt his family had received a good deal from the unit, stressed that the involvement was demanding and that he and his wife had played their part: *"I think as well we were quite good relatives"* (Int. 20, p 23).

These varied viewpoints convey an underlying contradiction. They suggest that the units wanted parents to work with them but were not necessarily aware of the precise nature of some parents' needs as this study revealed them through the parents' interviews. This lack of awareness skewed the relationship between some parents and the unit staff in a way that few staff interviewees, even the most senior ones, appeared to be aware.

3.4.3 Resources

Resources probably played a part in the staff's difficulties in engaging more demanding parents, because the time it would have taken was not available. This was Dr Black's view:

"I don't think parents get all the support they need in certain areas, but that, you know, that's largely a resource issue... I think with the most sensitive parents we don't succeed and I think, you know, if we had more capacity [i.e. more staff] and I doubt – I can't see us getting it – we could bring in the most sensitive, wounded, threatened parents in but I don't know..." (Int. 19, p.3).

No-one else mentioned it.

3.4.4 Distance

Some young people lived some distance away from the unit. Even in the same city, distances could be considerable if the family did not have a car. In a rural unit like Rannoch, attending meetings on a regular basis was not possible for some parents because of their health or finances. Bringing young people in was not necessary since the local authority provided contract taxis. Home visits would have filled the gap. Some took place and the staff, in particular the psychiatrists, travelled long distances. But it was time-consuming. When young people were admitted to a unit outside their region, family involvement, let alone therapy, was difficult except by telephone.

"We've a lot of contact with the parents over the telephone, keep them informed and explain to them that obviously they can 'phone any time of the day if there's things bothering them as well" (Int. 10, p. 19).

Distances were difficult to bridge except by staff or parents travelling long distances. Time and financial resources did not always allow it.

Conclusion

The staff interviewees conveyed a mixed picture in all but Fisherfield. The level of priority of parental involvement, the existence and shape of a formal structure for involving parents, the form taken by informal contact, the staff's evaluation of what was done and the nature of the obstacles in the way of parent participation all varied from staff to staff and unit to unit. This suggests confusion and the lack of an explicit policy in three of the four units. It may explain the relatively high level of dissatisfaction expressed by parents in these units described in Chapter 5.

CONCLUSION

The staff interviews conveyed a different message about the involvement of the young people and that of the parents. The young people's participation in the life of the units was generally valued, although involvement in treatment decisions was viewed as complex and the units varied in the way they dealt with the difficulties. Some units made considerable efforts and appeared to achieve a good level of success. Regarding the engagement and participation of parents, the message was mixed in three of the four units, suggesting difficulties and the lack of a coherent, collective commitment to parent involvement. In the next chapter, the unit cultures are described. They complement the staff's perspective and give a context to the views of the three groups of stakeholders: young people, parents and staff.

CHAPTER 7: UNIT CULTURES

INTRODUCTION

Data on the unit cultures was collected to answer the fourth question asked for the purpose of this study: ‘what did the unit cultures contribute to the young people’s and parents’ experience of treatment and participation?’ The findings came mainly from the staff interviews and were complemented by the fieldnotes and any document current in the unit at the time of the data collection.

In this chapter the four units where data collection took place are described in summaries, where quotations from interviews and fieldnotes are given mainly in references rather than in full, to avoid unnecessary length. During the data analysis, four categories emerged as indicators of unit culture: the local context (historical and geographical), the unit’s values, the staff’s understanding of treatment, and the staff community (understood here as inter and intra-disciplinary relationships, power issues, costs and benefits of the work). These categories are followed to present each unit’s data in turn, in the order it was collected.

1. KNOYDART

1.1 Introduction

The first set of data was collected in the day-centre of a large Scottish town. It was part of services for adolescents aged fourteen to twenty. Built in the grounds of the town’s psychiatric hospital, it was administered by a former NHS trust responsible for primary care. The service itself had been open for thirty years and included a day-unit and an outpatient department. Knoydart was open from 9 a.m. to 5 p.m. and occasionally in the evening. It was closed at weekends.

1.2 Base Data

The data consisted of fieldnotes, interview transcripts and unit documents, although the findings described here are mainly drawn from interviews, the fieldnotes and documents having served to check and complement the picture that emerged.

Six weeks of participant observation were spent at Knoydart. During that time, fourteen people were interviewed: five young people, four mothers and five members of staff. Findings from the young people interviews are reported in Chapter 4, those from the parent interviews in Chapter 5. The interviews from which the findings reported here were drawn were staff interviews. These interviews also yielded data on the staff's perception of the young people and their parents' involvement in treatment and these findings are related in Chapter 6.

Five members of staff were interviewed: three were key-workers to the sample of young people, all nurses. One of them, Mark, was working with three of the five young people and two, forty-five minute interviews were necessary. Two were senior members of staff, one the consultant psychiatrist in charge on the service, the other the nurse manager. Table 7.1 displays the sample of staff interviewed together with their function.

<i>NAME</i>	<i>FUNCTION</i>	<i>INTERVIEW</i>
<i>Ruth</i>	Nurse Manager	No 7
<i>Jan</i>	Charge-Nurse	No 8
<i>Mark</i>	Staff-Nurse	No 4 & 6
<i>Susan</i>	Staff-Nurse	No 11
<i>Dr Black</i>	Consultant Psychiatrist	No 19

Table 7.1: Knoydart Staff Sample and Function

(The names of the staff have been changed to preserve their anonymity)

The nurses were the only full time members of the Knoydart team. Two psychiatrists, one of who was the consultant in charge, shared their times between the unit and the outpatient department while other disciplines worked mainly in the outpatient department. Six nurses worked in the unit at the time of the study: one nurse manager, one charge-nurse and four E grade staff-nurses. All worked from 9 a.m. to 5 p.m., and occasional evenings. Table 7.2 displays Knoydart staff's profession, grade and number.

<i>PROFESSION</i>	<i>GRADE</i>	<i>NUMBERS</i>
<i>Nursing</i>	Manager (G)	1
"	Charge Nurse (F)	1
"	Staff Nurse (E)	4
<i>Psychiatry</i>	Consultant	1 (P/T)
"	Staff Grade	1 (P/T)

Table 7.2: Knoydart Staff: their Profession, Grade and Number

Mornings were used for meetings and administrative work while the young people were at school - either in the unit or at their own school – at college or otherwise occupied. The therapeutic programme started with lunch, followed by the community meeting then one or other therapeutic group. There was one regular evening group. The young people attended from once to five times a week. The data collection took place during the summer holidays and the young people arrived at the unit around noon.

Nine young people attended Knoydart regularly at the time of the study and most of them were girls. This is in keeping with the demographic trends mentioned in the literature review (page 37). A few others attended more sporadically. The sample of young people drawn from Knoydart, with their age, gender and mental health problems is displayed in Table 7.3.

<i>NAME</i>	<i>AGE</i>	<i>GENDER</i>	<i>PROBLEMS</i>	<i>INTERVIEW</i>
<i>Mairi</i>	14	F	Overdoses Unclear diagnosis	No 1
<i>Amanda</i>	15	F	Anxiety Depression	No 2
<i>Fran</i>	16	F	Anxiety Agoraphobia ?Abuse	No 3
<i>Carole</i>	17	F	Depression	No 5
<i>Michael</i>	16	M	Eating disorder	No 12

Table 7.3: Knoydart Young People Sample: Age, Gender and Mental Health Problems

(The names of the young people have been changed to preserve their anonymity)

1.3 Knoydart in Context

The consultant in charge, Dr Black, explained the reasons why Knoydart had been opened and how she understood its place in the context of the region's adolescent services. By closing a resource-greedy inpatient unit some years earlier and re-deploying the resources into a day-service (Knoydart), the hope had been to treat the same client group more efficiently and leave only a small remainder of young people to be admitted to adult wards. Knoydart had fulfilled its role well but inpatient treatment had been shown to be necessary for a greater number than anticipated (acutely psychotic young people and the most serious cases of anorexia nervosa, depression and self-harm) and adult wards still admitted more young people than was desirable. Young people recovering from a psychotic episode were admitted to a specialised day-unit, also part of the service. Knoydart itself catered for non-psychotic young people with very disabling, sometimes chronic, mental health problems (Int. 19, p. 6).

1.4 Underlying Values

Values were clarified as values by the researcher during the analysis of interview transcripts and fieldnotes; they were not named as such by the staff and did not figure on unit documentation. Nevertheless the nurses interviewed named them because they saw them as priorities in the culture.

1.4.1 Safety

The nurse manager thought that a central message to convey to the young people was the importance of safety: that the unit was safe and that their safety mattered to the staff (Int. 7, p. 8). One of the staff nurses wondered if her main role wasn't in fact to make the environment safe and supportive in order to enable the young people to attend to therapeutic tasks for themselves (Int. 11, p. 5). Safety was also mentioned in the fieldnotes with respect to special nursing observations of a young woman detained under the Mental Health Act. This young woman went on outings with the rest of the unit but she was never left alone, although the procedure was noted to be unobtrusive (Knoydart, week 2, p. 4-5).

1.4.2 Mutual Respect and Trust

These two values were named by the nurse manager as necessary in order to enable the young people to share their feelings with each other, which they were encouraged to do during their time in the unit. If they felt respected, they could trust each other, confide their feelings, accept feedback – even difficult and painful feedback – and grow in self-knowledge and confidence (Int. 7, p. 8). The young people seemed to put it into practice and were noted to be kind and respectful to each other in the groups (Knoydart, week 3, p. 12).

1.4.3 Having Fun

The importance of making the work of the unit enjoyable for the young people was stressed by the nurses and witnessed by the researcher (Int. 7, p 8; Int. 6, p. 1; Knoydart, week 6,

p.1). One of the nurses suggested that the young people had often been unable to socialise with their peers before admission and that fun in the unit was a way of catching up with a developmental task (Int. 6, p. 1).

1.4.4 Inclusiveness and Priority to the Young People

The fieldnotes commented on the communal atmosphere of meals and other social occasions, at which the staff worked hard and in which adults like the researcher were expected to join (Knoydart, week 1, p. 5; week 2, p. 21). The young people came first, as was noted in an outing where there was insufficient lunch for everyone (week 6, p. 2).

1.4.5 Self-Awareness

Self-awareness was seen as a therapeutic value derived from the psychodynamic approach used at Knoydart (see Chapter 2 p. 42). Staff members were expected to scrutinise their contribution to therapeutic relationships (moods, feelings, past experiences) in an effort to own what belonged to them. They grew in self-knowledge in the process, although this was not always a comfortable experience (Int. 8, p. 5). The nurses sought self-awareness through discussing with each other, both informally and in supervision, the relationships they had with young people, looking for feedback and insight (Int. 8, p. 10).

1.5 Staff's Understanding of Treatment

A contrast was noticeable in the data between the two senior staff members' views, which gave a rational overview of the treatment available, and the three key-workers' perceptions, which emphasised the parts of treatment that felt to them most significant in terms of impact on them, the young people and, ultimately, the unit culture. Although the executive and ground level voices harmonised, the overall message needed both to be complete.

1.5.1 Type of Problems Referred for Treatment

Young people were admitted to Knoydart because they needed more vigorous and sustained treatment than was possible in an outpatient department. It was a last resort (Int. 19, 160-163).

The young people referred to Knoydart were described in the information documents as having:

“A wide range of psychological and psychiatric difficulties including depression, school refusal, severe family dysfunction, child sexual abuse, anxiety neurosis, and eating disorders” (Information Handout, 1997).

Young people with a conduct disorder were not admitted because there was evidence that adolescence was too late for a therapeutic impact (Int. 7, p. 3).

1.5.2 Treatment Approaches

Knoydart deployed a number of therapeutic approaches and was described as ‘eclectic’ by the consultant. Psychodynamic, developmental, medical/biological, cognitive and behavioural approaches were all used (Int. 19, p. 7). To this list, the nurse manager added the therapeutic community approach, which she described as, *“young people taking part in their own treatment instead of being passive objects in their treatment”* (Int. 7, p. 1).

Ruth was the only member of staff to mention the therapeutic community approach, although the expression ‘living and learning’, coined by one of the founders of the therapeutic community movement Maxwell Jones (1968), had also been used by Dr Black and in the Knoydart Information Handout (1997). For further discussion of the therapeutic community movement and its relevance to adolescent units see Chapter 2, p. 41.

The psychodynamic approach, defined by Ruth as *“about understanding behaviour, and how past experience and past relationships affect what [young people] are now”* (Int. 7, p.1) was pervasive as a way of understanding young people’s problems, their behaviours and their relationships, but social learning, family therapy and medication were also available (Int. 7, p. 1).

Commitment to community living was demonstrated in the care that went into discharges. On their last day, young people went out for coffee with their key-worker to say goodbye, then had a festive lunch (or tea) to which they could invite significant other young people who had left the unit. Cards and presents were exchanged, then, in a ritual feedback session, the departing youngster was reminded by everyone else of various episodes of their stay at Knoydart (Knoydart, week 6, p. 5).

1.5.2.1 Working in Groups

Although many treatment approaches were available to the young people, the treatment programme was organised around group activities. A community meeting took place everyday and a different therapeutic or recreational group occurred every afternoon. Individual meetings with key-workers, doctors, psychologists or dieticians were interspersed between the groups. Lunches, tea and coffee breaks were shared by staff and young people and made into social occasions. It is interesting to note that when asked about the unit's treatment approach, two of the three key-workers had not referred to the eclectic combination of approaches mentioned by consultant and nurse manager. They had stressed the use of groups.

Both these key-workers thought the group therapy helpful: in groups, the young people discovered that they were not alone, that although their problems were different, they were dealing with many similar issues (Int. 6, p. 1). Groups were well suited to the adolescent phase of development when peers become more important than adults: *"when a young person challenges another young person about something, that carries, like, at least five times the weight as if a staff-nurse was saying it"* (Int. 11, p. 5).

Being in groups, young people learnt social skills from each other and practised life skills since much of life takes place in groups (Int. 6, p. 1).

The young people themselves were able to explain why they had groups, as they did in the researcher's first community meeting:

“Christine said it was for people to share feelings and to help each other... Carole added that it was also a way of seeing how people coped with difficult things” (Knoydart, week 4, p. 2).

1.5.2.2 Expressing Feelings

A prominent therapeutic ingredient in the Knoydart regime was the expression of feelings. A large majority of young people in the unit was not able to recognise or name the specific emotions they felt, particularly on the negative register of feelings like anger, resentment, hatred or anguish. They could not convey how they felt to others, which affected their behaviour and their relationships. Therefore the unit focused on feelings and emotions, chiefly in the groups but also informally (Int. 6, p. 2).

The researcher had noted a skill displayed by the most experienced nurses, which was the ability to relate to the young people near to the level of their real (but hidden) feelings, even in informal situations. This had the effect of making them feel safe and contained. This informal therapy seemed best achieved through a mixture of jokes and seriousness that allowed conflict and pain to be part of the conversation without becoming heavy or personal. Less experienced staff kept their conversation more evenly superficial and the atmosphere was then more like that of a youth club (Knoydart, week 3, p. 11).

1.5.2.3 Young People’s Contribution to their Treatment: Unit Expectations

When they were admitted to Knoydart, young people were expected (and helped) to take ownership of many aspects of the psychosocial difficulties that had brought them into the unit and to work at resolving them. Susan thought this was difficult for teenagers and that it pushed them to grow up (Int. 11, p. 5).

The emotional literacy work done in the groups for instance demanded that young people express themselves in front of several others. It was a high expectation but it paid off: *“they seem to take on these expectations and to manage them and actually it helps bring them out”* (Int. 11, p. 5).

When the expectation that young people would try to share their problems with others in a group was too high, they stayed out of groups and received individual therapy only. This

was assessed and decided by the staff, not by the young people. Dr Black evaluated the number of young people staying out of the groups to be about one third of the patients (Int. 19, p. 7). Staying out of groups was temporary and becoming able to tolerate groups and use them was a goal of treatment. This, said Ruth, was because spending time in a group was an indispensable life-skill and that those young people who stayed out of the unit groups felt excluded when it lasted too long (Int. 7, p. 3).

Such a way of dealing with mental health issues was part of the therapeutic community model, modified and adapted to an adolescent age group (Int. 7, p. 1). The emphasis on ownership of one's own life and circumstances was meant to be empowering. It led to a number of strategies for involving young people in the unit's decision-making. Findings regarding this central issue of the study are presented in Chapters 4 and 6 (young people and staff views). The staff interviewed were convinced that it worked: *"in my experience, I don't think I've seen anybody come in here and not get something from it"* (Int. 11, p. 6).

1.6 The staff

1.6.1 The Multi-Disciplinary Team

The eclectic treatment programme described by Dr Black, with its varied theoretical models, was delivered by the multi-disciplinary team of the outpatient department. The team as a whole was expected to have a grasp of all the therapeutic models in use in the service but each model had its experts: psychiatrists for psychopharmacology, psychologists for cognitive behaviour therapy and several people for psychodynamic and family work skills. Dr Black herself was trained in three therapeutic modalities and valued them all:

"It tends to be important that an individual like me, the child psychiatrist and consultant values these things" (Int. 19, p. 8).

The only full time members of the Knoydart team were nurses and they ran the unit. Members of other disciplines attended the unit's clinical meeting once a week and carried

out specific aspects of treatment with individual young people as necessary, but Knoydart was the nurses' territory.

Because the nurses had more contact than anyone with the young people and their families, decision-making regarding the running of the therapeutic programme was left to them. The nursing team used the weekly clinical meeting to air difficult issues and hear other people's views (Int. 7, p. 9).

If disagreements occurred regarding the treatment of a particular young person, Ruth was aware that the consultant was entitled to the last word, but this privilege was rarely exercised "*I think most of the time we agree actually, there aren't huge differences*" (Int. 7, p. 10).

A pre-requisite for achieving this degree of nursing involvement was to be well represented at key meetings:

"We also organise the team meeting so that we're all there, which is very different - I mean you can't do that in an inpatient setting - we make sure that four or five of us are there so that there is representation of the team" (Int. 7, p. 11).

1.6.2 The Nursing Team

The nurse manager outlined what was expected of nurses applying to work at Knoydart: some basic human qualities such as warmth, the ability to get on with people and to be a team player (listening, making links with others, encouraging them rather than competing). Skills in working with young people and group therapy were not necessary because training would be provided. In addition the unit needed a collective selection of qualities: organisational ability, creativity, thoughtfulness etc. "*I think nobody's got them all so you've got to look for what's missing in the team*" (Int. 7, p. 4).

The process of selection included a group interview to detect the 'team player' qualities mentioned above, and an interview with a panel of young people. The nurse manager found their presence useful because they were very perceptive about the candidates (Int. 7, p. 5).

Student nurses who had done well on placement at Knoydart were often employed at a later stage because working with them was a reliable way of finding out how suitable they would be.

In the team, decisions were mainly made by consensus, said Ruth, because people would not respond well to a rigid, hierarchical team. Things were discussed and argued about until a consensus emerged (Int. 7, p. 14). There were occasions when this was not possible, however, and it fell to the team leader to *“make hard decisions that actually other people will have to challenge”* (Int. 7, p. 14).

1.6.3 Being a Nurse at Knoydart

The three key-workers interviewed each said that working at Knoydart was unlike working anywhere else. Some people, including students, loved it and wanted to come back, others hated it (Int. 6, p. 1, Int. 8, p. 10, Int. 11, p. 12). What was so different about Knoydart?

All three key-workers found it a place that made high demands on its nurses. Susan explained that they had to be ready to explore and challenge their more difficult feelings because the young people had to do this. The example was given of an insect phobia which a nurse evoked as an excuse not to go to summer camp with the unit. This problem was not accepted at face value and the nurse had been encouraged to face her fears, with the help of her colleagues, and go camping (Int. 8, p. 10).

Nurses worked closely together and noticed less successful areas of each other’s professional performance. They would offer each other feedback. Clinical supervision was a serious and regular opportunity to discuss the interface between oneself and work. Looking at these areas of failure could be painful. At such times of challenge, Susan was reminded that, had she worked somewhere else, this would not have been necessary – yet she knew that the challenge was useful to her and wanted to accept it *“and you have to challenge yourself to take up the challenge”* (Int. 11, p. 9). It was clear that some nurses would have found this way of working threatening and refused to take a part in it (Int. 8, p. 10).

The culture of supervision in existence at Knoydart was unique in the parent psychiatric hospital in 1998. Key-worker Mark thought clinical supervision was indispensable because the feelings that passed between young people and staff in therapeutic relationships were “*very very powerful*” (Int. 6, p. 4): young people were at an age when feelings are strong and often projected onto others; staff came to the work with unresolved issues from their own adolescence. Feelings needed disentangled again and again.

The nurses interviewed wanted to work in this demanding environment because working with young people was stimulating (Int. 6, p. 4) and because being personally challenged made them grow professionally and personally (Int. 11, p 10). “*I know since I’ve been here I’ve grown as a person and changed*” (Int. 8, p. 10).

In order to balance the demands of work, the need for a good home life was emphasised by the three key-workers (Int. 8, p. 10; Int. 6, p. 6; Int. 11, p. 12).

1.7 Transmission of the Culture

In this account, Knoydart’s treatment culture comes over as unusual in the context of the adult mental hospital in which it was located – itself characteristic of approaches to treatment taken by other mental health care settings in the country at the time of the study. Two key-workers talked of a ‘tried and tested way’ developed over ‘years and years’ which amounted to a fairly rigid structure (Int. 11, p. 6; Int. 6, p. 2). They were acknowledging the long history of the unit’s culture, honed over many years, which, even if it sometimes felt restrictive, worked. How was such a culture transmitted?

Young people and their parents met their prospective key-worker at the time of their referral to Knoydart, when the unit’s workings were explained to them. There was a video and a brochure for young people. But, as the nurse manager pointed out, it was difficult to speak in words that young people could understand and anxiety could prevent the families from retaining information, so it had to be repeated again after admission (Int. 7, p. 1).

After admission, the culture was mainly transmitted by young people called 'culture carriers' who had been at Knoydart for some time and who had internalised the unit's philosophy. Ruth summarised it as:

"The importance of supporting other young people, confiding your feelings, the importance of confrontation, having fun, respecting the place" (Int. 7, p. 6).

If the majority of young people happened to be new, it would fall to the staff to take on the task of spelling out this philosophy time and again until new culture carriers were found (Int. 7, p. 7).

For new staff, much of the transmission of culture took place in supervision. All members of staff were supervised by a more experienced colleague every two weeks. This was an opportunity to discuss what the unit was about and how and why things happened (Int. 7, p. 7). Handovers, nurses' meetings and group supervision sessions were also opportunities to reiterate the reasons why Knoydart worked the way it did. In community meetings, new nurses saw experienced ones in action and learnt from them. A significant element of this induction of new nurses, however, came from the young people.

"Explaining the culture to new staff reinforces the role young people play in their own treatment, and it also reinforces the importance of the culture. It's a shared culture, it's not just for staff or for young people, it's for both..." (Int. 7, p. 7).

To summarise, Knoydart was a day unit for non-psychotic young people. Its treatment culture had been honed over a long time and included a combination of therapeutic community living, psychodynamic understanding of development and human relations, and group work, although other therapies were used as necessary. Young people were expected to take ownership of their problems and treatment and to become actively involved in the unit. The therapeutic programme was led by nurses, with access to other disciplines. The nurses interviewed found the work different from any other they had done but challenging

and rewarding. This culture was valued and its transmission to new staff and young people carefully engineered.

2. ARISAIG

2.1 Introduction

The second set of data was collected in the adolescent mental health service of a Scottish city. Its ten-bedded inpatient unit, Arisaig, was accommodated in the grounds of the psychiatric hospital and run by the then NHS Primary Care Trust. The age of the young people ranged from twelve to eighteen. Opened approximately twenty years ago, the unit shared one floor of a shabby two-storey building with the outpatient department. It was open seven days a week.

2.2 Base Data

As with Knoydart, the Arisaig data from which the findings were drawn consisted mainly of interview transcripts, with fieldnotes and documents serving as checks and complements to the emerging picture.

Eight weeks were spent observing Arisaig's activities, four hours at a time, three days a week. The life of this inpatient unit was observed from 7 a.m. to 10.30 p.m., at least once and in most cases many times (more details about the observation periods of the study are given in Chapter 3, section 3.3.3.1). The observations were recorded in the fieldnotes used in this section.

During that time seventeen people were interviewed: five young people, two pairs of parents, three mothers and seven members of staff. The transcripts from which the findings reported here were culled were of the staff interviews. These transcripts also yielded data on the staff's perception of the young people and their parents' involvement in treatment. These findings are related in Chapter 6.

Seven members of staff were interviewed: three were staff-nurses and key-workers to the sample of young people. As in Knoydart, the consultant psychiatrist in charge on the service and the nurse manager were included. An occupational therapist was added to the sample during the observation period because his views as he expressed them informally to the researcher seemed to point to a different experience from that of nurses and the psychiatrist. The unit had a school onsite but initially no teacher was interviewed. During data analysis, however, the school emerged as a significant component of the unit because it was well staffed and occupied all the young people mornings and afternoons. The head teacher had been there for a long time and her views were eventually sought, after the period of observation. Table 7.4 displays the sample of staff interviewed with their function.

<i>NAME</i>	<i>FUNCTION</i>	<i>INTERVIEW</i>
<i>Jane</i>	Nurse Manager	No 10A
<i>Kenneth</i>	Staff-Nurse	No 11A
<i>Sean</i>	Staff-Nurse	No 12A
<i>Trish</i>	Staff-Nurse	No 9A
<i>Dr White</i>	Consultant Psychiatrist	No 16A
<i>Harry</i>	Occupational Therapist	No 13A
<i>Margaret</i>	Head Teacher	No 17A

Table 7.4: Arisaig Staff Sample and Function

(The names of the staff have been changed to preserve their anonymity)

During the period of observation, Arisaig employed twenty-one nurses, six of whom were untrained, four psychiatrists, an occupational therapist and a part-time psychologist. Two staff-nurse posts were vacant and filled by agency nurses on an ad hoc basis. The nurses, graded from A to G, were responsible for the smooth running of the unit twenty-four hours

a day, seven days a week. Their time was split between a morning, a late and a night shift while Jane, the nurse manager, worked from 8 a.m. to 4 p.m. everyday. Table 7.5 display Arisaig's staff's profession, grade and number.

<i>PROFESSION</i>	<i>GRADE</i>	<i>NUMBERS</i>
<i>Nursing</i>	Nurse Manager (G)	1
"	Charge Nurse (F)	2
"	Staff Nurse (E)	8
"	Staff Nurse (D)	4
"	Nursing Assistant (A)	6
"	Student	2
<i>Psychiatry</i>	Consultant	1
"	Staff Grade	1
"	Specialist Registrar	1
"	Registrar	1
<i>Occupational Therapy</i>	Senior 1	1
<i>Psychology</i>	Grade Unknown	1 (P/T)

Table 7.5: Arisaig Staff, their Profession, Grade and Number

There were nine young people in Arisaig during the period of observation. Seven out of nine inpatients were girls, reflecting the demographic trend outlined in Chapter 2, section 2.6. All young people were under sixteen except two who were just seventeen. Diane had left school when she was sixteen and was the only young person not to attend the unit

school. The sample of young people drawn from Arisaig, with their age, gender and mental health problems is displayed in Table 7.6.

