"I am a normal man" A narrative analysis of the accounts of older people who have Down's syndrome who lived in long stay hospitals.

by

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Volume I

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For my sister, Jude.
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Academic Dossier

Essays

Problems Based Learning Reflective Accounts

Summaries of Process Accounts of Case Discussion Group
Essays

Adult Mental Health Essay

Professional Issues Essay
The Course Team is attempting to involve service users and carers in many aspects of the Surrey Clinical Psychology Training Programme. With reference to the evolving literature on involvement in both training and research, explore ways of involving users and carers in the Programme. What issues and dilemmas might such involvement create?

**Adult Mental Health Essay**

January 2005

Year 1
Over recent years, service users and professionals have been working together more and more in providing health services. The development of service user involvement has occurred due to many factors, including critical comments by service users of existing service provision and government policies. The Department of Health has produced various documents which state that people who use health services should be involved in the planning and delivery of services (DoH, 1999a; DoH, 2000). This policy shift covers a range of service users, such as children, people with mental health problems, people with learning disabilities and older people (DoH, 2001; DoH, 2004). The government also recognises the vital role of carers (DoH, 1999b). With this in mind, professional health training courses are shifting towards involving service users and carers in training.

I have chosen this essay as I wanted to learn more about service user involvement, particularly after a previous experience whilst working as a research assistant. When I was interviewed for the post, there was a person with learning disabilities on the panel. She asked me why I wanted to work with people with learning disabilities. For me, this was a challenging but thought provoking question. It made me question why I was working in the field, my values and more importantly my understanding of the potential capabilities and contribution of service users.

This essay will firstly discuss the definition of service user and carer involvement. A summary of the literature on service user and carer involvement in training will be presented. I will describe my understanding of what is currently happening at Surrey with respect to service user involvement. The essay will then discuss some of the ways users and carers could be involved on the course, in relation to the literature on involvement. A discussion of the issues and dilemmas that such an involvement may create will be presented. Finally, the main points of the essay will be summarised and future work will be recommended.

**What is service user and carer involvement?**

There is currently no agreed definition for 'service user and carer involvement.' There exist many different terms for people who have used or are currently using health services (including service user, consumer, patient and stakeholder). Livingston & Cooper (2004) emphasise that the different names reflect the different roles of the people or organisations concerned. The terminology is dependent on the purpose of involvement, attitudes and values of people in
organisation and resources available. This essay will be in keeping with the essay title and use the term 'service user', whilst recognising that other terms are used.

Similarly, the definition of ‘carers’ is rather vague. The government strategy for carers (DoH, 1999b) defines a carer as,

“...someone who provides or intends to provide practical and emotional support to someone with a mental health problem.”

Current literature on service user and carer involvement in training

With respect to involving users and carers in mental health education and training, Tew et al. (2004) have produced a good practice guide. The guide aims to build upon previous research and discusses involving service users and carers in all aspects of the educational process.

A useful tool to rate progress in involving service users and carers is ‘The Ladder of Involvement’ by Goss and Miller (1995) (as cited by Tew et al. 2004). This model consists of five levels ranging from Level 1: No Involvement to Level 5: Partnership. Different professions can be rated at different levels on the ladder of involvement. Harper et al. (2003) state that clinical psychology could learn from other professions, which have involved service users, such as social work or nursing. Forrest et al. (2000) describe a qualitative study whereby service users were asked about what knowledge and skills are important for nurses to possess. The authors stress that moving towards ‘Partnership’ level should be done carefully.

Clinical psychology as a profession is lagging behind other professions in involving service users in training. Harper et al. (2003) state the reasons for this lack of service user involvement include: the medical model and expert models (e.g. scientist practitioner); current British Psychological Society (BPS) accreditation criteria which emphasises that the majority of teaching should be provided by clinically qualified psychologists; lack of resources and uncertainties about how to do it effectively.
Across the UK, service user involvement on clinical psychology training courses appears to be variable. Allott et al. (2004) have produced a review of involving service users in clinical psychology training at the University of Manchester. They describe three main stages to user involvement: establishing partnerships, addressing concerns and implementing change. Linda Steen (personal communication, 5th December 2004) stated that the Manchester course is at the exciting stage of piloting some of their ideas such as: recruitment of a network of consumer and community representatives who will sit on the programme committee and advise on all aspects of the running of the course; increasing participation in curriculum development and selection of trainees; and provision of training about service user involvement for course team, supervisors and lecturers.

The current situation at Surrey
The Clinical Psychology Training Programme at Surrey has started to develop a model of service user and carer involvement on the training Programme, which is based on the model at the Exeter Clinical and Community Psychology Training Programme. This model involved a User and Carer Advisory Group. Curle and Mitchell (2004) describe the impact of setting up an Advisory Group such as having a greater emphasis on user centred values, user involvement in selection, new guidelines on consent and confidentiality and issues about power and inequalities being addressed more strongly. The authors also highlight the challenges of user involvement such as negotiating differences and gaining a representative sample of service users.

From my understanding, this process is just beginning at Surrey. Using the ‘Ladder of Involvement’ (Tew et al., 2004) the Surrey course appears to be at Stage 3: Growing Involvement. A service user involvement co-coordinator has been employed for one day a fortnight. This individual co-ordinates a working group composed of service users and professionals and is developing a process for involving service users. As well as the working group, there are other professionals and service users who contribute on a less regular basis.

Possible ways of involving user and carers
The following section will discuss the possible ways in which service users and carers could be involved on the Surrey Training Programme. The structure of this section will follow the good
practice guide by Tew et al (2004) and cover all aspects of training including: direct delivery of teaching; course/module planning; programme management; recruitment and selection of trainees; practice learning; student assessment and course evaluation. Additional aspects of clinical psychology training, such as research, will also be addressed.

Various different client groups will be mentioned, although it is accepted that there are difficulties involving certain client groups, such as children. This section will reflect the literature available and mainly discuss the involvement of adults with mental health problems.

Course and module planning

Tew et al. (2004) state that if courses are already running, service users and carers can be involved in incremental developments. Tew et al. (2004) also state that it is important to clarify what value will be attached to user and carer perspectives and to consider various issues, including environment for planning, administration and support and other resources. The Surrey course team will have to establish what value they will give user and carer perspectives. The Training Programme is comprised of many different tutors/lecturers/practitioners who should be consulted and kept up to date with the process.

The above paragraph confirms to me that it would be a good for Surrey to draft a policy and contract. In my opinion, having a policy on service user and carer involvement would show that the course team is committed to the project. The contract would define roles and responsibilities, clarify timetables, training and benefit entitlement issues.

Programme management

Tew et al. (2004) suggest that involving service users and carers in programme management may make the process more transparent and easier to understand. The report also recommends that a group of service users and carers is better than an individual. As with Manchester University, Surrey could have service users and carers on the Programme committee, who could contribute to all aspects of the running of the Programme.
Recruitment and selection of trainees.

Involving service users in selection and recruitment could have many benefits, such as empowering service users and allowing course staff to observe how trainees interact with service users.

Service user involvement in selection varies between courses. For example, Christine Curie stated that at Exeter, service users have been involved in selection through training and planning events over the past years. Moreover there is a plan to have service users on the interview panel next year (personal communication, 17th December). Allot et al. (2004) report a mixed support from service users for involving them in the selection of trainees for the Manchester Programme. The study stated there