<i>NAME</i>	<i>AGE</i>	<i>GENDER</i>	<i>PROBLEMS</i>	<i>INTERVIEW</i>
<i>Dean</i>	14	M	Schizophrenia	No 1A
<i>Diane</i>	17	F	Abuse, self-harm Attempted suicide	No 2A
<i>Kate</i>	13	F	Anorexia Nervosa	No 5A
<i>Helen</i>	17	F	Anorexia Nervosa	No 7A
<i>Jill</i>	16	F	Abuse Schizophrenia? PTSD?	No 16A

Table 7.6: Arisaig Young People Sample: Age, Gender and Mental Health Problems

(The names of the young people have been changed to preserve their anonymity)

2.3 Arisaig in Context

This inpatient unit had been opened by an adult psychiatrist some twenty years earlier to provide a general psychiatric service for adolescents who, until then, were admitted to adult wards. Neither this psychiatrist nor the staff who started the unit with him had specialist expertise in adolescent mental health (Int. 13A, p. 1).

In time, one, then another adolescent psychiatrist were appointed as well as a charge nurse trained in the mental health care of young people. All three had done a substantial part of their specialist training at a neighbouring inpatient unit. That service had a strong therapeutic community culture based on group therapy (see Chapter 2, p. 42). The three new staff had attempted to establish a similar culture in Arisaig but failed. This had caused some tension and distress and one of the psychiatrists had left. The other was now clinical director of the adolescent services (Int. 13A, p. 1-3).

Arisaig had as a catchment area a large urban conurbation as well as adjacent rural regions without inpatient units of their own. With ten beds, it could only treat the most seriously affected young people and had a slow turnover of about twenty young people a year (Int. 13A, p. 5).

Dr White described the unit's client group as "*more seriously mentally ill patients*" and "*different from the other units in Scotland*" (Int. 13A, p. 2), and therefore not able to accommodate a therapeutic community culture. The nurse manager, Jane, had similar views (Int. 10A, p. 2).

According to Jane, elements of therapeutic community had been transferred in a modified form, such as the use of the institution to therapeutic ends ("*a modified therapeutic milieu*") and a group culture (Int. 10A, p. 3). However, because Arisaig had little or no control over its admissions ("*always taking all comers 365 days a year*"), these imported elements of the treatment culture, although valued, frequently gave way to emergency care and the call of more pressing priorities (Int. 10A, p. 3). The culture of the unit was built on uncertainty "*because anything can happen at any time and often does*" (Int. 10A, p. 3). As a result there was no culture of note at Arisaig other than that of "*a general purpose psychiatric unit*" (Int. 10A, p. 4).

To the staff-nurses interviewed, the concept of culture evoked negative institutional traits about the unit: a place where it was difficult to innovate ("*things are done this way here*") and where you could feel excluded and unsupported (Int. 9A, p. 14; Int. 11A, p. 12). These issues will be developed in later sections.

2.4 Underlying Values

The values referred to in this section were mentioned directly in interviews. Although the word 'value' was not used in describing them, they were perceived as qualities that were, or should have been, important unit priorities.

2.4.1 Person-Centredness

On several occasions Jane asserted her and the unit's commitment to person-centredness:

"It's actually the people that's important. And in particular young people and their families" (Int. 10A, p. 3).

She lay particular emphasis on the power of the young people to help each other, stressing that this was what made the unit work (Int.10A, p. 3). Together with the person-centredness, Jane called the mutual support available in the unit "*people power*" (Int. 10A, p. 5). This, of course, is a feature more characteristic of therapeutic communities than of a "*general purpose psychiatric unit*" (Int. 10A, p. 4). But it was a vulnerable quality. Jane conveyed a sense of powerlessness at the influence new staff could have on the unit if they were not person-centred: they could drive away or change this value and the absence of a strong unit identity made it difficult to prevent (Int. 10A, p. 5).

Besides this positive but fragile value highlighted by Jane, the consultant described several qualities he felt the unit lacked. The absence of these values made people unhappy and the work difficult. As a result, staff relations at Arisaig were strained. This is explored in section 2.6. As the consultant in charge and team leader, Dr White appeared to deplore his own inability to change this.

2.4.2 Openness about One's Feelings and Vulnerability?

Dr White had noticed a "*very big reluctance*" among the staff to share feelings and to be seen to be vulnerable in their work with young people (Int. 13A, p. 3). This defensiveness was also mentioned by one of the staff-nurses who described a macho culture where being open about one's vulnerability "*was a sign of not being able to cope and not being as strong as what [one] should be*" (Int. 11A, p. 11).

2.4.3 Mutual Respect?

A pervasive lack of respect for each other was also described:

“I find it very difficult to gain respect, and I find it very difficult to have my views respected. I think you’ll probably hear that from all disciplines, and I think it’s sad that there is a sense that no discipline respects another in here” (Int. 13A, p. 3).

This sentiment was echoed by all interviewees, although words other than respect might have been used. The views of other staff are more explicitly described in section 6. In the absence of these values, Arisaig was a difficult place in which to work. *“So it’s a difficult place and I find it very very difficult” (Int. 13A, p. 3).*

2.4.4 Thirst for Learning?

Dr White also missed the absence of a curiosity to learn. There was a view among the senior medical staff that it had never been part of this unit’s culture (Int. 13A, p. 3). It was difficult therefore to establish an ethos of evidence-based practice (Int. 13A, p. 11).

2.5 Staff’s Understanding of Treatment

2.5.1 Types of Problems Referred for Treatment

The young people admitted to Arisaig suffered from a cluster of mental health problems but there were three main types: psychosis, suicidal depression and advanced anorexia nervosa (Int. 10A, p. 13). Young people who abused drugs or alcohol were not admitted but young people with a conduct disorder might be, one at a time, if their mental health difficulties extended beyond their behaviour (Int. 10A, p. 11-12).

In general, adolescent services across Scotland take different approaches to the issue of admission. As the gate-keepers of their own wards, consultant psychiatrists decide on the timing of an admission. Many negotiate admission with the inpatient nursing team and

compromise between the anticipated impact of a new admission on the current inpatient group and the needs of the prospective patient.

Arisaig was unusual in being mainly guided by the referrer and the new patient. As a result, about half of Arisaig's admissions were emergencies, which made it impossible to plan a young person's introduction into the unit or to give them time to orientate themselves (Int. 10A, p. 13). Although Jane was involved in the decision to admit, her views did not always prevail and when Jane was not on duty, her deputy was not consulted (Int. 10A, p. 15).

2.5.2 Treatment Approaches

2.5.2.1 Residential Treatment

Young people were in Arisaig because of the seriousness of their mental health problems. The unit's facilities to observe, assess and treat them twenty-four hours a day was a significant asset in their treatment. A number of them were a danger to themselves because of suicidal inclinations, psychotic ideation, or, in the case of young people with anorexia nervosa, starvation. One or two were a possible danger to others because of the psychotic delusions they experienced. To all these young people, the unit offered containment and safety. This was enhanced by the promotion of '*people-power*', as Jane called it, that is by positive relationships between people, particularly between young people "*being away from home and being with other kids works, we know that*" (Int.10A, p. 5).

When young people were better they were encouraged to go home, perhaps for a day or a half-day, then for a weekend, until it was felt that both the parents and the young person could manage outpatient treatment again. If the parents felt able to cope, their children could go home every weekend as soon as they were safe to do so (Int. 13A, p. 13).

2.5.2.2 Intensive Care

A number of the young people admitted to Arisaig were critically disturbed. These young people's treatment often entailed intensive psychiatric care interventions. However, the young people were rarely transferred to the Intensive Psychiatric Care Unit (IPCU) of the hospital because, thought Dr White, the unit was good at IPCU type work. "*The*

management of very disturbed patients in an adolescent environment is a real skill. That's something that's done very well" (Int. 13A, p. 7).

Intensive care interventions involved the use of the Mental Health (Scotland) Act 1984 to detain those at risk, physical restraint, special nursing observation and antipsychotic medication. Such interventions took their toll on the nurses. At the time of the study a very thin twelve-year old was restrained and fed through a nasogastric tube several times a day. The nurses found it emotionally demanding and ethically thorny.

"I find it difficult to justify to myself what I am doing and why I am doing it... and I think people kind of almost take it for granted that people are comfortable doing this thing, when it is not a nice thing to do" (Int. 9A, p. 12).

Antipsychotic and antidepressant medication were essential therapeutic ingredients in most young people's treatment. Psychopharmacology was another form of treatment at which Dr White thought the unit was good (Int. 13A, p. 8). The best medication available were used, often more expensive than common ones, something which the hospital finance department had accepted: *"I reckon that if it's needed I have to give it because they're young and we need to give them the best we can" (Int. 13A, p. 19).*

Apart from this intensive treatment Arisaig used a combination of therapies according to individual need.

2.5.2.3 Groups

Jane thought that group therapy was not relevant to the majority of her client group because they were too distressed and ill (Int. 10A, p. 7). Any young Arisaig patient in need of an insight-orientated group could be included in an outpatient one run by a sector team. The unit had recently run a social skills group.

Dr White thought a lot of group work took place in the unit (Int. 13A, p. 9). This was not the occupational therapist's perception, however. Harry had applied for a job in the unit because of his interest in group work with young people: *"I was surprised actually because I thought there would be a lot more group work here" (Int. 15A, 23-25).*

Harry set about organising groups: the social skills group, a leisure group and an art group which the young people had requested.

The community meeting was frequently mentioned. Jane described many changes made to it over the years, which turned it from the key event of a therapeutic community into an information sharing opportunity with little therapeutic ambition. It was now less formal, did not run at weekends or, often, in the evening, was not always attended by all young people and was not an occasion for sharing problems or intimate personal information (Int. 10A, p. 9-10).

Dr White thought the young people used the community meeting to discuss aspects of the unit's life and bring about changes (Int. 13A, p. 15). Harry recalled the definition of community meetings as they were originally conceived: the residents' own meeting, there to facilitate community living. But since the young people did not have much control over them he thought this function was not fulfilled (Int. 15A, p. 17). Trish thought it was mostly used to pass on information (Int. 9A, p. 14). This impression was also conveyed in the fieldnotes:

“There is a lack of group skills amongst the staff, I think, and a tradition that it is ok for young people not to use the meetings at all. I think the senior staff don't realise what non-events they are” (Arisaig, week 7, p. 10).

2.5.2.4 Family Work

A few members of staff had family therapy skills. Both Dr White and Jane thought they would have needed more because of the evidence base for this approach (Int. 13A, p. 8). But Jane was satisfied with the family support that was taking place informally (Int. 10A, p. 6). More findings are presented on the staff's views regarding informal work with parents in Chapter 6.

Two of the staff-nurses interviewed felt kept out of the family work that was taking place: Trish, key-worker to Kate, had not been involved in Kate's family work and had received no feedback (Int. 9A, p. 4). Sean disagreed that there were few family work skills available

in the unit but he felt the nurses' skills were not valued because they were built on experience rather than training (Int. 12A, p. 19).

2.5.2.5 Cognitive Behaviour Therapy (CBT)

CBT, which has become a therapeutic intervention of choice in all mental health settings, was being developed at Arisaig. Three people were competent and had started teaching others. One senior nurse had been sent on a training course at the unit's expense but had declined to complete it, causing distress and conflict (Int. 13A, p. 9). This was thought by some to be a proof of how poorly committed to learning some senior nurses were.

2.6.2.6 Psychodynamic Therapy

Individual psychodynamic therapy was rarely carried out because the young people in Arisaig tended to have mental health problems for which this approach was unsuitable. It was available from outpatient teams, however, should an inpatient need it (Int. 13A, p. 10, Int. 10A, p. 5).

In a similar way, psychodynamically orientated groups, which had been provided for a time, had been abandoned because they were thought contra-indicated for the kind of problems young people had (Int. 10A, p. 7).

Dr White valued the psychodynamic approach for its insights into therapeutic relationships and group dynamics. He occasionally turned to a psychodynamically trained worker for consultation.

"We do use them for consultation, to look at the effects the patients are having on the staff group; which is indirectly therapeutic because I think that if you look at your transference you can actually work better with the patient" (Int. 13A, p. 10).

No one else mentioned this and it was not in evidence during the period of observation.

2.5.2.7 Individual Therapy

Young people were seen individually by a variety of staff. Some of these therapeutic interviews were 'declared', that is, officially part of the treatment regime, usually supported

by a therapeutic theory like CBT or psychotherapy. Others were informal and were not accounted for other than casually. Trish, for instance, saw Kate to whom she was key-worker, every week at her own initiative. She used forms of therapy she had learnt and practised in another workplace (Int. 9A, p. 5). She did not think all key-workers did this.

Dr White was aware that informal sessions took place and spoke of them positively, although he was not sure what they involved: *"I think the best model they could claim is supportive...but definitely of benefit, there's no question about that"* (Int. 13A, p. 10).

2.5.2.8 Activities

Activities were not mentioned by either the consultant or the nurse manager as part of the therapeutic interventions available at Arisaig, which might indicate that they did not belong to that category. They were nonetheless valued by them because both alluded to them approvingly in the context of other topics (Int. 13A, p. 8; Int. 10A, p. 11).

To the occupational therapist, they were important and much of his job consisted of organising activities of one kind or another for individuals or for groups of young people. These activities contributed to a form of social therapy by helping young people to keep in contact with interests and communities (Int. 15A, p. 4).

Nurses also referred to activities as a significant therapeutic element but this was often in the context of unit politics. Since activities were what nurses did with the young people, some nurses appeared keen to show that activities were at least as valuable as other ways of spending time in the unit (Int. 12A, p. 14; Int. 11A, p. 10). Another nurse, however, pointed out that evening and weekend activities were not time-tabled and depended entirely on the nurses on duty (Int. 9A, p. 6).

In conclusion, it seems that a significant part of Arisaig's treatment was provided by residential facilities that offered young people with serious mental health problems safety and containment. In addition, good intensive care skills were available.

In terms of the therapeutic programme, there were conflicting messages and therapeutic interventions seemed to be caught up in staff conflict. There appeared to be two

programmes in Arisaig: a formal one where treatment and activities were delivered by a variety of health care professionals, mainly psychiatrists, a psychologist and an occupational therapist, all trained and supervised for the purpose. An informal programme took place alongside this, made up of individual therapeutic encounters with the young people and spontaneous activities like outings, football games or barbecues. The nurses ran this according to each nurse's initiative. They did not have to account for it, or report it except when handing over to the next shift. This parallel existence seemed to make them feel undervalued. How it also undermined the therapeutic value of the activities will be explored in the next section.

2.6 The Staff

The Arisaig staff team was constituted differently from that of Knoydart. Therefore the structure of this section is somewhat different from that used to describe the Knoydart team. The Arisaig team included four psychiatrists as well as an occupational therapist, while Knoydart was mainly a nursing unit. The Arisaig team was also considerably larger than the Knoydart team because it was resourced to be open twenty-four hours a day, seven days a week.

All the staff interviewed conveyed the feeling of a team in conflict. It was also a team where many of the staff had only recently been appointed (Int. 10A, p. 8). The nurse manager was concerned that a statement of the unit's mission had not been made and that people had different views and no common aim (Int. 10A, p. 8). Countering this point, the consultant stressed that the unit had been in crisis for a long time and that young people "*come in ill, and go out better, despite all this*" (Int. 13A, p. 5). But the management of the trust had acknowledged that things had to change because "*this is a unit that is not as healthy as it should be*" (Int. 13A, p. 21).

The unit's difficulties seemed to spring mainly from conflict between the nursing and medical members of the team.

2.6.1 *The Nursing Team*

The nursing team was large, comprising twenty-one nurses and five hierarchical grades. The nurse manager headed a team composed of two charge nurses, eleven staff-nurses and seven nursing assistants. Jane was an intermediary between the nurses and the rest of the multi-disciplinary team and received most of the significant information. She explained that the multi-disciplinary team did not trust the charge-nurses to replace her in her absence (Int. 10A, p. 20). The four most senior nurses had been there for many years and, according to a staff-nurse, formed a strong sub-culture (Int. 11A, p. 12).

Nurses were selected according to their *“people skills”* and their interest in young people whatever other qualities might be listed on the standard job description (Int. 10A, p. 24). Staff-nurses’ main responsibility was to be key-workers to a few young people each. A young person admitted to the unit had two key-workers who invested time and skills in building a therapeutic relationship with them and were responsible for the organisation of their nursing care. While Jane would have expected key-workers to work closely with the psychiatrists, the latter tended to ignore key-workers and to seek Jane out to discuss treatment issues (Int. 10A, p. 21). The key-workers themselves felt ignored and kept out of the main therapeutic work of the unit (Int. 9A, p. 4). One of them explained that the interdisciplinary conflict made work at the unit difficult for all the nurses. Some nurses withdrew, some argued loudly but no-one negotiated real changes (Int. 9A, p. 10). Staff-nurses felt they did not have the power to influence events.

2.6.2 *The Multi-Disciplinary Team*

The multi-disciplinary team was led firmly by the consultant psychiatrist who made most of the decisions, although some consultation took place (Int. 10A, p. 14). Jane was accepting of the situation, but she was given more say than most. Other nurses resented their lack of involvement. Key-workers like Trish did not have the opportunity to give their views about the treatment of their own young people *“I think it is really difficult, I must admit, having worked in other places where you have much more say”* (Int. 9A, p. 7).

Sean was extremely angry about it. He had made his views widely known and was unpopular. He did not see himself working in the unit for much longer (Int. 12A, p. 13).

Two interviewees pointed out that the unit had many psychiatrists for such a small unit (Int. 9A, p. 10). The occupational therapist thought it led to competition between them that was particularly obvious in the meetings: *“There’s very much a competitive air in there and I haven’t encountered this anywhere else”* (Int. 15A, p. 15).

Yet the consultant was aware that he had power and said he did not want to abuse it: *“I don’t want to be autocratic... I think you’re very very at risk when you’re a consultant of being autocratic and then people resent it”* (Int. 13A, p. 22).

The inpatient nature of the unit worked against the nurses, making it difficult for them to share their perspective on the young people’s treatment with the rest of the team because, unlike the Knoydart nurses who all attended the clinical meeting, they worked shifts and were rarely free at the time of the meeting.

In addition to the tensions created by unequal power between the nurses and the psychiatrists, there was another source of conflict: a profound difference of understanding regarding the knowledge necessary to work in the unit.

2.7.3 Experience versus Knowledge

The interviews highlighted contrasting views between the nurses and the other disciplines (represented in the sample by the consultant and the occupational therapist) about what constituted the kind of knowledge required to perform well in an adolescent unit.

The nurses emphasised the importance of experience in the management of young people, particularly young people disturbed by serious mental health problems. Experienced Arisaig nurses could handle young people in crisis (aggressive or suicidal), difficult emergency admissions and any other disturbance. They were able to impose control and containment with apparent ease and they kept the level of anxiety in the unit low, making patients, staff and visitors feel safe. Such skills were acquired on the job over a long period

of time. Those that had them were proud of them and were admired and emulated by others (Int. 10A, p. 19; Int. 11A, p. 10; Int. 12A, p. 15).

The consultant recognised the skills involved in managing young people in crisis and acknowledged that some of the nurses did indeed have such skills. But he thought they were not enough, the unit remained crisis-driven and a culture of learning and evidence based therapy was necessary to stabilise it. Installing this culture was his responsibility (Int. 13A, p. 12).

The occupational therapist was an example of what the non-nursing respondents (and one nurse interviewee) understood to be necessary in terms of knowledge.

“When I came here... I was surprised actually that so few people are trained in so few things”... “I would have expected sort of the majority of staff to be trained in lots of different... family therapy, groups therapy, CBT”... “Definitely a group which would have a lot of quite specific skills and I don’t think that is the case at all” (Int. 15A, p. 9).

Harry suspected that lack of enhanced therapeutic training was the cause of insecurity and he attributed some of the inter-disciplinary conflict partly to that (Int. 15A, p. 9).

The nurse manager, however, described the difficulties she encountered in promoting education in her team: it was difficult to free nurses to attend courses and to finance them. The outcome was not necessarily a positive one because on their return they got promoted and moved away (Int. 10A, p. 22).

There was a degree of crossover between the two professions’ positions. The consultant seemed genuinely to value the nurses’ experience in unit management, but he did not think there was enough of the right kind of knowledge. Some of the younger nurses agreed with him and longed for more learning (Int. 9A, p. 13).

2.7 The School

The school was a significant part of the unit because at that time the unit only admitted young people who went to school (Int. 17A, p. 1). There were seven part-time subject teachers. Unlike in other units, where a therapeutic programme of groups shared the day with school time, the young people in Arisaig spent the whole day at school if they were well enough to attend (Int. 17A, p. 2). The school's ethos was to normalise the young people's school day as much as possible

"Our ethos would mirror mainstream school ethos... We try and make them feel that no matter what is wrong at the moment they have got a future" (Int. 17A, p. 3).

Most teachers had been there for many years. Their continuing education programme was structured around study-days and conferences, both in education and in psychiatry (Int. 17A, p. 4-5) so that most of them well understood the nature of the young people's mental health problems. The young people appeared to enjoy going to school, although some classes were more popular than others. Visits also took place during the school day, to places of relevance to particular subjects. The fieldnotes repeatedly commented on the teachers' patience and good humour:

"I am full of admiration for these teachers: they have such a lovely manner with the kids; they manage to be dynamic in a patient sort of way. They always find new ideas and interesting things to do, in spite of the fact that the kids are mostly passive, tired and unresponsive" (Arisaig, week 7, p.2).

In summary, Arisaig was very different from Knoydart: it was an inpatient unit with no tradition other than a mainstream psychiatric unit. Half its young people came in as emergencies and the nurses had little control over their timing. Much of the work of the unit consisted of intensive care, at which the nurses were skilled. Other therapeutic approaches were available but depended mainly on psychiatrists. The unit staff relations were strained but all appeared to be dedicated to the young people's welfare, albeit in different ways. The school was an asset to the unit's time-table.

3. RANNOCH

3.1 Introduction

The third set of data was collected in the Child and Adolescent Mental Health Services of a rural area which comprised an outpatient department and a ten-bedded adolescent unit with four day places. The building was situated at the edge of the grounds of a regional, now sparsely populated, psychiatric hospital surrounded by fields and farms. The adolescent unit, Rannoch, admitted young people between the ages of twelve and eighteen. The service had been there in various forms for many years.

3.2 Base Data

As in the other sections, the findings presented here were based on the analysis of interviews, fieldnotes and unit documents, but primarily on the transcripts of staff interviews.

During the summer break, five weeks were spent observing Rannoch's activities from 8 a.m. to 7 p.m. in sections of four or five hours. It was decided that observation beyond 7 p.m. would be intrusive due to the very small number of inpatients. The resulting fieldnotes have been used here.

Fifteen interviews took place: five with young people, four with parents and six with staff. The latter, from which much of the material described here derives, included three nurses, key workers to the five young people of the sample, a support worker, the consultant in charge and the nurse manager. The support worker was added to the sample following advice from another interviewee who knew her to speak with a different voice from the rest of the staff team. Table 7.7 displays the sample of staff interviewed and their function.

<i>NAME</i>	<i>FUNCTION</i>	<i>INTERVIEW</i>
<i>John</i>	Nurse Manager	No 8B
<i>Madge</i>	Staff-Nurse	No 15B
<i>Olivia</i>	Staff-Nurse	No 10B
<i>Christine</i>	Staff-Nurse	No 11B
<i>Sarah</i>	Support Worker	No 12B
<i>Dr Brown</i>	Consultant Psychiatrist	No 14B

Table 7.7: Rannoch Staff Sample and Function

(The names of the staff have been changed to preserve their anonymity)

During this time, Rannoch employed fourteen nurses: a nurse manager, two charge nurses, eight staff-nurses, an enrolled nurse and two support workers. The nurses worked three shifts over twenty four hours in the usual way. Two psychiatrists shared their times between the inpatient and the outpatient departments. One of them was also the unit manager. Table 7.8 displays the staff who worked at Rannoch, their profession, grade and numbers.

<i>PROFESSION</i>	<i>GRADE</i>	<i>NUMBERS</i>
<i>Nursing</i>	Manager (G)	1
“	Charge Nurse (F)	2
“	Acting Charge Nurse (F)	
“	Staff Nurse (E)	8
“	Enrolled Nurse	1
“	Nursing Assistant	2
<i>Psychiatry</i>	Consultant	1
“	Staff Grade	1

Table 7.8: Rannoch Staff, their Profession, Grade and Number

The unit had room for fourteen young people, including ten inpatients. At the time of the study, there were thirteen young people, four of whom were inpatients: seven boys and six girls (an unusually high proportion of boys). The day patients attended two to five days a week. A young woman who lived far came for two days and stayed overnight. Inpatients went home at the weekend if possible. The sample of young people drawn from Rannoch, with their age, gender and mental health problems is displayed in Table 7.9.

<i>NAME</i>	<i>AGE</i>	<i>GENDER</i>	<i>PROBLEMS</i>	<i>INTERVIEW</i>
<i>Mary</i>	15	F	Sexual abuse Depression	No 1B
<i>John</i>	15	M	Depression Isolation	No 3B
<i>Alan</i>	18	M	Schizophrenia	No 4B
<i>Tom</i>	12	M	Acute anxiety Abuse?	No 6B
<i>Rosie</i>	15	F	Psychotic depression	No 7B

Table 7.9: Rannoch Young People Sample: Age, Gender and Mental Health Problems

(The names of the young people have been changed to preserve their anonymity)

3.3 Rannoch in Context

The consultant and the nurse manager had been appointed to Rannoch some ten years previously, at a time when it was failing, with the remit to turn it into an effective service. Both described the unit of those days as chaotic, with no clear aim or philosophy and causing concern for the safety of young people and staff (Int. 14B, p. 4; Int. 8B, p. 2).

The nurse manager, John, had no experience of working with adolescents. To facilitate the changes, the management sent him on a specialist course and appointed a second adolescent psychiatrist, Dr Grey. John returned from his course with a greater understanding of the mental health problems of adolescence, the treatment options and the principles of unit management. Together, John and Dr Grey became the unit's change agents.

Up until that point the unit had been managed by a Mental Health Trust for adults where there was little understanding of the needs of adolescents. Hospital nurse managers remained in charge of the unit, imposing on it nurses who had no professional interest in young people and interfering in the running of the unit:

“Strangers from the hospital [were sent], [nurses] we didn’t know, who’d had no experience of working with children or adolescents, and also who were very annoyed and frustrated at being asked to come and didn’t have any idea about the difficulties that young people were exposed to and just saw them as difficult or bad kids. And of course their view was that they had to be kept in line and that made it very difficult.” (Int. 8, p. 4).

At that point, a reorganisation placed Rannoch in a Child Health Trust. This Trust gave the unit some autonomy, allowing it to appoint and manage its own nurses and to adapt hospital policies to the needs of young people. Both Knoydart and Arisaig had had that kind of autonomy from their parent hospital for many years.

At the time of the study the service had inpatient, day-care and outpatient facilities which were run as a seamless treatment structure. This meant the young people could be transferred at short notice between facilities according to their needs without having to go on a waiting list or be transferred to another consultant (Int. 14B, p. 9).

The unit also tried to keep the waiting list flexible and always to have an emergency bed so as not to turn emergencies away (Int. 14B, p. 3).

Rannoch had a national role: apart from young people from the region, the unit also admitted young people from other parts of Scotland where there was no inpatient unit (Int. 14B, p. 2).

3.4 Underlying Values

Values were more clearly spelt out in these interviews, particularly by the nurse manager, than they had been by interviewees in previous units. They were explicitly articulated as priorities to be passed on as such to new staff and young people.

3.4.1 Autonomy

A strong theme of respect for autonomy ran through the culture of this unit. It was mentioned many times in different contexts: autonomy for the unit from its NHS Trust; autonomy for the nurses from the medical authority of the consultant (Int. 8B, p. 19);

autonomy for junior nurses to make decisions (Int. 8B, p. 17); autonomy for the young people from the authority of adults.

3.4.2 Respect

Respect was valued across the whole network of relationships, within Rannoch and without: mutual respect and awareness between staff and a new Trust manager (Int. 8B, p. 6); hard earned respect between nursing and medical staff (Int. 8B, p. 20); respect and regard expected of young people for each other (Anonymous unit document, 'Expectations of Young People', Nov. 1999).

3.4.3 Self-Awareness – Empathy – Warmth – Inner Strength – Willingness to Grow

When appointing new nurses, these were the qualities the unit looked for (Int. 8B, p. 26).

3.4.4 Support

Staff support was prized: *"We share with each other here. I mean there is no-one who you can't talk to about how you're feeling"* (Int. 15B, p. 19). And staff support was expected to ricochet to the young people because empowered nurses empowered young people: *"if you make people feel destroyed, then their relationship with young people will be destroyed"* (Int. 8B, p. 18).

3.4.5 Community

Staff and young people together shared the responsibility of making the unit work: *"there is this culture that the young people and the staff as a group try to resolve difficulties that arise..."* (Int. 14B, p. 5). This was spelt out in a document explaining to the young people what was expected of them in the unit.

3.4.6 Honesty?

Two interviewees complained of a lack of honesty – or “*straight talking*” as one of them called it – in the unit. Both were junior members of staff. This will be explored later.

3.5 Staff's Understanding of Treatment

These findings were mainly gleaned from interviews with the consultant and the nurse manager.

3.5.1 Types of Problems Referred for Treatment

Rannoch treated young people with various kinds of serious mental disorder. The unit was not averse to working with very difficult behaviour as long as this was caused by mental health problems. Young people with conduct disorders were not admitted if they had no other underlying mental health problem (Int. 8B, p. 18).

Apart from taking young people in need of inpatient care from other regions of Scotland, Rannoch had a reputation of expertise in the treatment of certain types of mental health difficulties (Int. 8B, p. 19; Int. 14B, p. 2).

3.5.2 Managing Admissions

Rannoch received referrals for admission from the region's outpatient psychiatrists and general practitioners as well as from psychiatrists from other regions. But it was not a rigid system: one young man in the sample had been taken by his family to the hospital reception desk in an acute psychotic state, had been seen at the adolescent unit and admitted straight away.

The nurse manager stressed that all admissions were discussed and the nurses always consulted, even in an emergency (Int. 8B, p. 19).

3.5.3 Treatment Structure

When a young person was admitted, assessment took place during the first three weeks. This was followed by a review during which decisions were made about treatment. Once treatment had started, it was reviewed weekly in clinical meetings and every four to six weeks in further reviews. Some young people were only admitted for an assessment and left after three weeks. Each review set goals for the next one so that everyone knew what to work towards (Int. 8B, p. 11).

3.5.4 Treatment Approaches

3.5.4.1 A Modified Therapeutic Community

Dr Brown explained that the unit was run as a modified therapeutic community (see Chapter 2, p. 41) but that it included all the medical treatments necessary for mental disorders. This meant that the young people were expected, as far as they were able, to play an active part in their treatment and to take responsibility for their own health, behaviour and problems (Int. 14B, p. 4-5).

The young people were expected to use the many treatment groups and community meetings to learn to understand themselves and their problems better. This expectation was made clear to them on admission in a handout (Anonymous unit document, 'Expectations of Young People', Nov. 1999). The same document told them that together with the staff they were expected to form an active community where people helped each other.

Young people knew from the outset that violence or the use of drugs and alcohol would not be tolerated. They had to answer for their behaviour to other members of the community in meetings where difficulties were examined and challenged by staff and young people alike (Int. 14B, p. 5). The unit could not accommodate too much divergence from the therapeutic culture offered to young people. Those that did not wish to invest in their treatment could be asked to go home and think again – although this would not apply to young people who were too ill to appreciate what the choices entailed (Int. 8B, p. 16).

In spite of the community emphasis, individual needs took priority. This could mean that a psychotic young person would not go to meetings, or that their difficult behaviour would not be challenged in the usual way.

“What we really try to do is to allow the unit to provide a system for the individual rather than the individual fitting into what the unit provides. That’s important. Whatever challenges we meet with the young person, we will try and make sure that we can provide that. And if that means changing the way we work with one young person, we will work that through and try and explain it to the rest of the young people” (Int. 8B, p. 8).

Within this overall philosophy, therapeutic approaches varied: medication and ECT, behaviour modification and CBT, family therapy and a number of therapeutic groups, led by the unit or outpatient staff according to expertise.

3.5.4.2 Intensive Care

As Dr Brown stressed in the above section, Rannoch had to be able to accommodate seriously disturbed young people whose mental illness needed medical management. Young people with a psychosis could not attend groups, they needed antipsychotic medication and some had to be closely supervised and occasionally restrained. A few were detained under a section of the Mental Health (Scotland) Act 1984.

- **Nursing Observation.** Rannoch’s observation policy was that of the NHS Trust to which it belonged, devised according to national recommendations. During the period of observation, the only person being closely observed by a nurse was Mary. This was done unobtrusively (Rannoch, week 1, p. 8).
- **Legal Detention.** The number of detained young people had increased since the implementation of the Children (Scotland) Act 1995.

“Whereas before, if you had a young person who was psychotic, you know, and was thirteen or fourteen, you could take them on parental authority and now you have to ask yourself the question, if they were well, would they be

able to give informed consent. Then if you think that they probably would be able to, then you use the Mental Health Act” (Int. 14B, p. 11).

Rannoch tried to minimise the use of the Mental Health Act by avoiding confrontations with psychotic young people about admission and taking the time to let them come to the decision of being admitted (Int. 14B, p. 12).

- **Restraint.** The physical restraint of a young person was not required on a regular basis during the period of observation. But the nurses had recent memories of a frail young woman being physically held down in order to be fed through a naso-gastric tube. They had found it traumatic.

“And you know, four of us lying down on top of this lassie – and there was no other option... and trying to convince yourself that you’re doing the best for her! It was a nightmare” (Int. 12B, p. 22).

- **Medication.** Some young people were on anti-psychotic or anti-depressant medication but medication as a method of treatment was not mentioned by any interviewee, except in relation to a specific young person.

3.5.4.3 The Key-Worker System

Key-workers were staff-nurses with experience of working in the unit. They played an important role in the young people’s treatment by *“establishing a trusting and therapeutic alliance, demonstrating empathy, warmth and understanding and being non-judgemental in their approach” (Anonymous Staff Information leaflet, undated).*

Key-workers offered individual counselling at least once a week for which they received supervision. The content of these sessions depended on the need of each young person (Int. 11B, p. 6).

It was also the key-workers’ responsibility to write the young people’s care-plans with them (which they both signed), to anticipate treatment decisions and to prepare reviews by discussing options with young people in advance (see Chapter 4, section 3 on young people’s participation in treatment decisions).

The key-workers were their young people's closest point of contact with the unit staff. They were more likely to know about the worries, concerns and state of mind of the young people. If a young person and a nurse were initially poorly matched and it became clear that the relationship wasn't working, then the pairing could be changed.

Each young person had a main key-worker and an associate one. This allowed new nurses to learn by shadowing a more experienced nurse. A support worker was also allocated to each young person to assist with practical tasks like going to the shops, or to help them learn life-skills like washing and cooking.

3.5.4.4 Working in Groups

Many therapeutic interventions took place in groups. An action therapy group, an anxiety management group, an art group, and a psychotherapy group were all available at the time of the study. All except the psychotherapy group were led by a nurse, with another nurse as co-therapist. The psychotherapy group was led by Dr Grey who had experience and training in this form of therapy. A community meeting took place twice a day.

The community meeting was the centre-piece of the unit's time-table (see Chapter 2, p. 42). Olivia, an experienced key-worker, explained why they were important:

"We find that... some young people benefit from them alone – being with other young people and people listening to their opinion and knowing they matter, that's quite important" (Int. 10B, p. 16).

New nurses learnt about groups in the community meetings, which all attended, and by screening the psychotherapy group through a one-way mirror, which Dr Grey used as a teaching tool (Int. 8B, p. 14). Diaries of all the groups were available with the young people's permission.

Once a nurse had some experience and understanding of how groups worked, she would become the co-therapist of a specific group, then, in time, the lead therapist. New groups were organised or dropped as required, depending on the needs of the current group of young people.

Rannoch seemed to be able to ally a therapeutic community approach with the treatment of serious and enduring mental health problems and the use of individually tailored treatment plans. This is interesting because other units in the study had found it impossible.

3.5.4.5 Activities

Activities were part of the unit programme. They were explained to the young people before admission in the following terms:

“An activity evening is organised weekly to promote group involvement, social skills and most importantly to have fun. All young people are actively encouraged to attend” (Anonymous unit document, ‘Expectations of Young People’, Nov. 1999).

During the study the young people were on holiday and several days were spent going out to parks, beaches and places of public leisure and entertainment. The choice was the young people’s but it was restricted because they had to meet the cost out of their pocket money, supplemented by unit funds that were limited (Int. 10B, p. 17).

The very existence of activities depended on the availability of the staff. During the study, the unit became busier as nurses took their annual summer break and an inpatient became more disturbed. The opportunity to go out seemed to stop for a week or two and young people remained confined to the unit or to short outings on foot (Rannoch, week 2, p. 11).

3.6 The Staff

3.6.1 The Multi-Disciplinary Team

3.6.1.1. Co-operation

The multi-disciplinary team consisted only of two disciplines: a large team of nurses and two senior psychiatrists, Dr Brown and Dr Grey. Those interviewed thought relationships between the disciplines were good: the nurses felt respected by their medical colleagues;

they had many therapeutic responsibilities and decisions about treatment were shared (Int. 8B, p. 19).

Dr Grey was particularly esteemed and respected by the nurses who found him a constant source of support and empowerment. He was trained in psychodynamic psychotherapy and group work and willingly responded to requests for teaching and explanations on these subjects (Int. 8B, p. 21). Nurses recently appointed were struck by the co-operative nature of the multi-disciplinary team (Int. 11B, p. 19).

Being taken seriously by medical and senior nursing colleagues allowed staff-nurses to operate autonomously – something on which they commented positively (Int. 15B, p. 14).

The multi-disciplinary team shared a culture of clinical supervision: each individual was regularly supervised by a member of their own profession and Dr Grey ran a weekly supervision session for the facilitators of therapeutic groups. In addition there were regular staff meetings to discuss issues that affected them.

3.6.1.2 Special Patients?

In contrast to these positive testimonies, two interviewees expressed doubts about certain aspects of the unit's therapeutic management. One was the special status of certain young people who were singled out for more time and attention from the staff than the rest (Int. 10B, p. 22). This, they thought, was wrong because it fostered unrealistic expectations for that young person and caused the others to be jealous. It was anti-therapeutic and might in fact be revealing of a need in the staff (Int. 12B, p. 15-16). One respondent wondered if it might not encourage young people to develop a 'psychiatric patient' identity: she thought she had met such young people in the adult services. One young person present in the unit at the time of the study and included in the sample, Mary, was a candidate for 'special patient' status. Her plight as alleged victim of incestuous abuse in great distress attracted much staff dedication.

John, the nurse manager, perceived this as a problem to be managed if the unit was to succeed in helping Mary: Rannoch was giving a young woman at risk of suicide or a

blighted life a chance to receive the help she had asked for. Although this was not without cost to individual members of staff, the team and the unit as a whole, John thought Mary's demanding treatment worthwhile. He expected clinical supervision and staff meetings to help deal with the tensions and difficulties created by caring for this young woman. This position was described in the fieldnotes after an incident where a support worker's distress had been discussed:

"John explained... that was what special patients did to the staff. There was no hint that he intended to give up on Mary. All this was just to be managed through supervision, reflection and staff meetings... He felt the staff were struggling with the care of Mary because of the depth of feelings she evoked in them. He felt that he needed to contain the staff and that if he could manage that, the staff would contain the young people" (Rannoch, week 2, p. 2).

The senior staff were proud of treating young people known to be almost unmanageable in other adolescent units. Others, like the two respondents mentioned above, thought the cost was too high.

3.6.1.3 Honesty?

The critique of these two respondents went further: one of them thought that the unit's autonomy from the hospital had encouraged those in charge to lose touch with the reality of Rannoch's limitations (Int. 10B, p. 25-26).

Both thought these issues needed to be discussed openly, but they found it difficult to be honest: *"the higher up the rank, the more difficult it gets: 'will I say it, will I not'" (Int. 10B, p. 23-24).*

The hierarchical aspect of the multi-disciplinary team meant that the views listened to were those of the people in power. Although everyone was encouraged to share their views, they felt it could be dangerous to express the 'wrong' views (Int. 12B, p. 9).

Yet in his interview, the nurse manager had explained that he expected to be challenged in staff meetings, particularly by junior members of staff. He saw this as an important way in which all could contribute to the unit's sense of perspective (Int. 8B, p. 29).

The conflict conveyed in these findings suggests that it was difficult for the senior staff to run Rannoch according to the clear and strong treatment philosophy they described and were proud of, without adopting a somewhat autocratic approach. The staff interviewed mainly agreed with the unit management but it became clear that one or two were not so sure.

3.6.2 The Nursing Team

The nurses working at Rannoch were carefully selected according to a lengthy process. All grades of nurses, including support workers, were interviewed over two days. During an informal interview, they spent time in the unit with the nurses and the young people, and a staff-nurse explained what the job entailed. They were expected to go into a community meeting where the young people asked them questions. The formal interview with the nurse manager and the charge-nurse took place the next day. The consultant only became involved in the appointment of a charge nurse. Qualities looked for were empathy, warmth and an interest in working with young people, as well as self-awareness and a willingness to learn.

With regard to support workers, maturity, life experience and health or social care experience were important criteria. Most important was a sense of personal boundaries so that they understood when not to be intrusive (Int. 8B, p. 28).

All the staff-nurses and the charge-nurse were key-workers. Their main role was to manage their small caseloads of young people, give them regular counselling sessions and keep in touch with parents. Each week, they took part in the clinical meeting and ran therapeutic groups. As they worked shifts, they were busy.

Because the nurses had heavy therapeutic responsibilities, the nurse manager laid much emphasis on continuing education. Each individual member of staff had annual goals: a short course every year and a longer one about every three years (Int. 8B, p. 30).

3.6.3 Being a Nurse at Rannoch

Life at Rannoch could be stressful due to the nature of the young people's problems and the therapeutic commitment of the staff. All the interviewees mentioned the challenge of not thinking about work when they were off-duty. Most of them thought being able to speak to each other about their feelings helped them debrief and leave difficult issues behind. A couple of interviewees said they found the work stressful (Int. 15B, p. 20).

Managing the unit staff team without help from the main hospital meant that when staff levels were down due to holidays, sickness or vacant posts, nurses were called upon to work overtime. This happened frequently during the last two weeks of the study. Nurses on an early shift would come back to do a night shift and days off would be forfeited to fill the on-duty rota. No staff was heard to complain and they were compensated with overtime payment or time in lieu. To the researcher, however, the demands appeared heavy (Rannoch, week 3, p. 2).

3.7 Transmission of the Culture

The culture of the unit, which had been carefully thought out, was also carefully nurtured. John, the nurse manager, paid attention to the process. During informal discussions in the office, history was passed on, stories were told and their meaning linked to current and future events. This allowed John to explain why certain priorities were important (Int. 8B, p. 7). He kept diaries and photographs: they were a record of the unit's history and enhanced the sense of continuity. They were available to new comers and laid the basis for discussions about different ways of working (Int. 8B, p. 7).

However, the most important thing was to spend time with newer and younger staff and to convince them that they were important; that they were the future of the unit.

"Little things that come up all the time, involving them in that so that they actually feel that they're involved in the culture and actually putting down some bricks" (Int. 8B, p. 8).

Some transmission of culture also took place in formal settings like community meetings and staff meetings. Passing on culture to staff was the main priority. If the staff accepted the culture and worked with it, the young people followed (Int. 8B, p. 24).

Rannoch, then, presented yet another version of the adolescent unit: it was an inpatient unit with spaces for day-patients and offered a continuous service from outpatient to seven-day residence. It catered for young people with a wide spectrum of mental health problems, including some of the most serious and enduring psychoses. In spite of that, it operated a modified therapeutic community approach based on a network of therapeutic groups. Like Knoydart, it expected young people to participate actively in the life of the unit, although the most distressed young people did not take part in the full programme. The multi-disciplinary team was small but harmonious and the nurses played a major role in the unit's therapeutic programme. Working at Rannoch was onerous on the staff as well as rewarding and two respondents conveyed a certain unease about some of the unit's practices. The culture was more recent than Knoydart's but it was carefully nurtured and transmitted.

4. FISHERFIELD

4.1 Introduction

This set of data was collected at Fisherfield. One of the first in Britain, this small unit had been set aside in 1989 for fourteen to twenty-two year-olds in need of assessment and treatment after a psychotic episode. It was part of urban services for adolescents located in the grounds of a large psychiatric hospital. It opened from 9 a.m. to 5 p.m., Monday to Friday.

4.2 Base Data

As in the other units, the data used in this section consisted of fieldnotes, interview transcripts and unit documents.

Fisherfield was small, therefore it was only observed for seven days. During that time three young people, two pairs of parents, one mother and two key-workers were interviewed; eight individuals in all. This was a unit run by mental health workers from different professions, doing the same job. In their interviews, the two key-workers dealt with the ground covered in the other units by the consultant and the nurse manager. It is from these two interviews, as well as fieldnotes and unit documentation, that these findings are drawn. The staff interviewees, Paul and Meave, were both senior mental health workers with a lot of experience. Paul was in charge of the unit and key-worker to two of the young people in the sample. Meave was key-worker to the other. Table 7.10 summarises the sample of staff and their function.

<i>NAME</i>	<i>FUNCTION</i>	<i>INTERVIEW</i>
<i>Paul</i>	Key-Worker	No 4C
<i>Meave</i>	Key-Worker	No 5C

Table 7.10: Fisherfield Staff Sample and their Function

(The names of the staff have been changed to preserve their anonymity)

Fisherfield was run by five workers, two of whom were part-time. A consultant psychiatrist oversaw the young people's treatment by attending a weekly clinical meeting and the young people's treatment reviews. He met some of the young people and parents individually. The unit had access to other disciplines in the wider service. Table 7.11 displays Fisherfield staff's profession, their grade and number.

<i>PROFESSION</i>	<i>GRADE</i>	<i>NUMBERS</i>
<i>Nursing</i>	Unit Manager (G)	1
“	Staff Nurse (E)	1
“	Student	1
<i>Occupational Therapist</i>	Senior	2 (1 P/T)
<i>Psychiatrist</i>	Consultant	1 (P/T)

Table 7.11: Fisherfield Staff’s Profession, their Grade and Numbers

The young people arrived at Fisherfield at lunchtime to share sandwiches and snacks provided by the hospital kitchen. A therapeutic programme of groups and activities took place after lunch. Attendance varied from one to five days a week depending on the needs and availability of the young people. Some came from acute wards accompanied by a nurse but most came from home.

Eight young people attended Fisherfield regularly during the two weeks of participant observation. Three were selected for the sample because they were in a stable enough state of mind and accepted to be interviewed. Although two out of the three were girls, the number of boys in attendance was greater than the number of girls, as would be expected from the gender statistics regarding the onset of psychotic illnesses. The Fisherfield sample of young people, with their age, gender and mental health problems is displayed in Table 7.12.

<i>NAME</i>	<i>AGE</i>	<i>GENDER</i>	<i>PROBLEMS</i>	<i>INTERVIEW</i>
<i>Sarah</i>	21	F	Bi-polar Affective Disorder	No 1C
<i>Isaac</i>	17	M	Psychotic Episode	No 2C
<i>Sinead</i>	17	F	Schizophrenia	No 3C

Table 7.12: Fisherfield Young People Sample: Age, Gender and Mental Health Problems

(The names of the young people have been changed to preserve their anonymity)

4.3 Fisherfield in Context

The unit had been set up to respond to the findings of research which indicated that people recovering from a psychotic episode are sensitive to high expressed emotion (high EE) - (See Chapter 2, p. 52). Adolescent units, with their focus on relationships, group interactions and emotional literacy, are in the main high EE environments, therefore here an alternative had been devised, one more suited to young people who had been psychotic. Fisherfield operated a highly structured, supportive and undemanding environment (Int. 4C, p. 12).

4.4 Underlying Values

The philosophy followed by Fisherfield was not specific to the unit. It was inspired by contemporary developments in the treatment of psychosis which recommended early treatment with medication, quickly followed by psychosocial interventions in order to minimise the worst effects of the first psychotic episode and prevent relapse (see Chapter 2, section 3.2.1). The unit had been particularly influenced by the work of the Early Psychosis Prevention and Intervention Centre (EPPIC), a service for young people in Melbourne. Led by the psychiatrist Dr Pat McGorry, the centre had devised a specialised treatment model for young people suffering from a first episode of psychosis on the basis that best practice in early psychosis was different from best practice in its later stages (McGorry and Edwards

1997). The EPPIC package adopted by Fisherfield was underpinned by a clear set of values. The unit applied these values and adapted them to its own use. This was detectable from the way it functioned and from the professed priorities of the staff in the course of their interviews.

4.4.1 Hope – Person-Centredness – Empowerment

Key values of the workbooks by McGorry and Edwards (1997) followed by Fisherfield were the instillation of realistic hope through a process of person-centred psycho-education. This process of personalised information-sharing regarding psychosis and its treatment, scheduled at a time when young people and their families were ready and willing to deal with them, aimed to help young people see the course of their psychotic episode in a realistic but hopeful light.

4.4.2 ‘Concentrating on the Positives’

A concentration on the positive aspects of the young people’s lives was mentioned by the respondents on several occasions and appeared to be the unit’s way of instilling a hope that the staff did not always feel. It meant helping the stricken young people to enhance the positives in their lives and develop new ones instead of focusing on the problems created by their psychotic symptoms. This pragmatic approach was particularly useful to the young people and their parents but it also helped the staff themselves remain hopeful in situations where ‘negatives’ tended to be more apparent (Int. 4C, p. 14).

4.4.3 A Safe and Shared Space

The young people seemed to enjoy coming to a unit where everybody valued each other (Fisherfield, p. 8). Apart from the activities that had been organised in advance, there were drop-in afternoons when the young people came in just to meet each other and the staff. On these occasions they helped themselves to drinks and biscuits from the kitchen and sat

around chatting (Fisherfield, p. 6). Key-workers and a doctor were easily accessible for an impromptu individual session (Fisherfield, p. 8 and 14).

4.5 Staff's Understanding of Treatment

4.5.1 Types of Problems Referred for Treatment

All the young people admitted to Fisherfield had had an acute psychotic episode and were between the ages of fourteen and twenty-two, the core age range for a first episode (Int. 5C, p. 5). The main types of psychoses were thought disorders such as schizophrenia, and affective disorders such as psychotic depression and bi-polar disorders (Fisherfield, Introduction, p. 2).

All these young people were in the recovery phase. The staff explained that it was important to wait until they had ceased to have florid psychotic symptoms because until then they would have found the unit too stressful. But for most of the young people, psychotic symptoms remained. During the period of observation, the young people's psychotic experiences were often in evidence and disturbed their daily activities (Fisherfield, p. 3). A sense of working with serious handicap was noted. Although a real rapport could be established with some young people, communication was liable to be disrupted by manifestations of inner disquiet (Fisherfield, p. 7). Sometimes, young people were too absorbed by their inner worlds to respond to others. At other times delusional thoughts became part of the conversation. Yet the young people seemed tolerant of each other's difficulties. They recognised these irrational conversations for what they were and coped with them well, perhaps because of their own experiences (Fisherfield, p. 8).

One young man had experienced a full recovery from a psychotic episode. Another, Isaac from the sample, demonstrated the difficulties there can be in establishing a satisfactory diagnosis. Retrospectively, the staff wondered if Isaac had ever been truly psychotic.

4.5.2 Managing Admissions

Young people were often admitted to Fisherfield from an adult acute admission ward where they had first been treated for psychosis. Once they started to recover under the influence of anti-psychotic medication, their future key-worker visited them, slowly introducing them to the unit. During the period of participant observation, one or two young people came to join a social occasion accompanied by the member of staff who had brought them. Usually, they looked fragile and everyone was protective of them. If they could manage it, they would have a cup of tea or a can of juice and sit with some of the current young people (Fisherfield, p. 8).

Once they felt able to manage Fisherfield they would come for an increasingly extended programme. Sometimes they stayed in the ward a few weeks longer, returning there after a Fisherfield activity. Most of the time they attended Fisherfield from home.

4.5.3 Treatment Approaches

Young people could attend the unit for a period of months to years. However, there was an upper age-limit of twenty-two years of age. Whatever treatment strategies were used, all focused on the problems brought about by a psychotic breakdown or a psychotic illness. General principles were integrated into a treatment philosophy based on current research and the staff's extensive experience of young people with such problems.

4.5.3.1 Treatment Philosophy

Here, psychosis was described as a mental health problem rather more distressing than most, but not as a qualitatively different type of human experience. All mental distress was on a continuum and psychosis did not suddenly "*jump the scale*" (Int. 4C, p 19).

"The difference between for instance anxiety about yourself in a social context – feeling ugly, feeling looked at etc. – is not substantially different from paranoid ideas. These are just rather worse" (Int. 4C, p. 19).

Psychotic symptoms like hallucinations and delusions were extreme manifestations of distress. Their origins did not necessarily disappear as the person got better, but the distress presented itself more like ordinary anxiety.

The main goal of treatment was to help young people re-establish for themselves as normal a pattern of life as possible before being discharged: a structured day, social activities, education, accommodation if necessary, and follow-up treatment (Int. 4C, p. 7). But the unit could not achieve these unless the young person had '*a will to do these things*' (Int. 16, p. 8).

Another goal (called secondary prevention) was to prevent a relapse, or if one occurred, to limit its damage, in particular an admission to hospital where the motivation to get better could be undermined by a growing identity as a "*psychiatric patient*" (Int. 5C, p. 3).

The best approach to secondary prevention, one in keeping with McGorry and Edwards (1997) and others (see Chapter 2, section 3.2.1), was to adopt a supportive approach which "*shored up*" the young people's mental defences. The exploration of distressing emotions, the effort to find their origins and to resolve them, were avoided because of the stress all this might cause (Int. 4C, p. 12). Instead, the emphasis was on consolidating the young people's strengths and helping them understand their problems and how they might manage them.

"Our focus is very much on – yeah, building young people's strength, pacing things at a level at which they can co-operate and feel part of what's happening... ...A psycho-educational approach where we give young people as much information as we have on their illness, without at the same time frightening them... And you, you know, give them space, young people and their families, to express their anxieties..." (Int. 4C, p. 12).

These general principles were applied to a few therapeutic approaches. Both key-workers stressed that therapy had to be pitched at the right level because of the young people's fluctuating mental states, which meant building a lot of flexibility into the therapeutic programme. This was witnessed on many occasions during the period of observation.

4.5.3.2 One to One Work

Encounters between one young person and one member of staff aimed at supporting and helping the young person in some way, were ubiquitous. Either party could initiate them; they could be planned or spontaneous and slots were left in the time-table for urgent appointments to take place if necessary. All young people had a key-worker whom they knew well and who was their first port of call in distress, although another member of staff could step in if required (Int. 4C, p. 13).

A part-time psychiatrist was available once a week to see young people. Some of these medical appointments were planned. Others could be requested on the day by a young person, often to discuss medication, its effects and side-effects (Fisherfield, p. 14).

Individual sessions for therapeutic work had over groups the advantage that they were less stressful and easier to adjust to each person's stress threshold. Therefore they were used for many different therapeutic interventions, such as teaching coping strategies (related to coping with voices or with anxiety, or problem solving), psycho-education or Cognitive Behaviour Therapy.

4.5.3.3 Medication

During the period of observation, all the young people in the unit were on anti-psychotic medication except Isaac who was about to be discharged. Anti-psychotic medication was understood to play a major role both in the management of psychotic symptoms and in the prevention of relapse: "*we are absolutely committed at the moment to knowing that it [medication] is the best tool that we've got*" (Int. 4C, p. 17). A tool the ambiguity of which Paul was nevertheless keenly aware:

"There is no getting away from the terrible side-effects that most medication we have to use, even the newest ones, have... major side-effects... And also you kind of think, well, we don't know what long term effects they're going to have, because they haven't been around long enough. And it's more than just a bit scary..." (Int. 4C, p. 17).

On some young people, some medications had an unpredictable and destructive effect:

“The pattern for Sinead is that the medication that she would be on would start to lose its effect on her, she would start to become unwell; we would then try and change her medication and we would find that a lot of medication she was acutely sensitive to, that she would become physically unwell. That would shake her psychologically as well as it would be such a stressful time, that she would be reeling from that and it would exacerbate all her psychological symptoms or psychiatric symptoms”. (Int. 5C, p. 2).

The way the unit staff dealt with having to recommend such problematic treatment to the young people and their parents was by being open about the difficulties:

“We just put our cards on the table really, and say: ‘this is what we know, this is what these drugs can help with, this is what these drugs can’t help with. This is what we know side-effects are, this is what we know the long term side-effects can be’... And it’s very unsatisfactory but we don’t make much of a secret of that” (Int. 4C, 18).

Unless a medication was making a difference however, the staff wouldn’t persevere with it. This was why Isaac’s anti-psychotic medication had been stopped nine months previously. But as far as the respondents were concerned, the best treatment packages had to include anti-psychotic medication because it was that which got young people to a level of functioning where they could go on to benefit from psycho-education and psychosocial rehabilitation.

“We believe that in combination with psycho-education and other therapies, we give the best package to young people” (Int. 4C, p. 17).

4.5.3.4 Family Work

Working with the young people’s families was a crucial form of therapy that was offered to everyone. It took the form of support, education and skills training with the aim of helping families deal with what had happened to their children more peacefully, confidently and competently (Int. 4C, p. 11).

Family support could take place in the home or in the unit (Int. 5C, p. 1). These individually tailored psycho-education sessions were interspersed, every few weeks, with treatment reviews which included the young person, the parents and the treatment team. Individual family work was usually followed by a relatives’ group. The individual work

had allowed the family's specific needs to be met but relatives' groups offered parents (or main carers) an opportunity to encounter people in situations similar to their own (Int. 4C, p. 15).

Parents struggled to take information on board intellectually and emotionally: *"they're in denial for quite a while"* (Int. 4C, p. 16). Having to face the fact that your child may have a debilitating mental illness and that the course of her life may not run as anticipated was painful; the uncertainty of this fact only increasing the anxiety. The complexity of the data regarding stress prevention, medication and the desirability of low expressed emotion required focus and commitment.

Fisherfield always checked with the young people before inviting their parents and staff remained available to them after their son or daughter had been discharged (Int. 4C, p. 16).

"There are some parents who continue to use the relatives' group for support long after their sons or daughters have left. Or there are some parents whose son or daughter flatly refuses to engage here. And they're saying we don't want the day-unit, we don't need it, but the parents say they need support. So you know, we like to be able to offer it" (Int. 4C, p. 16).

4.5.3.5 Groups and Meetings

Meeting people of the same age and being able to give and receive support from them offers adolescents a transition from childhood to adulthood. Fisherfield's way of tapping into this developmental ingredient was to run many activities in groups: recreational and skills training activities and discussion groups ran everyday. They were kept low-key, however, and could be adapted to the needs of group members from hour to hour (Int. 4C, p. 13). In advance of these groups, the young people held a meeting with the group facilitator and planned activities and topics for discussion (Fisherfield, p. 13).

Although groups were not the most important way of delivering treatment here in the way they had been at Knoydart or Rannoch, they were an important way of structuring the young people's week and helping them experience age appropriate relationships.

4.5.3.6 Activities

Many activities took place during the period of observation because it was the summer break. One week was spent on outdoor sports under the leadership of a youth club. Each day that week started with trust and team building exercises which were followed by different sports like rock climbing, canoeing and abseiling. The goals of the activities varied, from developing social skills and being mutually supportive, to practising physical fitness and co-ordination, as well as getting a taste of activities many young people experience in the normal course of their lives (Fisherfield, p. 3).

Other activities were organised by the unit and planned together with the young people, a lot of the unit's life revolving around food. The usual day started with lunch, which came from the kitchen, although some young people sometimes came in early in order to cook a pizza or a cake. Before the young people went home at the end of the afternoon, they usually had a cup of tea and a biscuit together. Eating was a social activity that drew people together but it was also one of the rare pleasures many youngsters were still able to enjoy; all the more so, as one of the common side-effects of anti-psychotic medication is an increased appetite. Weight gain too, was a serious problem for some of the young people and cooking activities included advice on nutrition and healthy eating (Fisherfield, p. 11).

4.5.3.7 Safety Measures

In a day-unit where clients had such potentially serious problems, it was interesting to see how issues of safety were dealt with. It is known that people going into or coming out of a psychotic episode are at greater risk of committing suicide, as are those acting under the influence of hallucinatory voices and delusional thoughts. These latter can also be, though rarely, a danger to others because of paranoid perceptions. At Fisherfield, the ratio of young people to staff was approximately two to one during outings. No young person was detained under the Mental Health (Scotland) Act 1984 at the time of the study, yet on a few occasions, the prominence of concerns in the staff's mind regarding the safety of particular young people became apparent (Fisherfield, p. 11).

One or two young people visiting from the hospital wards were accompanied back and forth by a member of staff. This was done inconspicuously and the fact that these young people were under close nursing observation for their own safety wasn't obvious, even to the experienced observer, until later. This discreet approach to safety allowed the young people to operate in a normalised environment where their mental health needs remained private.

4.6 The Staff

The team was small and multi-disciplinary, although there was little differentiation between the jobs each person did. The staff's work and their understanding of it, according to the interview transcripts and the fieldnotes, were analysed into three categories: 'caring', 'leadership' and 'coping'.

4.6.1 Caring

Although the staff interviewed found the work 'sad' and concentrated on the positives to help themselves as well as the young people, both respondents also talked of the sense of reward that came from doing something which they knew to be useful (Int. 4C, p. 14):

"We're giving young people strategies and we're building up their resources, and it actually feels very important in a lot of ways" (Int. 5C, p. 7).

Often, the staff was observed to be supportive of young people, as for instance, on the way back from lunch at a restaurant:

"The staff are calm, kind to and protective of the young people. They chat with them a lot, initiating quite a lot of the talk" (Fisherfield, p. 9).

The young people themselves did not seem to hesitate to ask for help: in the unit they requested to see their key worker or a doctor. At home, they might sometimes phone a member of staff and discuss with them strategies to cope with stress (Fisherfield, p. 10).

4.6.2 Leadership

In this unit, the young people could not be pressured into organising themselves or helping the staff as others might have been. While at Knoydart a packed lunch might have been made by the young people with some help and guidance from a member of staff, at Fisherfield, a student nurse was observed making up sandwiches on her own on her first day while the rest of the staff welcomed the young people, spoke to the parents and organised everyone to make ready to leave (Fisherfield, p. 2).

4.6.3 Coping

Paul, who was in charge of the unit, highlighted some qualities and skills he looked for in job applicants. These included: good personal boundaries, the ability to look after themselves and *“I suppose I look for people who are really quite confident and quite mature, and, you know, aren't going to flounder with some of the stressful, hard days (Int. 5C, p. 14).*

Another quality was the ability to deal with the difficult emotions young people were liable to elicit: sadness and despair were mentioned by both key-workers, and Karen, the student nurse, had to deal with a vulnerable young man's passionate crush on her during the unit's holiday: he followed her everywhere! (Fisherfield, p. 6).

To summarise, Fisherfield was a small day unit dedicated to the service of young people who had been psychotic and their families. Its culture was organised to suit the young people's needs for an undemanding and structured environment which would present no threat to their fragile mental states. It endeavoured to provide young people and their families with hope and support as well as the best chance of a normal life for which there was scientific evidence at the time. Working with the young people's parents was an essential part of this approach. The staff team was small and multi-disciplinary, with little distinction between the disciplines. The work was described as 'sad' but 'rewarding'.

CONCLUSION

In this chapter, the four units where data were collected have been described using staff interviews, fieldnotes and unit documents. The cultures of the four units all comprise the same four elements: a local context, values, treatment approaches taken from those available in the National Health Service in Britain today and a staff community, yet their description conveys how different they turned out to be. In the next chapter these differences and their possible impact on the goal of involving the young people and their parents in their care and treatment will be discussed.

CHAPTER 8: DISCUSSION

INTRODUCTION

Throughout the research findings, the views of different stakeholders in the units' lives were heard and four different unit cultures came to life. The initial focus of the study had been to find how young people perceived their treatment and their participation in it. The voices of their carers however, both parents and staff, soon emerged to convey their own needs and perspectives regarding the young people's treatment and participation. The units themselves revealed complex cultures, combined over the years into a unique blend for each unit. User and carer participation held a different place in each unit, suggesting that, in terms of the thirty-year or so life span of these NHS services, the participation movement was a relatively recent, and not entirely coherent, commitment.

In the literature review (Chapter 2), some of the key components of participation came to light. Reflective practice (Schön 1991), value clarification and value sharing (Woodbridge and Fulford 2004), respect for human rights, the central role of personal relationships (Swinton 2000), the importance of the community (Grey 1989) and the significance of the socio-political context of care (Pattison 1997) are all, arguably, crucial building blocks of a participative culture. The last three of these components (Swinton 2000, Grey 1989, Pattison 1997) were influenced by the liberation theology movement (see Chapter 2, p. 17 – 27) and belong to the field of Pastoral Theology. Liberation theology was one of the first participation movements. Its success and the systematic thinking which supported it, have influenced British theologians like Swinton, Grey and Pattison who have gone on to suggest important ethical priorities for the success of such movements in Britain. Therefore this discussion of the research findings is going to consist in a scrutiny of the voices of the young people, parents and staff and of the unit cultures in the light of these priorities. The goal of such a strategy is to highlight the successes and failures of participation, the obstacles to it and the value conflicts caused by it in these four Scottish units. It will then be possible to discern the shape a participative culture might take in settings like these, and to make recommendations for its implementation.

1. YOUNG PEOPLE'S PERSPECTIVE

1.1 A 'Friendship' Model of Interpersonal Relating

'Friendship' is the term Swinton (2000) uses to describe the personal, respectful relationships he suggests should be offered to people who experience mental health problems, to draw them into communities where they can belong (see Chapter 2, p. 21). The use of the word friendship here implies a commitment to the support and liberation of the other. It is not necessarily a relation based on congeniality as friendship usually is, but on the sharing of power. Such relationships have a humanising effect on those who are socially powerless, misunderstood and marginalised for their differences. They are liberating and empowering. Service users themselves have used the word 'friend' to refer to professionals whom they have found helpful because of their availability and their supportive and caring attitude, and they have said that they felt validated by such people (O'Toole et al. 2004).

It is therefore no surprise if the majority of the young people in the study said that what helped them most in their treatment was the people they met in the units (staff and peers), and the relationships of care they had with them. Some of them highlighted the contrast between the companionable quality of unit life and the incomprehension and stigma they had met before their admission. They reported that this humane context had a positive impact on their self-esteem. This means that many members of staff in these four Scottish units were able to offer a form of 'friendship' that the young people found affirming and liberating. Because respect and support between young people were encouraged and supervised, peer relations made a therapeutic contribution too. The most valued therapies were relationship-based. Over half the young people mentioned one-to-one therapies where they could explore their problems in safety, and a third mentioned groups, although these were experienced as more anxiety provoking.

However, the young people's comments on their experience of treatment offered a contrast: while relationships were valued, other interventions were criticised. Medication, for

instance, with its troublesome side-effects, evoked ambivalence. Coercive interventions, like special nursing observation and detainment under the Mental Health Act were disliked, although they were sometimes acknowledged retrospectively as having been helpful. These were interventions that made young people feel controlled and helpless: precisely the kind of experience which participation aims to minimise.

A number of young people mentioned medication with a sense that it could help but could also be damaging. Several stressed that medication was not enough and that they needed good caring relationships alongside it. Some young people referred to special nursing observation (see Chapter 2, p. 53). None of them found it pleasant but three could see that it had been useful. There were instances in the findings (both in interviews and in fieldnotes) when a context of 'friendship' had made these experiences more tolerable: some staff managed to supervise young people unobtrusively, appearing only to be keeping them company or to be engaged in play and discussion with them. One young person related how she had drawn up a programme with her key-worker for the staged withdrawal of special observation. She had appreciated this return of control based on negotiation. No interviewee was on a section of the Mental Health Act at the time of the study and only one young person talked about the experience, which she had hated because "*it makes the staff think they own you*" (Int. 2A, p. 9).

The views of the young people about each treatment intervention could be analysed in terms of these interventions relying on liberating personal relationships, with those interventions facilitating collaboration and negotiations being positively valued and those focused on safety and control increasing the young people's sense of alienation, helplessness and resentment. A continuum representing each intervention according to the young people's preferences is drawn in Figure 8.1.

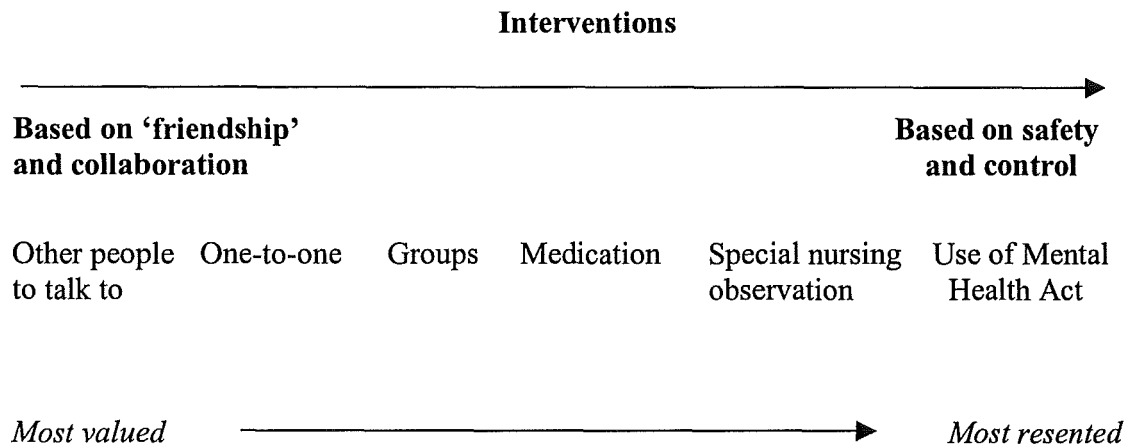


Figure 8.1: Continuum Representing Young People's Treatment Preferences

Surely, therefore, the challenge is to apply safety interventions in the least coercive way, making maximum use of personalised and liberating relationships to humanise them, as drawn in Figure 8.2.

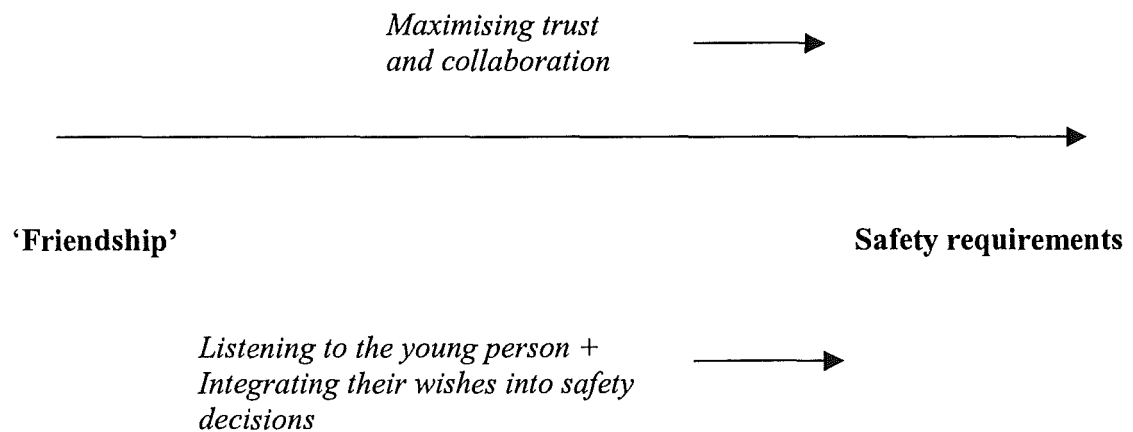


Figure 8.2: Continuum Showing the Enhancement of Young People's Treatment Preferences

In one of the units in the study where coercive treatment interventions were frequently used, there were specific examples where these had been negotiated but they were the exception rather than the rule. Even non-coercive aspects of treatment were imposed. Time out of the unit in the evening and at weekends was a particularly sensitive, non-negotiated area cited by all the young people in that unit as a cause of frustration. This suggests that a policy of negotiation was not in place and indeed, there was no evidence of one, and perhaps little awareness of what the young people valued.

1.2 Value Clarification, Value Sharing and Reflective Practice

Fulford et al. (2002) emphasised the importance of values, and of health professionals being aware of their values, so that they could remain focused on what mattered in their decision making. This point is significant in several ways here. It means that to enhance the collaboration of young people in safety decisions, often taken at time of stress and crisis, the value of collaboration must be explicitly and collectively rehearsed in order to minimise the temptation to act forcefully first, and to think second. Woodbridge and Fulford (2004) suggest that, to work in partnership, the key values of the partners must be shared: this means that staff and young people's views about specific treatment interventions, for example special observation, need to be known to both parties. One young woman for instance, Kate, stated that she preferred the nurse not to talk to her when she was observed. Unless the staff knew this, it is likely that a nurse following good practice guidelines would make every effort to engage Kate in conversation. The nurse would be observing the best values of her profession, yet Kate would find this intrusive. Time spent discussing this would allow them both to reflect on the best way to implement a personal yet respectful relationship. The focus for such sharing of personal preferences is what Schön (1991) called reflective practice, when both client and professional share their views of a situation and come to decisions based on an understanding of each other's position. This can apply to other situations which the young people found difficult, like imposed and prolonged admissions, limited opportunities to go out and having nothing to do in the evening and at weekends.

1.3 Levels of Participation

Participation is described as the process of taking part in decisions that affect one's life and community (Hart 1997). Young people's involvement in unit decisions might therefore be the index of their participation, and of the units' ability to offer participative environments. The young people's views regarding their own participation were not black and white, but there was a contrast between treatment decisions, to which fewer young people felt they contributed, and decisions about every-day unit matters, in which more thought they participated. Therefore it would appear that the level of participation in the four units overall, as judged in terms of involvement in decision-making, was significantly lower with regard to treatment decisions than to ordinary, non-treatment unit matters.

In terms of Hart's ladder of participation for young people (1997) adapted from Arnstein (1969), the focus of control for the initiative, process and outcome of decision-making is an important question. If the focus of control remains with adults, Hart (1997) diagnoses a tokenistic level of participation of which young people will soon tire. Shared, or even better, delegated control, is deemed necessary for involvement in decision-making to be truly participative. It seems clear from the findings however, that the young people did not think the control of decisions about their treatment was delegated to them. Less than half the young people thought that decisions were shared, but those who did described an adult-led style of decision-making, in which they acted as consultants.

Many young people referred to a number of obstacles to shared decision-making. One of these appeared to cause them particular resentment. According to them, it came from the assessment of their best interest by adults being different from their own. Admission to hospital, discharge from the unit or special observation were sometimes prescribed by the staff, with the agreement of parents, in spite of protestations from the young people concerned. This made them feel angry and powerless, although they not infrequently complied without the Mental Health Act being invoked. The two young people in the study who were most angry about their lack of participation in decisions regarding their treatment

had been diagnosed as anorexic, a diagnosis they did not entirely accept. This ambivalence was attributed to the very nature of anorexia nervosa, where people who are under-weight think wrongly that they are overweight. It was potentially life threatening. This conflict of perspective between young people and adults demonstrates the complexity of participation issues for young people in mental health care. In this context, Sinclair's recommendations, to consider the scope and consequences of decisions as well as the young people's age, disability and mental capacity before making blanket promises of shared decision-making, seem both wise and realistic (Sinclair 2004). In mental health units, the danger would be to use disability or lack of mental capacity as an excuse not to share any decisions with young people. But it seems clear that the decision-making process cannot be completely delegated, and in some cases may not even be shared. Hence, a more useful indicator of participation than control of the decision-making process (Hart 1997) might be the just quality of the relationship between the decision-makers (Grey 1989).

1.4 Just Relations

When power is exercised to support the interests of the strong, as it is often the case, relationships are devalued and unjust. Just relations, that is, relationships based on justice rather than power, make the interests of vulnerable people a matter of priority and make the community in which they take place a humanising place for them (Grey 1989). Justice is a characteristic of the 'friendship' model of interpersonal relations discussed earlier but 'friendship' stresses the personal nature of these healing relationships. Here the justice element is the focus of the discussion. To what extent did the young people feel that the relationships they had in the unit empower them to say what they wanted to say, and to contribute to their treatment and the unit's life to the extent that they wished?

Young people varied on this point: some felt heard and involved while others did not. On the whole, young people felt powerless beside the unit and its staff unless the adults made a special effort to empower them: "*I feel I don't have the right to tell them what's better*" (Int. 3, p. 10). Some did not have the confidence to approach a member of staff but one also said that the nurses usually guessed when something was wrong and approached her. There

were also empowerment failures. No negotiation of time out of the unit, occasional arbitrary decisions regarding activities, the staff being preoccupied and not listening or treatment decisions having already been made were examples the young people gave.

The relationships young people found empowering were those where they knew they were heard and could participate in decisions if they wished to do so. Some young people stated that they did not wish to make decisions because the treatment choices (going into hospital or taking medication) were unappealing or because they found the whole business of treatment difficult and depressing. Empowering adolescents who have the developmental right to distance themselves from adults and their plans requires more discretion and subtlety than empowering adults. It may mean accepting the responsibility of making decisions about young people without them. All the young people interviewed had strong feelings about some aspects of the unit and their treatment. This was when they were keen to intervene. There was no indication in the findings that they wished to have complete control of the decisions or that they were discouraged by a lack of complete control, as Hart stipulated (Hart 1997). This is probably due to the complexity of mental health problems, treatment and treatment settings where even adults look for partnership rather than complete control.

Conclusions

In summary, the findings regarding young people's views of their treatment were not particularly new or surprising. What helped them most was also what is now recognised as good practice, as it is stated in recent guidelines for the application of nursing observation (CRAG 2002) and the new Mental Health (Care and Treatment) (Scotland) Act 2003 (Scottish Executive 2004). The units in the study seemed to offer young people a good standard of personal, respectful and liberating relationships in line with those described by Swinton (2000). Difficulties arose when interventions involved the need to impose control for safety reasons. In order to ensure that such interventions are framed in a context of negotiations where young people's preferences are known and met to the maximum extent, clarification of what they value needs to take place on a regular basis and to be enshrined in

policy. Reflective practice, which is already prized in health and social care settings, at least in theory, needs to apply to the shared space between young people and the staff in order to provide an opportunity for value sharing.

With regard to participation in decision-making, the findings show that young people appreciated efforts to collaborate with them. The level of young people participation operative in the units under study was not high in terms of control of decision-making. But in the context of mental health care of an intensive nature, control of decision-making may not be the right index of participation because of the complexity of such decisions. Just relations between the decision-makers is perhaps more important. In terms of relationships of justice however, where young people could be heard and empowered to a level they were able to implement, the findings revealed many examples of empowerment success and some failures. An analysis of the views of other stakeholders in these same situations will help throw more light on the implementation of participation.

2. PARENTS' PERSPECTIVE

2.1 *'Friendship' and Just Relations*

The parents interviewed for the study had much to say about their relationship with the unit and its staff. They needed a great deal: help and support, to be listened to and understood, to be advised about the management of their child, to have mental health problems and their treatment explained to them and to be involved in decisions regarding the young person. A number of the families interviewed found the help they needed but a few did not.

The young people's mental health problems, which in most cases had gone on for many months, had seriously disrupted all these families' lives. The parents felt vulnerable and guilty that they had not, somehow, protected a child of theirs, or that they had perhaps caused the problems. Young people had often manifested their difficulties through bad or dangerous behaviour, showing an inability to conform to social expectations. This had isolated their parents from relatives, friends and colleagues who did not understand. So these parents were truly in need of 'friendship' (Swinton 2000) and of the kind of

empowering relationship (Grey 1989) that would help them feel rehabilitated as effective parents in their own eyes. Siblings also needed support to understand and cope with what was happening.

For the units, this was a heavy set of expectations. In practical terms, it meant one or two members of staff becoming a family's special 'friend(s)', developing a relationship of trust with them, frequently setting time aside to meet with them, learning to know them, their difficulties and their needs. It meant organising meetings at their request, in their own home or in the unit, perhaps with different family members at different times. Ten sets of parents thought the support and care they had received from the unit were good enough, which demonstrates that a good standard of family work was in place, although it was unevenly spread throughout the units.

The difficulties encountered by parents were revealing: a young person's key-worker was not available when his mother visited, so she went back home with her worries. A key-worker was on holiday, so the family did not speak to someone else. Both these incidents demonstrate these parents' lack of confidence that the unit was interested in them, and that someone committed to their welfare could be reached by telephone or appointment. Some parents said that they were intimidated by the professional settings of the units because the staff was knowledgeable and articulate (*"I feel sometimes like a stupid wee lassie myself when I'm trying to tell them things"* Int. 9, p. 16). Just relations required the power between parents and the unit staff to be redistributed and parents empowered through a careful process of respectful, supportive relating. The findings suggest several obstacles to this.

- Some staff members lacked experience and skills. The study showed that the units left much of the work with parents to the young people's key-workers. These nurses were often the least experienced members of the health care team. In cases where parents had been particularly complimentary about the support they had received from the units, the staff involved had been senior members of the medical and nursing professions, and key-workers with many years of professional and life experience behind them.

Some of the skills involved were complex. They included: the ability to contain different and sometimes conflictual points of view without judging or taking sides, while at the same time suggesting and encouraging concrete solutions; the capacity to speak about complex scientific matters in every day language; the sensitivity to appreciate the vulnerability of parents who might otherwise appear to be competent ordinary people; and in addition to these, a willingness to negotiate compromises and acknowledge mistakes.

- The parents' levels of social skills, mental health and ability to meet the staff half way differed. Some required more active, lengthy and skilful approaches than others. Yet a consultant psychiatrist and three key-workers understood the policy of parent involvement in terms of an open invitation to them to contact the unit whenever they wished. By the admission of other interviewees, the success of this approach varied with the families' ability to implement it. As one psychiatrist suggested, it was particularly difficult for those whose confidence was fragile (*"I think with the most sensitive, wounded, threatened parents we don't succeed"* Int. 19, p. 3). One father, who praised the support of the unit, stressed that he and his wife had had to work hard.
- The resources required to be able to invest the kind of time and skills necessary to carry out the work requested by parents, particularly with the more vulnerable, chaotic or threatened families, were lacking.

The parents' need for 'friendship' and just relations was almost as great as that of their children. Although the units succeeded in seeing to these needs in two thirds of the sample, one third of parents felt left on the margin of unit life. These tended to be parents and families who were vulnerable or whose link person in the staff was inexperienced. The right to be involved, which both young people and parents could have invoked, could also make parents' needs more difficult to fulfil.

2.2 Human Rights

The right to participation in all issues regarding their lives is a right for young people (United Nations 1989, Great Britain HM Government 1989/1995), although it is a fairly new right to which adults find it difficult to adjust (Marshall and Parvis 2004). The units in the study had begun to incorporate young people's rights into their philosophy of care, although to varying degrees. They were now facing the challenge pointed out by Hill et al. (1995) of balancing the rights of young people with the rights of their parents. It was an ambiguous and difficult task and there was evidence that increased respect for individual young people's rights was leading to a decreased focus on parents.

Some parents in the study pointed out that their children's rights took precedence over their own. They felt alienated from the unit and thought that their point of view had not been heard, although the reverse was also true and one young person complained that her mother had more rights than she had. All these cases involved conflict between parent and young person in which the unit was asked to take sides. Some key-workers had found it difficult to contain the diverging, conflicting views of the protagonists.

A problem mentioned by two parents in this position was that the young people's behaviours remained problematic at home while improving in the unit, and that communication between staff and parents was not good enough for the parents to feel confident that the home-based problems were being addressed. A strong alliance between family and staff underpinned by good communication would have helped to resolve these young people's continuing home-based difficulties. Robust work with the family was more difficult but also more necessary when the young person's mental health problems had caused a serious rift between them and their parents. The challenge was to make an alliance with both parties and slowly to bring each to see the other's needs and viewpoints.

In a few cases, confidentiality had become a catalyst for conflict. Some parents had experienced confidentiality as a barrier to involvement. One young woman had insisted on having all details of her treatment withheld from her mother, which had made it difficult for

the staff to keep this mother involved, although they had persevered in their support of her. Another parent who felt poorly informed had been suspicious that confidentiality was a surreptitious reason why this was the case. This is a problem of which the carers of adults with mental health problems also complain (Gardner 2000). Patients' rights have reinforced this difficulty and intimidated health care staff who now hesitate to share information with clients' relatives and young people's parents.

All the staff members in the study were very aware of their duty of confidentiality towards the young people. The advice given by the Department of Health (DoH) in the NHS Confidentiality Code of Practice (DoH 2003), that every effort should be made to support carers' work and that competent young people should involve their parents, had not been published at the time of this project's data collection. An earlier document on confidentiality written for the NHS in Scotland was less explicit (Scottish Home and Health Department, undated). Although the DoH does not absolve the staff of their duty of confidentiality, it does suggest that systems might be put in place from admission onwards to discuss the practicalities of information sharing, as had been proposed by Woods et al. (2000).

The perception that children's new rights undermine their parents' rights is becoming widespread. When parents and young people disagree about diagnosis or treatment, skilful and patient negotiations are desirable, if difficult to carry out. Conflicts between individual rights need not lead to relationship breakdown. They challenge everyone to respectful and collaborative relationships that enhance justice for all parties (Marshall and Parvis 2004).

2.3 A Community of Care

Three of the units expressed a general willingness to work with parents but did not give this work the same priority as to the young people's treatment. Mainstream units, represented in the study by Knoydart and Rannoch, focused on working with individual young people in line with an ethos of personalised care, in the context of a therapeutic milieu which included young people and staff but not parents. In these units, some parents felt disenfranchised.

In view of the parents' expressed needs for involvement and the government's commitment to parent participation (Scottish Executive 1999 and 2001) however, an alternative philosophy of care would have been to make explicit mention of the family as one of the main stakeholders, alongside the young people. It would rely on the integration of two apparently diverging principles of care: focus on the individual and the involvement of carers. More staff time and advanced skills than are currently available in residential services would be required successfully to reconcile such divergences in practice.

Fisherfield, the small unit for young people who had been psychotic, offered a contrast. In line with a philosophy of care for this client group that was not specific to this unit, but one of the first services in the country to apply it, it operated an explicit policy of parent support, education and empowerment. Fisherfield met the needs of the parents in the sample and was an example of successful parent involvement. It was also a unit where the key-workers had both life and family work experience. In many ways the unit fitted the description Grey (1989) gives of a liberating community of care, with its collective commitment to the most vulnerable of its members and to respectful, non-exploitative, power-sharing relationships with all.

Conclusions

In their interviews, the young people's parents conveyed many needs, some of which remained unmet. To fulfil these needs the units would have needed assets that they appeared to lack: greater awareness of the nature of these needs, greater skills in working with families and more resources, particularly more time, to attend to them. Other difficulties were not specific to the units but seemed to spring from the potential for conflict between the differing rights of individual family members, born of the stress on individual rights (Hill et al 1995, 2004). In health care, this conflict often manifests itself in a polarisation between patients' right to confidentiality and carers' need for information, and between a philosophy of individualised care and a commitment to the involvement of carers. Both these difficulties were reflected in three of the four units in the study. The successful involvement of parents in the fourth unit, Fisherfield, demonstrated that these

difficulties were not insurmountable but were considerably helped by an explicit policy of parent empowerment which had led to their full inclusion in the unit's community of care.

3. STAFF'S PERSPECTIVE

Like the young people, the staff interviewed made a distinction between participation in day-to-day unit life, and participation in treatment decisions. All the interviewees declared a commitment to the involvement of young people in day-to-day life and this aspect is not discussed further. Their perspective on the involvement of young people in decisions regarding their treatment however, conveyed commitment but also an awareness of the difficulties of the task. This section concentrates on the staff's perspective regarding the young people's participation in treatment decisions. It also discusses briefly their perception of parental involvement.

3.1 Just Relations and the Use of Power

The characteristic of just relations is a redistribution of power whereby the more powerful party in a relationship does not use this power to obtain what they want but treats the weaker party with the respect due to an equal. Relationships of justice are based on a mutual awareness of each person's experience, so that transactions can be negotiated and compromises reached that suit both parties. This is not to say that there is no place for authority and leadership but that authority is better based on principles of consultation and empowerment than on domination and control. Vulnerable people experience transactions that impose an outcome on them as oppressive, whereas just relations are supportive and empowering (Grey 1989). A commitment to justice in relationships springs from solidarity and compassion and humanises the group in which it takes place (Grey 1997a). Swinton (2000) suggests that such relations with people who have mental health problems are lacking in society, but necessary. Article 12 of the Convention on the Rights of the Child (UN 1989) affirms the same with regard to children. Young people who have mental health problems belong to both groups and are therefore highly in need of just relations.

In a mental health unit for young people, the challenge of participation is to enhance justice and empowerment without taking unacceptable risks with the life and health of the young people. The staff interviewed revealed concerns about how to reconcile their responsibility for the young people's welfare and best interest with the requirements of participation. For some, it was also difficult to trust that the young people could make good decisions because of their age and mental state. The difference in power between mental health workers of all disciplines and young people is based on two main elements: the staff's expertise regarding the young people's mental health problems, and the difference in age and life experience between adults and adolescents. Both are challenges to relationships of justice: the way each challenge was met according the staff interviewed is discussed in turn.

3.1.1 The Power of Expertise

Knowledge of mental health problems and their treatment, and the responsibility to help young people with their mental health, imposed upon the staff the use of their expertise. It was not a source of power they could ignore or bypass. When safety or future welfare were involved, the force of expert advice had to be used to the full. Several members of staff cited occasions when their treatment recommendations were unpleasant to the young people (medication, admission, nursing observation, high-calorie diets for anorexics), yet necessary. Then, a particular form of treatment would be offered "*in a very directive way*" (Int. 19, p. 1), as when Sinead was saying "*I don't want to go to hospital*" and the staff replied "*we really think you should*" (Int. 4C, p. 8).

Although the young people appeared to have the power to refuse as well as accept this forcefully given advice, should they refuse, the staff had the option of enforcing treatment by legal means. To add to the impetus of expertise, professional responsibility exposed to blame and litigation those experts who did not ensure the best treatment of a young person or who put a life at risk. This situation was not favourable to just relations. Only deliberate and skilful manoeuvres of empowerment could re-establish a degree of human solidarity and negotiation. A strong commitment to compassion and justice, both individual and

collective, was necessary to motivate members of staff to such complex, time-consuming and potentially risk-taking, decision-making.

The staff interviewees were deeply aware of this dilemma, which was not the context of all treatment decisions but of many since the young people referred to the four services in the study had serious and enduring mental health problems. In their comments, they made a difference between those situations where safety was at risk and those where it was not.

When emergency and immediate safety were involved, responsibilities could weigh heavily upon the decision-maker. This was particularly so for senior staff, and consultant psychiatrists commented on it. In parallel situations, they imposed limits to negotiations more or less cautiously. One psychiatrist expressed fears of litigation (Int. 13A, p. 18), as well as doubt that young people's mental state allowed them to appreciate their best interest (Int. 13A, p. 14). In contrast, another psychiatrist talked of having sent an acutely psychotic young man home with his mother after an emergency consultation, in the hope that it would give him a chance to let himself be admitted voluntarily the next day: *"it involved a little bit of risk taking"* (Int. 14B, p. 12). Although senior staff members like consultant psychiatrists took greater responsibility for the young people's welfare, their experience and training also allowed them to assess risks with greater accuracy. One of them noted that he was more willing to take risks than his trainees: *"It's one of the struggles I have with my junior doctors. They're much more likely to be autocratic with young people than I am. And I am much more likely to negotiate even with detained patients"* (Int. 13A, p. 4).

In situations where safety was not at risk, the majority of the staff interviewed appeared satisfied that they could use their relationships with young people to inform them about the treatment offered and advise them about their choices. Several key-workers stated a commitment to participation: *"I don't think nurses should make all the decisions. We can recommend and hope that our recommendations are taken up"* (Int. 11B, p. 24). To achieve this, good relationships with young people were important and one nurse manager was proud that her team was *"good at engaging young people"* (Int. 7, p. 2). A few interviewees described situations when young people made a therapeutic choice with their help, such as

whether or not to accept group therapy (Int. 10B, p. 8). Persuasion was nevertheless necessary to lead young people to the right decisions (Int. 10B, p. 8, Int. 11B, p. 25). When young people had long-term, chronic but not life-threatening mental health problems, admission to a day-unit would be offered to them but they would only be referred with their agreement. Their own volition was needed for treatment to take place, particularly the more active psychosocial treatments (Int. 19, p. 1, Int. 7, p. 2). So that if young people refused to be admitted or were coerced into admission, it might not be possible to work with them (*"Sometimes that means we can't actually work with a young person"*, Int. 6, p. 3). The same key-worker stressed that the staff was not always right in their recommendations, so that a young person's refusal could be an opportunity to do something else (Int. 6, p. 3).

Different units set limits to participation differently: Rannoch had a clear policy of young people involvement. This seemed to lead the staff to make clear individual statements of commitment so that a consensual picture emerged. A coherent structure for the systematic involvement of young people in their treatment was in place, in spite of many young people admitted to this unit having serious and disabling mental health problems. Other findings corroborated this: the young people's interviews reported that they felt reasonably involved in their treatment, as did the fieldnotes. Conversely, a policy of young people participation was not in evidence in Arisaig and its senior and junior staff gave conflicting views regarding its achievement. There was no explicit structure for treatment involvement. The majority of young people in the sample said they did not feel involved in their treatment and the fieldnotes supported this view. But the picture that emerged in that unit remained uneven. Two young people reported examples of difficult and successful negotiations with them (Int. 7A, p. 7, Int. 2A, p. 9). And two key-workers made strong statements of commitment to participation (*"In terms of what I do with them I always ask them and I always try and use their ideas"*, Int. 15A, p. 15, Int. 12A, p. 15).

Two important messages come through from this discussion: firstly, when decisions included safety issues, the involvement of young people was uncertain and different staff took different levels of risks. Their seniority, experience, level of responsibility and anxiety appeared to contribute to their decisions. Secondly, the staff found involving young people

in decisions regarding their treatment easier when the decisions were not life-threatening. Then, they used their relationships with the young people and acted as partners and leaders in decision-making. The units also varied: a policy of young people involvement made a difference to its overall success, leading to individual staff commitment and organisational structures for its implementation. The lack of a policy undermined participation but did not exclude it altogether. It was then more likely to be haphazard.

Apart from the expertise of the staff, and the power it gave them to make decisions about the lives of the young people, age was another factor that might induce relationships of domination rather than justice between the staff and the young people.

3.1.2 The Power of Age

The recent emphasis in the sociology of childhood is that children are members of society in their own right: they affect it and they are affected by it. To build a coherent social picture, their contribution is important and it is unjust to plan anything in society without taking into account the children and young people who are part of it. This sociological stance contrasts with and challenges the view that children are in transit to adulthood and only socially relevant in terms of their development. The affirmation that children have rights which include the right to contribute to decisions regarding their lives, enshrined in the UN Convention on the Rights of the Child (1989) and recent British legislation (Children Act 1989 and Children (Scotland) Act 1995), supports the sociological view. Just relations with young people therefore means finding ways of empowering them rather than simply taking control.

Age was a variable perceived by the staff to affect young people's involvement in their treatment. Some found them too immature. A psychiatrist worried that treatment decisions were *"too big for [young people] to make... How do we involve them without falling into the trap of seeing them as more developmentally advanced than they are?"* (Int. 13A, p. 16).

The Scottish legislation that supports young people making decisions about their medical treatment asserts that this should start as soon as they are able to understand the issues at stake, which, for most children, would be before adolescence (see Chapter 2, p. 35). It leaves the assessment of the child's capacity to the staff in charge (Norrie 1991). This supposes that the staff has acquired the skills to assess children's mental competence, which includes affective, cognitive and cultural criteria (Fundudis 2003). Staff members experienced with young people are likely to possess those skills, but there is evidence that health care staff are over cautious in their implementation of the legislation (Orr 1999, Sutherland and Cleland 2001). The psychiatrist's anxious comment about the young people's immaturity supports this view and suggests that the most senior member of that staff team saw young people as needing more protection than involvement. A key-worker from the same team found its approach over cautious: "...they [the young people] should... be asked their opinion an awful lot more" (Int. 12A, p. 15). However, trust in the participation process grows with experience of it. It is likely to be more alarming at the beginning, as a key-worker recently introduced to it testified: "To have them [the young people] involved in absolutely everything that's going on, that took a bit of getting used to" (Int. 11B, p. 23).

Some interviewees thought the young people needed guidance to make a sound contribution. One key-worker stressed that some fourteen or fifteen year-olds were immature and needed the staff to take the lead in decision-making (Int. 11B, p. 24). Another was concerned that being present in the treatment review did not give young people the best platform for involvement because it was intimidating and they might not have the words to convey their thoughts because of their youth. She discussed the reviews in advance with them and offered to represent their views (Int. 8, p. 8). Only commitment, experience and group supervision would allow health care workers to make realistic assessments of the young people's need for help and guidance. The findings did not reveal whether the examples given were over or under-protective.

Another example of age as a variable of participation was mentioned by three key-workers. It was the need of adolescents to draw away from adults to exercise their budding

autonomy. As experienced key-workers, they were understanding of this developmental feature. However, they pointed out that it could stand in the way of partnership in decision making because young people might agree on a course of action which they subsequently felt impelled to challenge (Int. 6, p. 3, Int. 11, p. 7, Int. 5C, p. 9).

These findings suggest that age added to the challenge presented to the staff by participation in treatment decisions. A commitment to just and empowering relationships as well as skills and experience was required to prevent the differences in expertise and age between staff and young people leading to power-based and oppressive decision-making.

3.2 A Community of Care

Interviews with staff members in the four units demonstrated that they attempted to have empowering relationships with the young people which facilitated their participation in treatment but entailed a degree of risk to themselves and the young people. It suggests that an understanding and supportive environment is necessary to promote just relating and participation.

Relationships of justice, says Grey (1989), are a feature of communities where vulnerability is met with understanding and compassion, and where the experience of a shared humanity leads to solidarity and empowerment. In adolescent mental health units, the most vulnerable members are the young people on account of their age and mental health problems, but the findings show that the staff also felt vulnerable when they took risks on behalf of the young people. Therefore the staff also needed relationships of justice, where their anxieties would be empathised with, and their efforts to share decision-making supported. All staff, even the most senior, would benefit from group supervision with their colleagues and discussion of difficult decisions. This would also provide experience and training for newer, less experienced staff. Besides, it seems impossible for a staff member to apply values of justice, friendship and empowerment unless these values are respected by the rest of the team and all are in receipt of just and empowering relationships.

With regard to parental involvement, the findings from the staff interviews confirmed those of the parent interviews: apart from Fisherfield where the policy of work with parents was clear and explicit, they conveyed the lack of a robust policy of parent involvement. Contradictions between the views of interviewees within units suggested that the work with parents was not clearly conceptualised and applied. The senior staff gave a picture of parental involvement that was often contradicted by staff on the ground, some of whom had doubts about the success of their relationships with parents. The parents' own ability to engage the staff and take initiatives regarding communication seemed to play a significant part in the success of their involvement, leaving out the more vulnerable, powerless parents.

The systematic involvement of parents in the treatment units has already been suggested in order to fulfil the need for involvement that their interviews revealed. The findings from the staff interviews support the case for these units to be managed as communities of care, based on explicit values of justice, friendship and empowerment, for the benefit of the young people, the parents and the staff.

Conclusions

Interviews with a selection of staff from the four units in the study suggested that they were committed to the involvement of young people in the units' life but that they found the young people's participation in treatment decisions challenging. The staff's expertise and their age gave them considerable power over the young people. Good therapeutic relationships were an ideal setting for sharing this power but it was easier to do when safety and long-term welfare were not at stake. Different members of staff evaluated risk and the young people's need for protection differently according to their training, experience and level of anxiety. This suggests that the staff, as well as the young people and their parents, needed support. Treatment settings where vulnerability is respected and supported through just and caring relationships, in other words communities of the type defined by Grey (1989), would provide that support. The next section examines to what extent this was the case in the four units of the study.

4. UNIT CULTURES

The unit cultures were defined by four main categories: their values, philosophies of care, treatment approaches and staff dynamics. Together, these categories allowed a picture of the units to emerge which suggests three distinct cultural families: the explicitly participative unit, here Fisherfield, with its policy of young people and parent involvement (see Appendix 8, Model 1); the modified therapeutic community, with its positive involvement of unit residents, represented by Knoydart and Rannoch (see Appendix 8, Model 2); and the general purpose psychiatric unit, here Arisaig, with no cultural ambition other than the medical model (see Appendix 8, Model 3). Each of these cultural groups highlighted features which appeared to support or impair participation. Each is discussed in turn, with reference to friendship, just relations and community.

4.1 The Explicitly Participative Unit: Fisherfield

Fisherfield followed the philosophy of care advocated by McGorry (1996) for the early treatment of psychosis, which included a strong user and carer involvement element. Its priority was to offer a place of safety to the day-patients who attended in a vulnerable state after a psychotic episode. Its staff aimed for a person-centred form of care and tried to empower young people to regain control of their lives. Trust between the young people and their key-workers was evident: the youngsters did not hesitate to phone the staff for advice or to ask them for meetings. The therapeutic relationships seemed to be both personal and just (Swinton 2000).

There were opportunities for the young people to experience the companionship of others in the same position as themselves. Parent support groups also aimed to integrate parents into shared experiences with other parents. Mutual support and acceptance of vulnerability were explicit ambitions, making the unit into a typical community of care as defined by Grey (1989).

A significant feature of the McGorry et al (1997) philosophy of care was to instil hope. The staff called it "*concentrating on the positives*" (of the young people's lives). The problems

of this client group were known to make mental health specialists feel gloomy: although there was a deliberate effort to deal with this, the Fisherfield staff, of their own admission, found it difficult.

Also typical of the McGorry et al (1997) approach was the inclusion of young people and their parents in the conceptualisation of the young people's problems, in a combination of science and experience, through information and education. Fisherfield was the only unit in the study explicitly committed to the participation of both users and carers. This policy was an integral part of treatment and considered essential to its success.

The staff delivered the service with a sense of pride, finding their work sad, but useful and rewarding. They were selected for qualities of confidence, maturity and emotional robustness. All the findings converged to suggest that this unit was a participative community. The involvement of young people in their treatment however, was acknowledged by both the staff and the young people to be a difficult endeavour due to the complex nature of the decisions to be made.

4.2 Modified Therapeutic Communities: Knoydart and Rannoch

Knoydart and Rannoch both subscribed to milieu therapy and both called themselves a 'modified therapeutic community'. Milieu therapy, as it has been practised in adolescent mental health units, was born out of the therapeutic community movement. Its philosophy includes a commitment to just relations between staff and patients and to the involvement of residents in unit life (see Chapter 2, p. 40). Both these units were committed to involving the young people in unit activities.

Both units were committed to building relationships of quality with the young people, emphasising Rogerian values of respect, warmth, trust and empathy. This appeared to facilitate personalised relationships of care like the ones Swinton (2000) called 'friendship'.

The units tried to be normalising environments for teenagers: the age of the client group led Knoydart to stress the importance of having fun, while Rannoch emphasised autonomy. Both units tried to organise themselves as inclusive communities where everyone worked

together. Young people and staff met for meals and breaks. *"It's a shared culture, it's not just for the staff or for young people, it's for both"* (Int. 7, p. 7). At those times, the adults' priority was to ensure the young people were included in conversations and made to feel valued. These commitments reflected participation priorities and seemed close to the 'preferential option for the poor' of liberation theology (Boff and Boff 1987). Both units explained this in handouts given to young people and parents before admission.

A definition of the therapeutic community approach given, with variations, in both units was that young people were active participants in their treatment, not passive recipients of it (Int. 7, p. 1). An underlying psychotherapeutic assumption was that it was necessary to face one's vulnerabilities, understand them and share them in a caring environment. The young people were helped to learn about themselves, particularly their more painful feelings, and to share them with other young people in therapy groups. Psychodynamic principles were used to understand the links between past and present in the young people's lives. Group activities helped to create a sense of belonging.

This philosophy of care did not suit young people who had been psychotic because it tended to generate emotional turmoil. In Rannoch in particular, where emergencies and young people in acute psychotic states were admitted, individualised care went alongside the community organisation. Both units offered other forms of treatment within this framework, like medication, cognitive and behavioural therapy, and family therapy.

Both units were primarily managed by the nurses. Strong and experienced nurse managers led them, with the full support of the psychiatrist in charge. Other disciplines working in the outpatient department were called upon as necessary. In both units, the nurses were active decision-makers and their colleagues from other disciplines respected and trusted them.

Decisions in the nursing teams were mainly consensus-based. The responsibility and therapeutic authority the nurses commanded were rewarding. They were buttressed by regular supervision and substantial amounts of continuing education, so that individuals had a real chance to grow. Openness to challenge and willingness to change were prerequisites of selection, together with a robust personality and a good home life.

Potential pitfalls were perceivable, however. The changes either staff or young people could make to such strong cultures honed over many years were limited (Int. 11, p. 6). The young people from the Knoydart sample found the treatment helpful but their involvement in treatment decisions restricted. In Rannoch, two junior nurses complained that it was difficult to dissent or to express critical views. Both experienced the culture as oppressive. The units' commitment to just and personal relations required an emotional involvement which exposed the nurses to high levels of human distress, making them vulnerable. Rannoch was short of staff and the nurses did overtime, which increased their vulnerability. There was evidence of stress and unhappiness in the team. Yet in such a close-knit unit, it was difficult to criticise or to be unhelpful by refusing overtime.

What these difficulties imply is that communities of care are easily unsettled by their own power, the power of some of their members or simply by lack of time in which to provide support and relief from the pressure of human suffering.

Overall, both units offered young people a place of friendship and just relations. Through the therapeutic milieu, they cultivated a community ethos that they and the young people shared. The parents, however, were not full stakeholders in these communities.

4.3 A General Purpose Psychiatric Unit: Arisaig

The philosophy of care in Arisaig was that of "*general purpose psychiatric unit*" (Int. 10A, p. 4) where medical care took priority. It lacked a policy of participation and seemed to have difficulties involving young people, although they participated in a number of day-to-day decisions.

Half of Arisaig's admissions were emergencies, making life in the unit unpredictable. The daily routine was frequently altered by the requirements of emergency and intensive care nursing and the unit lived in a constant state of crisis (Int. 9A, p. 4). Arisaig's most successful treatment skills were related to the residential management of acutely disturbed young people. These forms of treatment, which included medication, restraint, special nursing observation and the use of the Mental Health Act, were difficult to negotiate with young people. In their interviews, the young people did not rate their participation in

treatment highly and complained their evening and weekend visits home were not negotiated with them. The staff interviewees conveyed a picture of anxiety and disagreement among themselves regarding the involvement of young people in treatment. Therapeutic interventions like group work, cognitive-behaviour therapy and family therapy were available, although not systematically used and not delivered by nurses.

The Rogerian value of person-centredness was named as central and applied to the mutual help the unit encouraged among the young people (Int. 10A, p. 5). It was described as fragile because new members of staff who did not understand or prize it could ignore it. The absence of other Rogerian values like trust and respect between staff members was lamented by three interviewees: it was difficult for the staff to share their vulnerability; one key-worker called it "*macho*" (Int. 13A, p. 3, Int. 11A, p. 11). Two interviewees also complained of a lack of interest in learning and an unwillingness to change (Int. 13A, p. 11, 15A, p. 9).

The staff team comprised mainly nurses and psychiatrists. It was a team in conflict. Staff-nurses were chosen for their skills with people and their interest in adolescents but they felt they were kept on the margins of treatment decisions. The main decision-maker was the psychiatrist in charge. Although he expressly stated "*I don't want to be autocratic*" (Int. 13A, p. 22), he was perceived as such and resented by the nurses. The nurses' experience of managing difficult young people and a unit in crisis was set against other staff's perception of knowledge understood as therapeutic skills and the ability to appreciate and carry out evidence-based practice. Conflict, insecurity and distress ensued. The nurses received no systematic supervision. In the absence of a therapeutic programme, the young people spent mornings and afternoons at school. This provided them with a cohesive experience by a well-resourced team of dedicated teachers whose philosophy was to convey hope "*we try to make them feel that they have a future*" (Int. 17A, p. 3).

Despite its difficulties, Arisaig seemed to fulfil its functions: "*this unit's kept going and it's seen patients, and patients come in ill and go out better, despite all this*" (Int. 13A, p. 5). But it was not a happy unit. The young people met with care and kindness from the staff

but the latter's distress and lack of support endangered the quality of therapeutic relationships. Empowerment did not appear to be valued and participation of both young people and parents was haphazard. There was no community of care.

Conclusions

Fisherfield was a treatment setting explicitly committed to the involvement of young people and their parents as a part of treatment. All the findings converged to demonstrate that, from all the stakeholders' perspective and from that of the participant observer, it was successful in its participation policy. Key components of participation highlighted by pastoral theologians, in particular personal and just relations and a community of care based on values of justice and respect for the vulnerability of all its members, were present. Nevertheless, the involvement of young people in treatment decisions, particularly those which included safety aspects, remained difficult.

The modified therapeutic communities exemplified by Knoydart and Rannoch went a long way to meeting participation priorities like caring and empowering relationships in the context of a supportive community. This was due to the connection of their philosophy of care to therapeutic community principles more than to the user and carer movement. Probably as a consequence of this, one set of stakeholders, the carers, had not been explicitly committed to and their involvement had varied over the years, diminishing recently with the growing demands of children's rights. The community ethos was strong, but there were hints of potential difficulties created by the power of the culture and the relentless nature of the work. More resources would have been helpful, such as time to listen to those young people and staff who felt disempowered and extra nurses to cover sick-leave and holidays.

The 'general purpose psychiatric unit', Arisaig, was hampered from successful user and carer participation by several difficulties. Firstly, its aims were modest due to its lack of control over its admissions: much of the time was spent dealing with the crises generated by emergencies and acute care needs. Secondly, the lack of just and supportive relationships among the staff was noteworthy: it was oppressive to all those interviewed

and deprived them of support. Thirdly, participation was not one of the unit's aims. Although general good will was expressed towards the involvement of young people and parents, there was no structure for it to take place. Individual staff members nevertheless tried to implement negotiations with young people and their parents and instances were described where it had worked well. Overall, none of the priorities outlined earlier as necessary conditions of participation appeared to be present.

5. CONCLUSION: PRIORITIES FOR PARTICIPATION

5.1 Relationships Based on Justice and Personalised Empathy

One recurring theme of this discussion of the findings has been the need for relationships with young people based on respect, empowerment and a personalised interest of the type Swinton (2000) called 'friendship'. Such relationships existed in the units: the young people valued them as therapeutic and complained when they were overtaken by coercive interventions. The importance of therapeutic relationships in mental health care is not new. Indeed, the staff interviewees invoked Rogerian values of person-centredness, warmth, respect and empathy without conscious reference to Carl Rogers' work on therapeutic relationships (Rogers 1951). The relationships discussed here, however, have an added dimension, that of justice and the deliberate sharing of power. They aim to pay attention to the way control – of a situation, through the use of power – is managed within relationships. Relationships of 'friendship' aim to share power, not to exercise control.

In the context of treatment decisions however, the sharing of control between staff and young people has to be carefully weighed. The exact configuration of the sharing varies depending on a young person's age, maturity and mental capacity, as well as on the staff's communication and risk assessment skills, their level of anxiety and the support available to them. Nevertheless, consideration for the need to share professional power with the young people and their parents, reflect on the issues and discuss the difficulties should always be the background of these decisions.

From the findings, it emerged that parents as well as young people needed empowering relationships, a need of which the units were not always aware. It also became clear that the staff needed to have empowering relationships with their colleagues in order to be able to sustain just relations with the young people. A network of just relations between all the stakeholders is a community of care, which, according to Grey (1989), is central to participation.

5.2 Communities of Care that are Participative

The values of participation include relationship values of the kind Rogers (1951) outlined as well as an awareness of power, its origin and its oppressive potential, and a preferential option for those who are vulnerable and powerless, here the young people and some of the parents. Vulnerability however, is not only the characteristic of a few individuals, it is also a reality for those who are willing to share their power instead of using it to protect themselves, because in sharing it, they make themselves vulnerable. The findings from the staff interviews demonstrated that members of staff who attempted to share treatment considerations with young people in situations where risk was involved and coercion the norm felt vulnerable. At these times, the support of a community committed to participation was necessary to them. Therefore it is important that units which take the national policy of participation seriously organise themselves to implement its values across every aspect of their philosophy of care, turning the unit culture into a cohesively participative one.

Findings regarding the unit cultures showed that where the culture of a unit had produced explicit policies of participation, there followed commitment by individual staff and coherent structures to encourage implementation. These policies also allowed units to appoint staff according to chosen criteria, more specific than those of NHS job descriptions. Communities of care based on an explicit commitment to participation values would make the appointment of suitable staff easier and would prevent conflicts regarding those basic commitments. But unit cultures can be undermined from outside the unit as well as from inside. This is where it becomes necessary to pay attention to the socio-political context of care, as recommended by Pattison (1997).

5.3 Focus on the Socio-political Context of Care

The young people and their family's awareness of the stigmatising effect of having mental health problems, and some members of staff's anxiety regarding litigation, belonged to the wider socio-political context of care. Ambiguous social politics regarding mental health problems are a handicap to participation. The current preoccupation of the public with the danger represented by people with mental health problems is an example of this. The need to make members of health and social care staff pay for their mistakes through the courts is another. In her Reith Lectures (2002), Dame Onora O'Neil drew attention to the problems caused by the litigation culture in the public services.

The lack of resources to resolve staff shortages and the need for more educational opportunities regarding collaboration and family work skills belonged to the wider health service, both at local and national levels. It seems clear that one NHS service cannot implement a comprehensive policy of participation without the appropriate external support from the wider institution. Although the NHS has adopted a national participation policy, insufficient financial support prevents this policy from being applied well.

Services committed to participation operate in an unsupportive context. Pattison (1997) stressed that the failure to recognise the importance of social and political factors in the context of care led in practice to a failure to promote justice and equality. Political action is probably necessary to address some of these factors. Like many adults, young people are not effective promoters of their own empowerment and professionals can help by involving themselves actively with the service users' socio-political struggle. Research into health care staff's interest and actual involvement in political action for participation would be useful.

There are two diagrammatic representations of the conceptual framework discussed in this concluding section in Appendix 9.

This conceptual framework has been inspired by the thoughts of three British theologians whose reference point has been liberation theology (see Chapter 2, p. 17 – 27), namely John

Swinton (2000) for the concept of 'friendship', Mary Grey (1989) regarding the participative community, and Stephen Pattison (1997) for a socio-political emphasis. Nevertheless, the framework cannot claim to be a liberation theology one because the hallmark of liberation theology is that it takes place from within the oppressed group (Pattison 1997, Swinton 2000). As a researcher and a member of the nursing profession who has not had mental health problems, the author of this thesis is an outsider to the young people's group and their families. The conceptual framework used here as a model to facilitate participation in mental health services for young people is therefore a carers' model, motivated by solidarity with young people who have serious mental health problems and knowledge of some of their priorities. Pattison (1997) and Swinton (2000) both highlight the importance of professional carers and academics putting their resources at the service of liberationist groups who often labour against the forces of social stigma and economic deprivation. To do this, and to encourage other health care professionals to do the same, seems worthwhile.

This study has shown that participation in public services like adolescent mental health units is a complex endeavour that requires whole-hearted commitment and good support networks. Its importance to young people and their parents was evident, and the staff offered an honest appreciation of its difficulties. Units where the philosophy of care was based on milieu therapy served it better than a general purpose psychiatric unit. At a time when policy decisions regarding inpatient and day-care services are being made with insufficient evidence from research to support them, these findings may help to decide how such services can best serve their purpose in the future.

CHAPTER 9: CONCLUSIONS OF THE STUDY

- The young people interviewed for this study preferred treatment interventions based on relationships and mutual trust, both with members of staff and other young people. They found coercive interventions difficult, although potentially helpful if initiated and delivered in the context of an empowering therapeutic relationship.
- Under half these young people felt satisfied with their level of participation in treatment decisions. They were aware of many factors influencing this, from disagreements with the staff regarding their best interest, to a sense of powerlessness, and a reluctance to take responsibility due to hopelessness. Proportionally more young people (twelve out of eighteen) said they contributed to decisions regarding everyday life in the unit.
- The parents interviewed were appreciative of the help the units gave them simply by offering treatment to their child. They conveyed a wish to be involved and detailed many needs of their own, some of which remained unmet. Some felt alienated from the young people's treatment. Two thirds of the parents felt satisfied with the help they had received: the most satisfied were those who had been able to take initiatives in their contacts with the unit.
- The breadth of needs the parents described overall suggests that meeting these needs would require more commitment, skills and resources than was available.
- The staff interviewed made a distinction between participation in day-to-day unit life, which was largely successful, and participation in treatment decisions, which was viewed as complex.
- When the decisions involved were life threatening, different staff took different levels of risk according to their seniority, experience, level of responsibility and anxiety.

- When safety or long-term welfare was not at stake, the staff found involving young people in their treatment easier and used the relationships they had with the young people to advise them. Three units had a structure for the involvement of young people in their treatment.
- Regarding the engagement and participation of parents, only one unit had an explicit commitment to it and treated parents as partners in care.
- The cultures of the four units which were the object of this study comprised similar elements yet three different types of culture were discernible. One unit dedicated to the care of young people who had been psychotic had an explicit policy of young people and parent participation. This was implemented in a variety of structures and initiatives. Two units based their philosophy of care on therapeutic community principles, adapted to the needs of a younger age group. In line with these principles, they were committed to the involvement of young people in the unit and had structures of participation in place for its implementation. Although they were interested in involving parents, they were not explicitly committed to it and the results were haphazard. The fourth unit was a 'general purpose psychiatric unit' with a crisis-driven culture. Good will towards young people and parent involvement was noted but it did not translate into an explicit policy of participation. No structures of involvement were in place, although there were examples of participation. The first three units had cohesive and supportive staff teams, whereas in the last unit, staff members were isolated and unhappy. There are diagrammatic models of the three types of unit cultures in Appendix 8.
- Young people valued participation. The best medium for it seemed to be therapeutic relationships between young people and staff provided they incorporated participation values like the promotion of justice, power sharing, consultation and empowerment. These relationships of justice were better indicators of participation than the involvement of young people in treatment decisions. These depended on the young people's maturity, mental state and willingness to take part on the one hand, the staff's experience, skills and willingness to take risks on the other.

- Units which were explicitly committed to the young people's participation and the staff members of which were supportive of each other were better able to provide the conditions necessary for the implementation of participation. Since parents also expressed a wish for participation and support, units would serve participation best by becoming participative communities, committed to the support of young people, parents and staff through just and empowering relationships.
- External socio-political interference with the units' participation efforts was noted in the litigation culture that made taking risks in treatment decisions a worry for staff members. It was also clear in the stigma young people and their families experienced as a result of their mental health problems. Further research into such factors, and into professionals' willingness to support groups lobbying for political change, would help to make the national participation policy more coherent and effective.
- The findings were structured into a conceptual framework that conveys the priorities of a participation-friendly environment. This framework draws together three inter-related communication systems: one-to-one relationships (1), relationships within the unit (2) and relationships between the unit and the outside world (3). To promote participation, these relationships must be characterised by justice, power sharing and support of vulnerability as well as by Rogerian values of empathy, respect and unconditional regard (Rogers 1951). In the case of relationships between the unit and the outside world, socio-political action to promote these relationships may be necessary. Two diagrammatic representations of this framework are in Appendix 9.
- Fruitful insights into the priorities of participation movements emerged from the exploration of the neighbouring academic field of pastoral theology where humanistic and ethical values are at the core of participation efforts. It is an example of the cross-fertilisation that can take place between academic subjects.

CHAPTER 10: RECOMMENDATIONS

All the following recommendations apply to the context of young people's treatment for mental health problems: in practice settings, in policy, in educational programmes and for further research. This context is not repeated for each recommendation to enhance readability but as a result, each recommendation sounds more general than the methods used in the study warrants.

Recommendations for Practice

- *To emphasise the empowering potential of therapeutic relationships between young people and the staff, particularly values of justice and collaboration, in addition to the currently accepted Rogerian values of respect, warmth, empathy and unconditional positive regard (Rogers 1951).*
- *To maximise the use of such relationships to discuss all facets of treatment, even those features which, of their very nature, aim to impose control.*
- *To offer empowering relationships to all parents or carers unless it is against a young person's best interest.*
- *To base philosophies of care on participation values (justice and empowerment) and to make participation an explicit unit policy based on these values.*
- *To apply the concept of empowering relationships to staff teams in order to promote a supportive community of care among the staff and between all the treatment stakeholders (young people, parents and staff).*

Recommendations for Policy

- *To provide units with the resources necessary to offer empowering relationships to all parents or carers. This includes both personnel and skills training opportunities.*
- *To value and support existing units which apply philosophies of care that support participation, such as those based on therapeutic community principles.*
- *To promote participation values and value-based practice alongside evidence-based practice in order to achieve a more rounded definition of quality care.*

Recommendations for Education

- *To include participation values in the philosophy of all educational modules and programmes for the health and social care professions.*
- *To include ethics teaching regarding participation values and value-based practice in the curriculum of these programmes.*
- *To include collaborative skills in the curriculum of these programmes.*
- *To include the theory and practice of family work in the curriculum of these programmes.*
- *To apply participation values to teaching environments so that students may experience a participative milieu.*

Recommendations for Research

- *To explore young people, parents and staff's experience of home-based treatment alternatives (intensive outreach) to inpatient and day-care units.*
- *To implement a similar study in one or two other European countries to explore their commitment to participation and the type of unit cultures available there.*
- *To explore a residential setting for vulnerable children or young people based on Christian values and compare its commitment to participation and its unit culture with those of the NHS settings which took part in this study.*
- *To investigate the socio-political context of care at local and national levels to highlight values, attitudes and policies which may enhance or interfere with the health and social care commitment to participation.*
- *To collaborate with relevant groups in these investigations (adult user and carer groups, young people and parents groups in other aspects of health and social care, professional organisations etc.).*
- *To investigate staff members' individual and collective commitment to socio-political action in support of participation.*

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APPENDICES

Appendix 1: Sample Interview Transcript

Appendix 2: Sample Set of Fieldnotes

Appendix 3: Paper Published from Material in the Thesis

Appendix 4: Copies of Information Sheets

Appendix 5: Copies of Consent Forms

Appendix 6: Letters of Approval from Research Ethics Committees

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Appendix 1

SAMPLE INTERVIEW TRANSCRIPT

This interview was the 17th in the study. The interviewee was a 17 year-old young woman who had been given a diagnosis of schizophrenia and attended Fisherfield. She was particularly articulate, spoke quite spontaneously and raised a number of issues that have been discussed in the thesis. This is why this interview was chosen as sample.

Int.: Thank you very much for giving me this interview, Sinead, it is really helpful. Can I ask how you came to be here and how long you have had the problem?

Sinead: I've been coming here for about 4 years now, since I was about 14.

Int.: Right.

Sinead: My GP referred me.

Int.: Okay. How did you notice you had a problem initially, what happened to you?

Sinead: I started hearing voices when I was about 10 and I always thought it was something everybody went through, just like an imaginary friend. By the time I was 13 I was really struggling and I started behaving really weird at school and the teachers and all the other kids were noticing it and eventually I stopped eating for a while so I had to be taken to the GP who just referred me to here.

Int.: Did you think there was a problem when you were acting weird as you call it?

Sinead: Not really because I just thought it was something everyone went through and it was a kind of teenage stage. But then when it started to get a bit more serious when I stopped eating and everybody was really worried about me and I couldn't see what the worry was then I realised I had to admit to myself that something was wrong.

Int.: So you admitted it to yourself. You accepted the other people's views. Were you unhappy? Was it an unpleasant experience?

Sinead: It was really yes, because I was having really bad arguments with my mum and dad and they wouldn't let me out at night and things like that. And some of the kids at school were starting to bully me because I was strange and I was acting really odd. So really it wasn't a nice experience, especially when I had to tell them I was coming up to see a psychiatrist – telling my friends...

Int.: So it was causing you a lot of hassle?

Sinead: Yes

Int.: Did the hearing of voices in itself... were they unpleasant voices?

Sinead: At first they weren't, they were okay. I just thought it was an imaginary friend kind of thing and when they started to get nasty and tell me not to eat then it really got quite scary.

Int.: You couldn't control them?

Sinead: No

Int.: Okay, so you, your parents and the school got you to stop in your tracks and take note that something was going wrong and you went to your GP. Was that the first thing that happened?

Sinead: Yes. She asked me what was happening and everything. She wrote down all these notes and things and then she referred me here. And when I came here I saw a doctor who was very new here and I mean it was quite scary because, I mean, I was really sceptical that she was going to be able to help me and I was like, 'yeah, yeah, I'm not coming back here, it's just stupid'. But I kept getting dragged back.

Int.: So it was a bit of a battle. You didn't find coming here helpful at the start?

Sinead: No. I just thought it was a waste of time and there was no reason for me to be here.

Int.: What was happening I mean, what was this doctor trying to do, do you know?

Sinead: Well I'd been referred here as being anorexic and then Jean, who was the doctor who I first saw, gave me all these questionnaires and made me draw pictures of what I looked like compared to what she looked like, and things like that, and to me it was all kind of TV programme stuff, what you see on TV and just like in soaps and stuff and it was like 'hang on a minute, I'm not coming to see a quack' and things like that. I was really determined I wasn't going to come.

Int.: So you couldn't take it seriously?

Sinead: No.

Int.: And was it helping you to eat more?

Sinead: No.

Int.: So it wasn't working.

Sinead: Then when eventually, after about 3 or 4 months, they found out that I was hearing voices...

Int.: They hadn't known?

Sinead: They hadn't known because I wouldn't tell them. And up until then they just thought I was anorexic and I was about to be given ?? [some form of treatment?] when the last questionnaire I filled in asked if I heard voices and I put down yes just thinking it was another questionnaire and then Jean, the doctor, when she saw this – read it – she went “Oh” and said this is something different and she put me on medication. The medication was horrible.

Int.: The medication was horrible?

Sinead: It was a really really old one called Sulpiride. It was horrible because it made me put on weight, which was almost defeating the purpose of trying to make me eat again because it was making me put on weight which I still haven't lost. I was getting more and more down and the voices were coming on stronger saying to me 'you can't eat, you just can't eat' because this was making me put on weight. I remember going on holiday that year when I was put on Sulpiride and I can't even remember being on holiday.

Int.: You were that doped up?

Sinead: Yes, I was in Spain and can't even remember it.

Int.: so that wasn't helpful?

Sinead: no

Int.: Did you initially... you know when you stopped eating, when the voices got onto you for eating... did you feel you were too big?

Sinead: I didn't, but the voices convinced me that I was and that I just had to keep losing weight. And then I started to make myself sick as well because the voices kept telling me that because I was putting on weight. And my mum and dad were making me eat and watching me whenever I was eating something so the voices said basically 'if you're going to have to eat you are going to have to get rid of it as well'.

Int.: And then the medication meant that whatever you ate made you become fat?

Sinead: Yes.

Int.: So it sounds like the first 4 months of treatment were not a success.

Sinead: No

Int.: But one of the good things about that time was that people found out what was really happening to you and that it was through the voices that you were on a diet, it wasn't simply an anorexic thing. So what happened after that?

Sinead: Well then I wouldn't go to school because the kids were bullying me and the teachers weren't really understanding what was happening for me. They kept on giving me rows if I was acting strangely and the kids were being really cruel and really nasty

me, so I just refused to go to school. And when I eventually accepted that I was going to have to come and see a doctor here, then the doctor said, 'right, okay I think you should take a wee break from school'. And that's what happened and I'd asked if I could have a week off more than everybody else at Easter that year, and she said 'I'm sure that would be okay' and I didn't go back after that.

Int.: So you didn't go back through your own decision?

Sinead: Well I had this kind of ideal picture in my mind that because the doctor had referred me to the unit school here that I was going to be able to go part-time to my own school and part-time here. But it never worked out that way and it just ended up that I was coming here all the time.

Int.: And from your point of view was that a better arrangement?

Sinead: Yes, because I wouldn't have been able to cope looking back I just would not have been able to cope going back full-time to school.

Int.: And were you happy with the unit school here?

Sinead: No I wasn't. I thought it was horrible. I thought it was just a lot of crap, because it seemed to be like all day we worked on stuff that I had done before and that the teachers weren't qualified enough. And how could I learn every subject with 2 teachers when there wasn't even a home economics department or a science lab or anything? And I couldn't understand why it was a school in the first place, it didn't do anything like that and I just thought, like, there is no way I'm coming here but there was no other choice because I couldn't go back to mainstream school.

Int.: So you kind of accepted it.

Sinead: Yes

Int.: It sounds like school, apart from the environment which wasn't pleasant, school work was okay with you?

Sinead: Yes, yes. I was always a straight A student and I couldn't understand why I was getting lower grades because I was doing the same amount of work but I wasn't managing to get as good grades when I left mainstream school. And when I came here to the unit school my grades continued to fall and I think at one point – I was supposed to be sitting my Standard Grades because I had to re-sit this year – so last year when I was supposed to be doing them I had written some essay and I had been getting straight 1s and things, and this teacher from mainstream school handed back an essay and it was given a 3 or something. I was so devastated because I was always sort of, I am still a perfectionist and I just couldn't believe that I was given a 3 for this and how could that have happened. I was really upset.

Int.: Why did you think it had happened?

Sinead: I just kept thinking it is because I'm in this stupid unit school and why can't I just go back to mainstream school where I know all the teachers and they can teach you properly and I just thought everybody here was just a big joke.

Int.: Right so that was your experience with the unit school then.

Sinead: Yes.

Int.: Did you come to anything else here?

Sinead: Well after a couple of months I was very reluctant to come to any kind of day unit style thing because I just thought 'oh, it will just be a lot of wee psycho people running around screaming and shouting and things, and I thought, nah!' And I just kept on saying 'no no no, I'm not going' and then I think it actually happened by accident one day. A taxi was taking me home from here [out-patient department], it was late and I was invited through to come and have a cup of tea [in the day unit] and it ended up that I said 'oh, right, it sounds ok, I might as well just try it'. And I was so so reluctant to come, and then everyone was so surprised when I said I would try it.

Then after that I started to come to the day unit which wasn't too bad but it was kind of disorientating because there were so many different places in the unit that I hadn't actually seen. Because I had only seen the school room and the doctors' offices and then there was this whole new bit I hadn't seen before and all these new people and it was really daunting. Because at that time I was really stressed and anxious and really nervous about meeting people and to meet all those new people and new nurses who I hadn't really noticed before. It was like, 'oh no, nurses, psychiatric nurses, no I don't want to know them' but once I started coming I was okay.

Int.: So visiting here for a cup of tea made you realise that the young people weren't just wee psychos running about and it felt like it was perhaps okay. But there were still lots of people – and groups probably?

Sinead: Yeah. I wasn't... because of the nature of my illness, because it was more of a psychotic... because this day unit I think is more for kind of eating disorders and depressions. I wasn't allowed into community meeting or feedback or things like that, some of the more difficult groups, because it was too stressful. But I was actually quite keen after a while to go into them, but the nurses still wouldn't let me and I was like 'okay okay okay'.

Then I went to hospital [adult ward]. At first they were really lenient with me and they were really sensitive to things. And then when I started to refuse to come up here at all and all I wanted to do was stay down in the ward in my bed, they started to get quite aggressive. And they would say you've got to come up, you've got to come up, you've got to mix with people and I would tell them 'you can't make me do anything'. Now looking back, I would have said, they probably done the right thing, I mean to lie in my bed all day would just have been the wrong thing to do.

Int.: That's what you wanted to do?

Sinead: Yes, that's just all I wanted to do.

Int.: So you think it was probably fair, that the best thing to do was to fight with you about that?

Sinead: Yes

Int.: So you went into the ward. Things must have got worse then?

Sinead: Oh, definitely. I went through a period of time where I tried a couple of new medications. And I think at one point I went in just to try a new one and it ended up I had to stay in because trying a new one meant I had to come off my old one and that made me a bit more unstable again which meant that I was getting more and more voices and then I started to cut my arms and things. And then I was trying to kill myself so that's when I was admitted to the ward: I was in there for 3 months. And it was a long long time, and it ended up actually that I didn't want to go home because it was like, the ward was my home now because I'd been there for so long. And the nurses down there started to tell me to get my stuff out, take the stuff home, because it was more like my own bedroom rather than a hospital ward. I didn't like it down there at all, I really didn't, it was because I had been institutionalised for so long that it just seemed the place I was wanting to be.

Int.: I suppose there's one thing about hospital, it's a sheltered place.

Sinead: Yes.

Int.: So it was difficult to shift you on from the ward and while you were in the ward people had to hassle you to come to the unit. Was this successful? Did you come up?

Sinead: Yes but always grouchy about it. I didn't want to be there, I just wanted to lie in my bed. But near the end of my stay in the ward I'd been meeting Meave [Sinead's current key-worker] from Fisherfield [for young people with a psychotic illness] for periods of time. She came down one day and said 'hello do you want to come up and see the Unit [Fisherfield]?' sort of thing... And when I said right, okay I might as well go for it, I went in for a cup of tea one day. And Meave was, like, 'you're coming for a coffee, stay for half an hour' kind of thing, and they couldn't get me out of the place because I just loved it so much because it was such a different atmosphere from the first day-unit. It was almost as if it was more relaxed and people could just talk without being in groups or anything. It was just like, everyone was just sitting about smoking without someone coming up and saying 'you're under 16' and things like that, and it was just more relaxed.

Int.: So you liked [Fisherfield]?

Sinead: I liked it, yeah. I'm kind of outgrowing it at the moment and I'm trying to move on but throughout the time I've been here – I've been here for a year now, or just over a year – they have helped me a lot, they really have. I wasn't at school at all, I wasn't at mainstream school and successfully they managed to make me go.

Int.: So you went back to school, your own school?

Sinead: Yes, and now I'm doing 2½ days a week at my own school and 2 days here. I'm gradually getting back into things, especially over the past 6 months. I started new medication last October and it has been a wonder drug to me it really has.

Int.: What is it?

Sinead: Its called Quetiapine it's a really new one and I think I was one of the youngest people in X [the region] to actually try it because I was only 16 at the time. But it really has been a wonder drug to me. It's been brilliant, even though I'm still very big and overweight, but at least I'm not putting more on, I'm just stable at the moment.

I was taken into hospital again last October just before I started this one. And I was in there for 2 weeks and they put me on the Quetiapine and I've been okay ever since and gradually building up going back to school again. Especially over the last 2 months, I've been interacting more with my friends outwith the unit. But I've got a friend who has always stood by me since I started in the unit. We'd actually broken apart for a while because she was kind of scared of me almost, and then one day she realised... She is my next door neighbour... She came over to my house one day and said 'do you want to come across for a coffee' and since then she has been brilliant, she really has and she has interacted with me and with everybody else and I've got more of a social life now outside the Unit. And I can see a really really good future for myself, especially with my exam results that came in.

Int.: So things are picking up, are they?

Sinead: Yes.

Int.: Has the medication got any side effects?

Sinead: It has but you get used to them just like everybody else, you get used to their side effects. I mean, I am quite sensitive to most medications and I've had to have yellow cards sent into a lot of drug companies. But at the moment the worst side effect is sweating, which is horrible because my temperature just seems to rise higher than anyone else's and I seem to get hot in the coldest of places which is really annoying. There is no pain factor, it's just really annoying. Other things I've just got used to and don't even notice anymore like joint stiffness or dry mouth. You just get used to it and don't even notice after a while. It just seems perfectly natural.

Int.: What about the voices? Do they come back?

Sinead: Very occasionally, I mean, at the most 2 or 3 times a week. I've got used to it, because the people at [Fisherfield] and doctors have helped me realise that they may be inside my head, I'm the only one that can hear them. That they are not really real – and deep down, I know that they are not real, but when it is happening to you, it just seems so real. It's not helpful for people to say its all in your imagination, but when it is not happening, deep down, I know it's not real.

Int.: Have you got more control over it?

Sinead: Yes. I have this technique where... I think it's Meave that told me it, Meave and Lisa, the psychologist, told me that what you do is just say 'I don't want to speak to you at the moment, come back later'. It's almost just like putting them off, putting them off. And it does actually work. It's almost as if... I mean, I'm saying that deep down I know that they are not real but you've got to almost pretend that they're real so that you almost know them. So that you can know what the voices are like, even though you know they're not real. Just till you have control over them.

Int.: Like... what kind of a person they would be if they were real?

Sinead: Yeah.

Int.: Right. So that's useful clever work because it means even if they come back, it's not the end of the world.

Sinead: Yes, you can keep them under control.

Int.: The other thing I was going to ask you was, during that time, especially at the beginning, did other people understand what was going on for you?

Sinead: Well the people in the first day-unit not so much because, as I said earlier a lot of people there have more kind of eating disorders and depression so a lot of people there didn't really understand at all. I mean, even some of the nurses didn't really understand and they would really really treat me like wrapping me up in cotton wool. And I still felt like, kind of an oddball because I wasn't allowed into community meetings or some of the heavier groups and it almost felt like I was being pushed out and them saying 'no, you're different'. Even though I was in a place that everybody is supposed to be treated equally.

So when I came to [Fisherfield] I thought 'oh no here we go, I'm going to be the same again, this oddball'... But when I walked in, everyone just seemed just like me and everyone was having the same problems. And the staff understood more and they were all experienced in psychotic illnesses and it just seemed like more of a natural place to be because 'cause people there understood.

Even though the techniques used in [Fisherfield] are much more different, because in the first day-unit it's more kind of, everyone is open with each other. But down in [Fisherfield], because it is more of a sensitive issue, because not everyone wants to hear about everyone's voices and things like that and hallucinations, it was more kind of closed. And you only spoke to your key-worker or a nurse about things. You didn't really speak to other young people out, like, very openly, which was kind of weird to get used to and sometimes I kind of put my foot in it a lot because I would just say things openly and then I would get the lecture later on, saying 'you can't say that, you can't say that because it makes everybody else self-conscious'. The techniques used in both places are very different.

Int.: It is very interesting to hear your viewpoint on that. It sounds like here [Fisherfield], although people aren't open about everything that is going on inside them, is still a very friendly place?

Sinead: Yes

Int.: Where you can get close to people?

Sinead: Yes. You get a lot of students in and it usually ends up we all get really close to the students usually because they're all usually really really nice. I think they learn a lot from being beside young people, especially the student that's with us at the moment [a student nurse]. She's doing her conversion training between psychiatry and general and I think for a lot of students who are doing that, the conversion between general and psychiatry, I mean I'm sure they actually think, 'oh no, what am I letting myself in for: I'm going to a unit where it's all those psychiatrically ill young people, what am I going to let myself in for?'. But I think we are always a really good experience for everybody because we all are basically normal people, and it's just that we suffer from something and it's just a problem like anybody else has, except it means we have to come into maybe an out-patient or see a different doctor from a different field rather than a general doctor, but I think its useful for people to see. I think it should be more openly discussed in mainstream school about this. Mentally ill youngsters or mentally ill people, the majority aren't axe murderers or anything. And they should just be treated like normal people.

Int.: We are very ignorant in society aren't we?

Sinead: Yes, yes.

Int.: Ignorant also in the very negative sense of the word, like rude and horrible about it...

Sinead: Yes, yes.

Int.: I am struck by how articulate you are about it all. You seem to understand a lot of what has been happening to you.

Sinead: Yes, because I have had this illness for so long I've just gradually had to get used to it. Actually the other night there, an insurance man came and he has refused me a policy and he has loaded it with lots more money I have to pay for per month. And I was so annoyed because it was total discrimination. I saw it as total discrimination but, I mean, I've had to realise over the years that I'm going to be labelled with 'schizophrenic' or 'mentally ill' for the rest of my life and I am going to have to deal with it. And the people that matter aren't going to see me as schizophrenic or mentally ill they're going to see me as Sinead, and people that don't see me as Sinead, then they don't matter they're not worth it. But I've had to get used to that.

Int.: Was this a big obstacle to get to grips with?

Sinead: Yes, and at 17, I mean, it's hard to think that every job you go for, or everything you apply for, you're going to have to declare that you are mentally ill and that some little man in a suit in an office is going to look at statistics and say, 'oh no, she's schizophrenic we can't do this' or 'she can't work with children' or things like that and I mean I'm just going to have to get used to it.

Int.: You're going to have to find somebody reliable and understanding to work for.

Sinead: Yes

Int.: Yes I know, it's a hard lesson for us all and I hope we get better at it. I mean people like you will have a big influence. I hope, you know, I would like to think that you can change things...

What about your family because we haven't mentioned them. You've got your mum and dad and... any brothers and sisters?

Sinead: I've got a brother.

Int.: Younger or older?

Sinead: He's 15.

Int.: And how have they reacted throughout that time?

Sinead: My mum and dad have been very supportive. My mum especially because she really is a sensitive person and she used to get really really upset when I was ill and I mean I wasn't Sinead at that time I was a very ill person and she was really upset at that. My dad still gets quite angry with me, but my little brother, he hasn't coped well with it at all. He's still very... he can be quite cruel at times.

Int.: He doesn't understand?

Sinead: No.

Int.: And your dad gets angry with you, what, because of your illness? Or because of your behaviour?

Sinead: I mean he used to get really angry with me at first when he didn't know what was going on, just because he didn't understand and he wanted to understand.

Int.: He was kind of frustrated.

Sinead: Yes. I mean he has been very supportive, but he still gets pretty frustrated sometimes when he doesn't understand what's going on.

Int.: So it's hard for parents?

Sinead: Yes.

Int.: Have they been involved with the treatment?

Sinead: Yes, I suppose they have. I mean I have regular meetings with mum regarding medication levels with the consultant or a nurse. They've been pretty involved. And they've been involved in the parents' group and the campaign for a new unit...

Int.: So yes they've taken an active part. And are you happy with that or do you wish they were less involved?

Sinead: I think they are at the right level [interruption in the interview: someone came into the room then withdrew]

Int.: Are you happy with the level of involvement the family has had?

Sinead: I'm sure that they should really have had more. When I was in the hospital [adult ward], some of the communication between doctors and parents, especially with young people, wasn't very good at all. One minute, if you asked them to treat you more like an adult and not like a 5 year old, they would not involve anyone else apart from you, and they would put all the responsibility on you. And for someone who was 16 at the time it was either that, or when I said 'look I can't make these decisions for medication' and they were like then 'all right, then, okay, we will make decisions for you'. But that's not what I meant, I just wanted someone else to help me and be there to say 'right I'm on Sinead's side and I'll help you out here'. Because a lot of things I didn't understand, things like sections and observation levels and things like that. I was actually looking for someone to say, 'look this is what it's all about'. And things like ward rounds as well were really bad. I mean mum and dad were never ever invited, and sometimes I wasn't even invited. I made a point of saying 'look, I want to be in my ward round because I want to know what's going on for me. You're making all the decisions and I don't know what's happening'. And mum and dad at one point said to the consultant down there, 'look this isn't on, we really need to know what is going on'. They weren't even... [end of side 1 of the tape]

...they got really upset. They were coming in one day and I'd be on one medication on one dose, and they'd come in the next day and I'd be fine and they would say what are you on now? And nobody would tell them anything. It was really upsetting, I didn't even know what was going on so I couldn't even tell them... Sending young people to adult psychiatric hospital is absolutely horrific, it's terrifying...

I am going to get involved in an advocacy project soon.

Int.: Are you?

Sinead: Yes. To help people know what their rights are. Everyone sees mentally ill people as, like, scary. They have a fear of us, as if we are another race, but really, it shouldn't be like that. We're sufferers as well.

Int.: May be one last question: although you've already mentioned it quite a few times. Do you feel you're taking part in decisions regarding you, your treatment, your life?

Sinead: Yes, I think so. Especially in the unit. It really is a high priority with all the staff, all the people here. As you say, it is my life and I should be making the decisions, so I really have been involved in a lot – in fact in most of the decisions made about my life. Even though I might not have liked it – some of the things that have been said... But I know that in the end everyone was just trying to prepare me... And I have been involved quite a lot.

Int.: I imagine there may be times when you are more ill, and perhaps when you need hospital and these are the times when you least understand because of the way you're feeling...

Sinead: Yeah.

Int.: What's the best way of getting around that? The fact that you perhaps need more intensive care and the last thing you want is more intensive care?

Sinead: Well, I think someone to explain, someone to be there and to say 'look, if you have questions, just ask'. I mean because some of the things, I just couldn't understand why I needed to be in hospital, and then after a while I just couldn't understand why they wanted me to go home. And I knew I needed that intensive care to be more supported than usual but I think what was needed was someone to be there to say, 'look, come and ask' or they should come and explain. Because some of the decisions that were made then, I didn't have a clue what they were talking about. And I wasn't sure whether to ask, that it was ok to ask. People weren't approachable to go and ask.... But the nurses in the hospital, they really don't have a clue about young people, they really don't have a clue.

Int.: How can you tell that?

Sinead: The way they speak to you. They can be really really patronising, really really sarcastic and they just don't have the right attitude, they really don't.

Int.: Right. Okay. Well, I couldn't have hoped for a more complete answer! [laughter. Sinead joins in] Anything else do you think?

Sinead: Er..., no.

Int.: Okay, thank you very much, Sinead.

Appendix 2

SAMPLE SET OF FIELDNOTES

This set of fieldnotes is from the third week of observation in Arisaig: as it was the week before Easter, a long weekend was coming up. It was also the first week of the school holidays.

It has been chosen as sample because it came at a time in the period of observation when the researcher had begun to know the setting and to interact with it. It raised several important issues.

Day One

I went in at 11.30am. I noticed I was going in with discomfort, almost a kind of dread.

[What was I anticipating? My experience of unstructured time in the unit (i.e. time when the senior staff, who are friendly and positive, are not on), or of the non-school time (the teachers are equally goal directed and also friendly towards me), is of a world where nothing much happens, manned by junior staff (mostly nursing assistants), where I feel I don't understand what is going on and people are ill at ease with me. There is a sense of confusion, boredom and low grade resentment. I wonder what it is like for the young people to be in this sort of atmosphere? Is it worse at particular times of day? How does it affect them? Same questions for staff. I intend to include some of these questions in my interview guides for the young people and the staff. The problem is, will the staff-nurses ever trust me enough to answer them honestly?]

When I arrived at 11.20 am the clinical meeting [weekly multi-disciplinary meeting where decisions were made about the young people's therapeutic management] was going on. I went into the coffee room and a staff-nurse I had not met before came to ask me if she could help me. I explained who I was and she immediately connected. Her name is Peggy. I gave her an info sheet, and also one to Norrie [nursing assistant] who was sitting in the corridor supervising Tessa [young person] who was on the telephone. He seemed pleased and read it attentively.

[I always feel the nursing assistants are surprised when I take them into consideration like this.]

I went into the office where I found Becky [staff-nurse and ex-student of mine]. She said she'd like to ask me about courses (the specialist practitioner course). I explained.

[She was to talk to me on a few occasions during the next two days. I felt she had relaxed with me [she had initially avoided me] and could acknowledge her previous relationship with me.]

Another nurse was there whom I had not met before: Trish. She was at [other unit I knew

well] for six months before coming here six months ago.

I made myself a cup of coffee but left it to see if the young people were getting ready for the community meeting. Brian [young person - YP] was in the TV room on his own. I asked him how he was. He was bored. I stayed a few minutes and asked him about his weekend. It had been fine. Jo (the Senior House Officer - SHO) came in to see if Brian would take the dogs out to the park with her this afternoon. He was not keen. I left them and went to retrieve my cup of coffee. The clinical meeting was out. Harry (Occupational Therapist - OT) was in the coffee room making himself a cup of coffee. He introduced his student who had started on Monday: a bright, cheerful girl whose name I have forgotten. Dr White [consultant psychiatrist] was there too. Harry was explaining to him that he was not keen to take his turn to chair the meeting because he found it daunting. He's been here six months. Dr White thought it was better if the chair rotated so that people brought different things, rather than himself always chairing. Harry feels he is still very new. Dr White thinks it is a long time by the unit's standards (he was alluding to many people coming and going, as he had said during the first meeting I had with the staff). I asked him if I could go into the clinical meeting next week: he said he would check in the staff meeting and let me know. I also asked him if he had any objections to my starting to interview the young people, esp. from a mental state point of view. He said no. He also said that Moira [YP] might be a bit volatile: she'd shouted at him yesterday and had been in a right state.

I then went back into the TV room for the community meeting. Kate [YP] arrived. I spoke to her. Then others arrived. No staff appeared. Brian came to ask me if I knew who was taking this meeting. Of course I did not, but it gave me an idea of where he thinks I stand in the knowledge-of-what's-going-on hierarchy. Then Jane [nurse manager - NM] arrived, apologising for being late.

	Jane	Tessa	Diane (in dressing gown)
Dean Christopher	Me	Kate (chairing)	Helen (minutes)

Jane [NM] said that Moira [YP] was just back from hospital. I don't know much about what happened to her but she is in some sort of crisis. She has been on special nursing observation all day and has not come out of her room. I shall find it all out in the clinical meeting next week. Jill [YP] was not up, I don't think, but then I did not see her all day, or the next day. Joan [YP] was out at a hospital appointment. Kate [YP] and Tessa [YP] would be going for ECGs in the afternoon.

The first item on the agenda is a reading of the account of the last meeting. I found that it had been at 11 pm and that Jane [NM] was still there then. There had been some kind of crisis and people were very subdued. The kids told me later that Diane [YP] had brought drinks into the unit. It seems that Kate, Helen and Joan [3 young women with anorexia nervosa] knew about it and connived, although Kate tells me that she didn't drink any. Dr White was going to have a meeting with them and some punishment would be meted out. News of the decisions taken in the clinical meeting were shared by Jane. Quite a few Easter passes were allowed, from Thursday to Monday. Kate was getting one. Helen's pass wasn't sure: it seemed to depend on the meeting with Dr White. In the end she got one overnight and was fed-up about that. Brian was getting a pass and also Dean: an overnight for the first time in six months. The precise time was to be decided with his parents. Tessa [very withdrawn 13-year old] was congratulated for coming out of her room more. They were hoping to diminish the level of her nursing observation. She could also come out with the unit sometimes. Kate thought some of her meal supervision was going to be relaxed following her meeting with the dietitian. She thought this would also apply to Helen and Joan. Helen was dead keen to hear more but Jane cautioned her to wait until she was sure it applied to her too. Brian [overweight young man] was due to go to the gym with Ian [SN] this afternoon (physio department). Ian is off-sick and Jane said to Brian that anyone he wanted would accompany him instead. Brian said he didn't want to go. Jane said this was OK. Later, early in the afternoon, Peggy [SN] came to remind Brian of his appointment: Jane had evidently not passed on the decision. Diane could go on pass if she wanted. Jane asked how I was getting on: I said I was finding out how things were and I was hoping to start having chats with young people individually soon. Jane said to them: 'would this be OK?' There was no reply. As I looked into the meeting book later I noticed that someone had asked what it was like having me here. The reply was not minuted.

After the meeting I asked Jane if I could see her at some point. She indicated that it would be difficult today but that we could make an appointment for next week.

[I was feeling in need of catching up with someone when I came in, but after the interactions I had had, I felt I could wait.]

I made an appointment with Jane on my way to lunch and paid my coffee for the next four weeks. Lunch was being supervised by Sarah and Norrie [Nursing Assistants – NA]. Kate had finished; she apparently had chips with some meat. Helen and Joan were quibbling a bit about what they were going to eat: Helen had two slices of dry bread with her soup. Sarah (NA) said her diet sheet suggested a yoghurt too. Helen replied that she had not been having one. Sarah checked the diet diary which the nurses keep every day and appeared to think that was true. She then picked Joan up because she took ready made sandwiches when she was meant to have something else. Joan just refused to listen and went on with what she was doing. Sarah seemed to lack the confidence to insist. Norrie was there and seemed ready to support her but taking his cue from her. I wonder if he is quite new? Joan and Helen ate in a very abnormal way: pulling the food to bits, Joan getting the inside of the sandwich out and eating it separately. I would have thought that a registered nurse would have picked this up, but there wasn't one. Sarah and Norrie started talking to each other and teasing each other over the young people's head. Diane, who had dressed, came to join us. I was feeling rather out of it. I found it difficult to make out what people were saying: their Glasgow accent + a fair amount of mumbling made it difficult. I noticed the kids were often asked to repeat what they'd say, but I could not really do that when I was just observing in other people's conversations. I was getting pessimistic about interviews with the kids because there seemed to be a fair number of passes. I expected Diane to go, and Kate as well. These were the kids who had said last week that they would see me tomorrow.

Jane joined us and sat down with her meal. The atmosphere relaxed. She knows how to chat to the kids and make them feel good about themselves. She teased Helen about what she was like when she first came in: she'd refused to be shown around. It was four months ago. She'd had to be in a general hospital for a short spell because she needed extra feeding and tests. They all got involved in what it had been like on theirs and other people's first day.

Then I went into the TV room via the coffee room. There I was introduced to a new doctor, the specialist registrar who is just back from holiday: Dr Pink. She is also starting some research with Newcastle University. In the TV room the boys were playing a computer game. The OT student was there. I mentioned interviews and asked Dean if he might be here tomorrow. He appeared vague and some of his information was contradictory as it sometimes is (see end of interview 1A). So I suggested a time and went to get him a consent form because he needs to have it for 24 hours before he signs it. Then I asked Diane if she was still OK for tomorrow. She was and we fixed 2 pm. I gave her a consent form too. Suddenly I was back in business and very relieved. I chatted to Diane for a while: she was surprised I wanted to interview Brian: he has only been in the unit 6 to 8 weeks. I explained that it was because he is a boy. I asked her who came in first; she showed me a series of drawings / cartoons on the wall of the young people in the unit that she had made. They were in order of admission and Brian was missing. She told me all the admission dates. Then she decided she was going to redo them and proceeded to do so, adding Brian. Dean was also sitting there watching TV. I sat beside him and we commented on the show from time to time. We also watched the progress of Diane's drawings. No staff appeared at any time and I wondered if it may feel quite good to them to have an adult spending time with them. I don't know. Both were very friendly towards me at this point. I spent the rest of the time in the TV room with Diane and Dean, then Brian who joined us. Brian had been playing pool with the OT student. I had a bit of banter with him. He was quite cheeky and laughing. Jo [SHO] came in to renew her offer to him of walking the dogs with her. He didn't want to. She said that then he would have to meet her in her office. He tried to get out of that too but we teased him and he finally agreed to meet her at 3.30 pm. About 3 pm I went to make some notes. Jane suggested I used the director's office, which I did. I came back into the nurses' office before I left and chatted to Becky [SN]. She showed me the off-duty and I was able to check the people I had met and those I had not. Also those who were NAs and those who were SNs. Sean [SN] was in the room and told me why I had not met a couple of people: they were either off-sick or on night duty. The girls with eating disorders had retreated into their rooms supervised by a nursing assistant sitting outside the room.

Day Two

I arrived at 11am by bike. The first thing I did was to look for the key of the bike shed to put my bike away. Then I went into the office and told Jane (NM) that I planned to see Dean. She said that was fine although he was seeing his sister at 12.30. I also checked that I could use the director's office, which was fine. I set up the room for the interview then went to see Dean in the TV room. He was quite happy to be interviewed, although he wanted to finish watching a programme that finished at 11.10. I stayed and watched it with him. He had taken the consent form and info sheet I had given him yesterday to his room so we went to get them. I had brought some more with me and we asked Jane to sign as a witness. I explained to Dean why we had to sign 4 forms, which seemed to him to be an unnecessary fuss (one for himself, one for me, one for the case-notes and one for the GP). Later I set up the next interview, which was Diane's. When I met her she appeared quite happy to start there and then. It was 2.40 by then and she expressed the wish to have a break before her family meeting at 4 pm. I promised we would finish by 3.30 at the latest and we did.

After I had tidied everything up I went looking for young people to say goodbye before setting off. There was no-one in the TV room. The 'girls' [with anorexia] were finishing their break. Diane was there talking to Kate and I got the distinct impression (to the point of certainty) that she was speaking about her interview with me to Kate in negative terms: the expression on her face was sneering and she stopped dead when I came in. I sat at the table and the silence went on, the two girls looking distinctly embarrassed. I said lightly to her: 'are you telling Kate how awful it was?' She said no, then she said limply that she was talking about a staff meeting. I did not believe her and I got up and went to see those who were playing pool. Helen [YP] was playing with a young woman [staff member] I had not met before. She made some remarks to the girls about how hot it was, and how they should go outside and take some of their clothes off. The comments were brash and disparaging and they irritated the girls who said nothing but looked at each other. She asked me who I was and I named myself briefly, unwilling to co-operate further. She said she was Jackie. There is someone of that name on the nursing assistants' list. I had assumed it was the student nurse who left who was also called Jackie. I asked Helen if she was getting an overnight pass, as she had hoped. She said she was, just one night. She sounded frustrated

and unwilling to talk. I left it at that. By that time Diane had come to our side of the room. I said to her I hoped she would have a good break, then I went over to Kate to say the same to her. She was waiting for her Mum, she said. I also spoke to Joan who had her head on her arms on the table. She sounded quite irritated by this and just muttered something. I left feeling the atmosphere in the room was awful: the girls angry and frustrated and the NA unhelpful. I went to the office before I left and found a not dissimilar atmosphere there: John [charge-nurse] was on his own, writing some admin. I said I was going. I made some remark about him being busy and he replied something like 'you could say that'.

[The atmosphere pursued me during the night and I woke up feeling very oppressed by it and dreading going back. The feeling wore off slowly over the weekend.]

**PUBLISHED PAPER
NOT INCLUDED**

Appendix 4

NAPIER UNIVERSITY
DEPARTMENT OF CHILD HEALTH, MENTAL HEALTH AND
LEARNING DISABILITIES

The Experience Of Young People In Adolescent Mental Health Units

YOUNG PEOPLE INFORMATION SHEET

My name is Anne Claveirole. I am an adolescent mental health nurse and a member of staff at Napier University.

The research

As part of my work, I am carrying out a research project to find out how young people like you who come to an adolescent unit for treatment find the experience. I will be working in the unit as a volunteer for five weeks so that I can learn about the unit. While I am here I would like to speak to the young people who are likely to be in the unit for most of these five weeks about their experience.

My hope is that by learning more about how young people feel when they are in an adolescent unit I can help to meet their needs. You may not benefit directly from this research but your participation will help other young people who come into an adolescent unit in the future.

What does it mean for you?

I would like to learn about your experience by speaking to you. I will tape-record what you say, or, if you prefer, I will write it down. The tape-recording is better because it will record exactly what you say. I will do one interview, of about 45 minutes, at a time and place that suit you. I will not discuss what you tell me with the staff in the unit. The only exception to this would be if I heard that yourself or someone else was in danger. Then I would have to tell a member of staff but I would discuss it with you first.

Being involved in this research will not affect your treatment in any way so that you can stop at anytime if you want to.

Who will know about it?

The information I collect while I am in the unit and during interviews will be disguised: your name will be replaced by a number, and the name and address of the unit will not be used. I will not discuss what you have told me with anyone else. Although my research work will be supervised, my supervisor will not know who the people are. This is to make sure that everything is kept confidential. The information I collect will be kept in a locked place until the end of the research project, after which it will be destroyed. When I write my final report for Napier University, no unit or person will be identified by name.

If you wish to talk to someone about this project please contact Maureen Macmillan, Napier University, Canaan Lane Campus, 74 Canaan Lane, Edinburgh EH10 4TB. Tel.: 0131 536 5666. There is also a person not connected with the project who can give you detached advice about it. This is Susanne Forrest, Napier University, Comely Bank Campus, 13 Crewe Road South, Edinburgh EH4 2LD. Tel.: 0131 343 7900.

**NAPIER UNIVERSITY
DEPARTMENT OF CHILD HEALTH, MENTAL HEALTH AND
LEARNING DISABILITIES**

The Experience Of Young People In Adolescent Mental Health Units

PARENTS / CARERS' INFORMATION SHEET

My name is Anne Claveirole. I am an adolescent mental health nurse and a member of staff at Napier University.

The research

As part of my work, I am carrying out a research project to find out how young people who come to an adolescent unit for treatment find the experience. I will be working as a volunteer in this unit for five weeks so that I can learn about the unit. I have selected the young people who are likely to be in the unit for most of these five weeks. I would find it helpful if I could ask you about your experience as a parent / carer while I am here.

My hope is that by learning more about how young people feel when they are in an adolescent unit I can help to meet their needs. You may not benefit directly from this research but your participation will help young people and parents / carers in the future.

What does it mean for you?

I would like to learn about your experience by speaking to you. I will tape-record what you say, or, if you prefer, I will write it down. The tape-recording is better because it will record exactly what you say. I will do interviews at a time and place that suit you. I will not discuss what you tell me with the staff in the unit. The only exception to this would be if I heard that yourself or someone else was in danger. In this case I would have to tell someone but I would discuss it with you first.

Being involved in this research will not affect the young person's treatment in any way so that you can stop at anytime if you want to.

Who will know about it?

The information I collect while I am in the unit and during interviews will be disguised: your name will be replaced by a number, and the name and address of the unit will not be used. I will not discuss what you have told me with anyone else. Although my research work will be supervised, my supervisor will not know who the people are. This is to make sure that everything is kept confidential. The information I collect will be kept in a locked place until the end of the research project, after which it will be destroyed. When I write my final report for Napier University, no unit or person will be identified by name.

If you wish to talk to someone about this project please contact Maureen Macmillan, Napier University, Canaan Lane Campus, 74 Canaan Lane, Edinburgh EH10 4TB. Tel.: 0131 536 5600. There is also a person not connected with the project who can give you detached advice about it. This is Susanne Forrest, Napier University, Comely Bank Campus, 13 Crewe Road South, Edinburgh EH4 2LD. Tel.: 0131 343 7900.

NAPIER UNIVERSITY
DEPARTMENT OF CHILD HEALTH, MENTAL HEALTH AND
LEARNING DISABILITIES

The Experience Of Young People In Adolescent Mental Health Units

STAFF INFORMATION SHEET

My name is Anne Claveirole. I am an adolescent mental health nurse and a member of staff at Napier University.

The research

As part of my work, I am carrying out a research project to find out how young people who come to an adolescent unit for treatment find the experience. I will draw my data from three different units and I will be working here as a volunteer for five weeks so that I can learn about the unit. I have selected the young people who are likely to be in the unit for most of these five weeks. I would find it helpful if I could ask you about your work as a named nurse / link worker while I am here.

My hope is that by learning more about how young people view the experience of being in an adolescent unit I can help to meet their needs. It is fundamentally important, however, to find out how the health professionals most involved with them view the situation; it will allow me to set what they say into context and so get a more rounded understanding of it.

What does it mean for you?

I would like to collect information about your views by interviewing you. I would like to tape-record our conversation or, if you prefer, I will take notes. I would prefer to use a tape-recorder because it means that what you say will be more accurately recorded. I will do interviews at a time and place that suit you. Their content will only be used for the purpose of the research.

Confidentiality

The information I collect while I am in the unit and during interviews will be disguised: your name will be replaced by a number, and the name and address of the unit will not be used. I will not discuss what you have told me with anyone else. Although my research work will be supervised, my supervisor will not be given any names. This is to make sure that everything is kept confidential. The information I collect will be kept in a locked place. When I write my final report for Napier University, no unit or person will be identified by name. The results of the research will be shared with the unit.

You can withdraw from the research at anytime. If you wish to discuss the research with someone other than me contact Dr Maureen Macmillan who is the supervisor of the project at Napier University, Canaan Lane Campus, 74 Canaan Lane, Edinburgh EH10 4TB. Tel.: 0131 536 5666. There is also an independent adviser, Mrs Susanne Forrest, Napier University, Comely Bank Campus, 13 Crewe Road South, Edinburgh EH4 2LD. Tel.: 0131 343 7900.

Appendix 5

NAPIER UNIVERSITY

DEPARTMENT OF CHILD HEALTH, MENTAL HEALTH AND LEARNING DISABILITY

YOUNG PEOPLE CONSENT FORM

TITLE OF THE PROPOSED RESEARCH:

The Experience of Young People in Adolescent Mental Health Units

NAME OF THE RESEARCHER:

Anne Claveirole

ADDRESS:

Napier University, Comely Bank Campus, 13 Crewe Road South, Edinburgh EH4 2LD

TELEPHONE:

0131 343 7900

FURTHER INFORMATION IS AVAILABLE FROM (A person who is not involved in the study):

Susanne Forrest, Napier University, Comely Bank Campus, 13 Crewe Road South,
Edinburgh EH4 2LD

- **I agree to participate in this study.**
- **I have read this consent form and the Young People Information Sheet and had the opportunity to ask questions about them.**
- **I am satisfied that the information will remain confidential unless it reveals a risk of danger to someone.**

- **I agree for notice to be sent to my General Practitioner about my participation in this study.**
- **I understand that I am under no obligation to take part in this study and that a decision not to participate will not alter the treatment that I would normally receive.**
- **I understand that I have the right to withdraw from this study at any stage and that to do so will not affect my treatment.**
- **I understand that this is non-therapeutic research from which I cannot expect to derive direct therapeutic benefits.**

Signature of the Young Person:

Name of the Young Person:

Signature of the Researcher:

Date:

Two copies to be made:

One copy to be retained by the researcher

Second copy to be retained by the young person

Third copy to be sent to the young person's general practitioner

Fourth copy to be filed in any relevant hospital case notes

NAPIER UNIVERSITY

DEPARTMENT OF CHILD HEALTH, MENTAL HEALTH AND LEARNING DISABILITY

PARENTS / CARERS' CONSENT FORM

TITLE OF THE PROPOSED RESEARCH:

The Experience of Young People in Adolescent Mental Health Units

NAME OF THE RESEARCHER:

Anne Claveirole

ADDRESS:

Napier University, Comely Bank Campus, 13 Crewe Road South, Edinburgh EH4 2LD

TELEPHONE:

0131 343 7900

FURTHER INFORMATION IS AVAILABLE FROM (A person who is not involved in the study):

Susanne Forrest, Napier University, Comely Bank Campus, 13 Crewe Road South,
Edinburgh EH4 2LD

- **I agree to participate in this study.**
- **I have read this consent form and the Parents / Carers' Information Sheet and had the opportunity to ask questions about them.**
- **I understand that I am under no obligation to take part in this study and that a decision not to take part will not alter the treatment that my son or daughter would normally receive.**

- **I understand that I have the right to withdraw from it at any stage.**

Signature of the Respondent:

Name of the Respondent:

Signature of the Researcher:

Date:

Two copies to be made:

One copy to be retained by the researcher

Second copy to be retained by the respondent

NAPIER UNIVERSITY

DEPARTMENT OF CHILD HEALTH, MENTAL HEALTH AND LEARNING DISABILITY

STAFF CONSENT FORM

TITLE OF THE PROPOSED RESEARCH:

The Experience of Young People in Adolescent Mental Health Units

NAME OF THE RESEARCHER:

Anne Claveirole

ADDRESS:

Napier University, Comely Bank Campus, 13 Crewe Road South, Edinburgh EH4 2LD

TELEPHONE:

0131 343 7900

FURTHER INFORMATION IS AVAILABLE FROM (A person who is not involved in the study):

Susanne Forrest, Napier University, Comely Bank Campus, 13 Crewe Road South,
Edinburgh EH4 2LD

- **I agree to participate in this study.**
- **I have read this consent form and the Staff Information Sheet and had the opportunity to ask questions about them.**
- **I understand that I am under no obligation to take part in this study and that I have the right to withdraw from this study at any stage.**

Signature of the Respondent:

Name of the Respondent:

Signature of the Researcher:

Date:

Two copies to be made:

One copy to be retained by the researcher

Second copy to be retained by the respondent

Appendix 6

12 April 2000

Ms. A. Claveirole
Lecturer
Napier University
Faculty of Health Studies
13 Crewe Road South
EDINBURGH
EH4 2LD

Dear Ms. Claveirole

AN EXPLORATION OF YOUNG PEOPLE'S EXPERIENCE OF CARE AND PARTICIPATION IN THE PLANNING AND DELIVERY OF THEIR TREATMENT IN THREE SPECIALIST MENTAL HEALTH SERVICES: A QUALITATIVE STUDY

I refer to your application to the Research Ethics Committee for the above study.

I write to confirm that the Research Ethics Committee at its meeting on 4 April 2000 approved your application.

The remit of the Committee requires that they follow up projects they have approved to determine the success or otherwise of such studies.

I would be pleased, therefore, if you would provide a copy of any final reports produced as a result of your study or alternatively to receive from you written confirmation of the results of your study for submission to the Committee.

Yours sincerely

Secretary
Research Ethics Committee



Miss Anne Claveirole
Napier University
Faculty of Health Studies
Department of Maternal and Child Health
Mental Health and Learning Disability
13 Crewe Road South
Edinburgh EH4 2LD

9th June 1998
Psychological Medicine
Tel: 536 2875
Fax: 536 3408

Dear Miss Claveirole

23/98

The experience of young people in three adolescent mental health units

Thank you for your letter of 5th June. Your systematic and clear responses were much appreciated. All qualifications raised by our committee have been satisfactorily resolved and I am pleased to confirm ethical approval for your study without further qualification.

Yours sincerely

CHAIRMAN
RESEARCH ETHICS SUBCOMMITTEE
(PSYCHIATRY & CLINICAL PSYCHOLOGY)
c.c. Secretary, Research Ethics Subcommittee,



Miss Anne Claveirole
Napier University
Faculty of Health Studies
Comely Bank Campus
13 Crewe Road South
Edinburgh
EH4 2LD

Dear Miss Claveirole

PROJECT: *Young people's experience of care and treatment in three specialist mental health services: a qualitative study*

Thank you for sending the required amendments to this submission. I am pleased to be able to tell you that the Committee now has no objections from an ethical point of view, to this project proceeding and ethical approval is formally granted. You will know that you should also inform the Research & Development Directorate.

I would also like to take this opportunity to remind you that you should notify the Committee if there are any changes, or untoward developments, connected with the study – the Committee would then require to further reconsider your application for approval. The Committee would be grateful if a brief final report on your project could be forwarded to the Committee when the project reaches its conclusion.

May I wish you every success with your study.

Yours sincerely

Administrator – Research Ethics Committee

Appendix 7

Miss Anne Claveirole
Dept Child Health, Mental Health and Learning Disability
Napier University
13 Crewe Road, EDINBURGH
EH4 2LD

Dear Miss Claveirole

Research Proposal: An Exploration of Young People's Experience of Care and Participation in the Planning and Delivery of their Treatment in Three Specialist Mental Health Services: a Qualitative Study

A copy of the above research proposal has recently been submitted to me for management approval. I would like to confirm that the Healthcare NHS Trust approves your proposal subject to the written approval of the Research Ethics Sub-Committee.

A condition of this approval is that you advise me, in advance, of any significant proposed deviation from the original protocol.

Finally, if for any reason this research does not go ahead I would be grateful if you could advise me.

With best wishes.

Yours sincerely

CHIEF EXECUTIVE

29 April, 1998

Ms. Anne Claveirole
Lecturer in Mental Health,
Napier University,
13, Crewe Road South,
Edinburgh EH4 2LD

Dear Ms. Claveirole.

An Exploration of Young People's Experience of Care and Participation in the Planning and Delivery of their Treatment in Three Specialist Mental Health Services: a Qualitative Study.

Following our meeting today, I am writing to confirm that I am happy to support this proposal and for data to be collected at the _____ by the method described. I understand that this will probably take place in July and August of 1998.

Yours sincerely,

Lead Clinical and Consultant Psychiatrist

CONFIDENTIAL

Ms Anne Claveirole
Napier University
Faculty of Health Studies
13 Crewe Road South
EDINBURGH
EH4 2LD

4 February 1999

Dear Ms Claveirole

Thank you for your helpful meeting with us in the _____ and for the information that you faxed. Your proposals have been widely discussed by various members of the multidisciplinary team and we would be happy to participate in the research. Please get in touch to let us know where we go from here.

I look forward to hearing from you.

Yours sincerely

Consultant Adolescent Psychiatrist

24 March 1999

Ms A Claveirole
Lecturer in Mental Health Nursing
Faculty of Health Studies
Napier University
Comely Bank Campus
13 Crewe Road South
EDINBURGH
EH4 2LD

Dear Ms Claveirole

Project Title: An exploration of young people's experience of care and participation in the planning and delivery of their treatment in 3 specialist mental health services: a qualitative study.

Project Ref: 99AD01

Thank you very much for completing the data collection form and summary of costs, and recent telephone enquiry about your project. I am writing to confirm that your project is registered, and can commence.

Yours sincerely

PP

Research Manager

20 January 2000

PRIVATE & CONFIDENTIAL

*Ann Claveirole
Lecturer (Mental Health)
Napier University
Faculty of Health Studies
13 Crewe Road South
EDINBURGH
EH4 2L*

Dear Ann

Thank you very much for your written correspondence concerning your research project. I am sorry I am not sure where the first copy of this went but I have certainly not it before.

*I was very happy with the protocol and information you supplied and will be delighted to support this research, both in terms of contact with our Ethical Committee and in the contact you would need with
If there is anything practical I need to do to expedite the matter please do not hesitate to
contact me.*

Yours sincerely

**CONSULTANT CHILD & ADOLESCENT PSYCHIATRIST
CHILD MENTAL HEALTH**

Dear

PROJECT: AN EXPLANATION OF YOUNG PEOPLE'S EXPERIENCE OF CARE AND PARTICIPATION IN THE PLANNING AND DELIVERY OF THEIR TREATMENT IN THREE SPECIALIST MENTAL HEALTH SERVICES A QUALITATIVE STUDY BY ANNE CLAVEIROLE

I have considered the comprehensive research proposal provided by Anne Claveirole for the above project. She has already sought approval from _____ Lead Clinician for the _____ Service and _____ the Ward Manager to participate.

For the Trust I can confirm that the project takes due account of confidentiality and informed consent. I happy to support this project taking place within the Trust's services.

Yours sincerely

Medical Director

c.c. Miss Anne Claveirole



Awarded for excellence
to Nutrition and Dietetic Department

Appendix 8

Systemic Models of the Unit Cultures Found in the Study

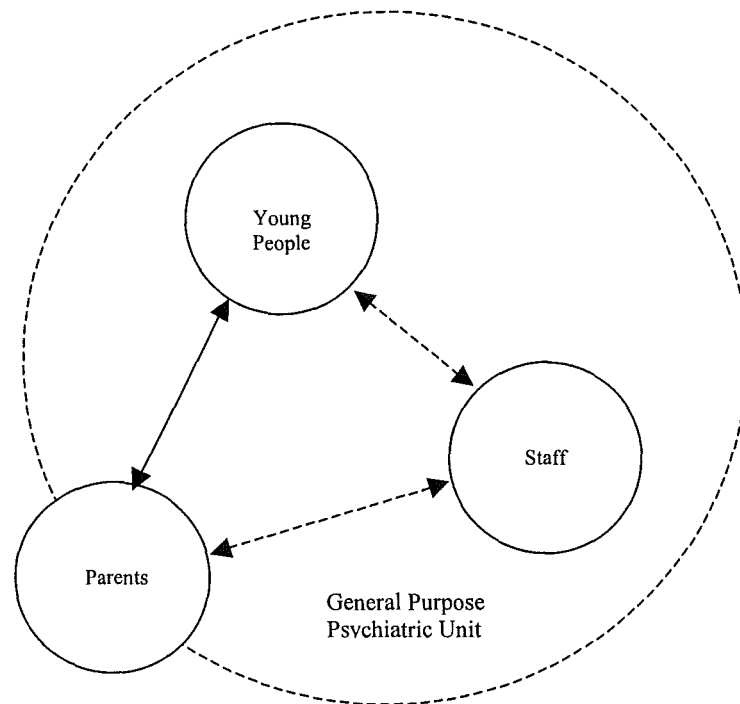


Diagram 1: Unit Culture – Model 3

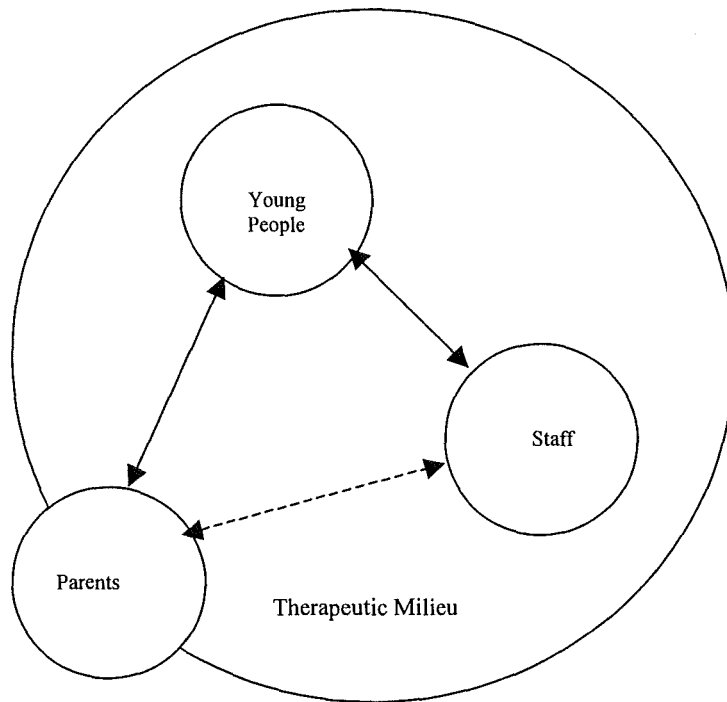


Diagram 2: Unit Culture - Model 2

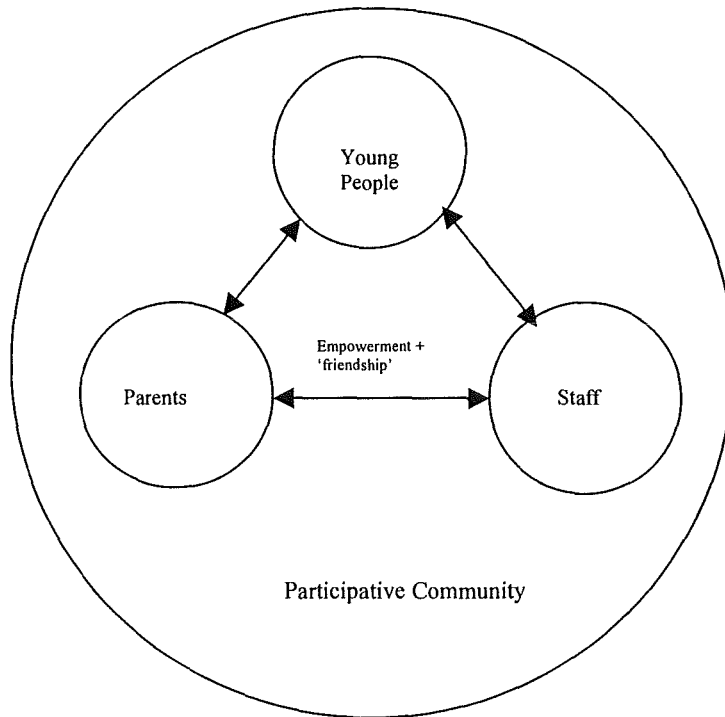


Diagram 3: Unit Culture - Model 1

Symbols:

Circles represent the units and their sub-systems: young people, parents and staff
 The circle with a dotted line boundary represents a unit without a clear culture

Arrows represent relationships between stakeholders

Arrows with full lines represent personal relationships between stakeholders

Arrows with dotted lines represent haphazard relationships between stakeholders

Appendix 9

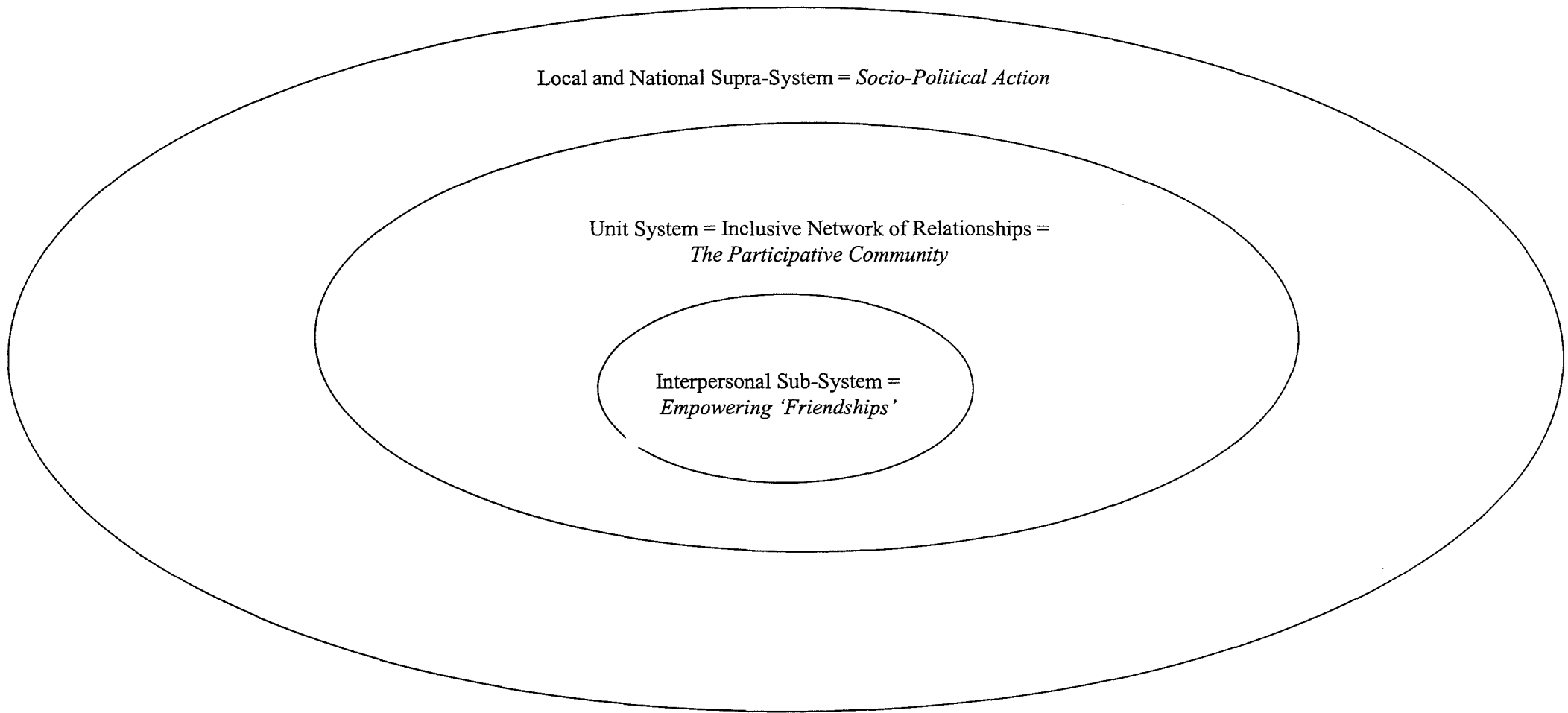


Diagram 1: Systemic Representation of Unit Interactions Linked to Participation

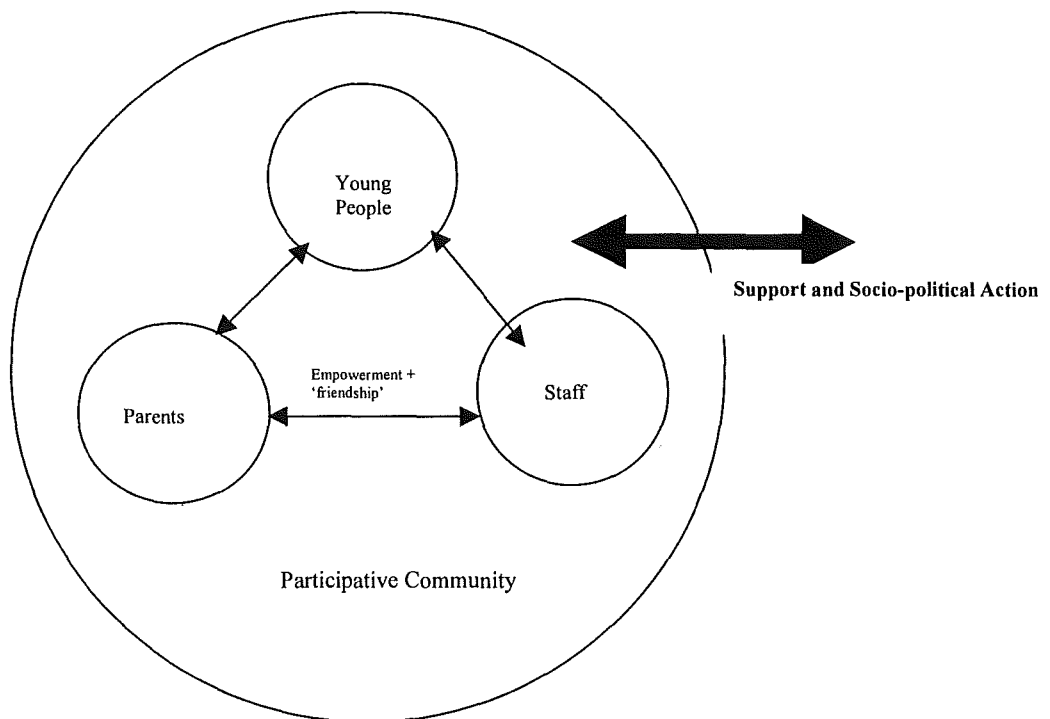


Diagram 2: Systemic Model of the Recommended Unit Culture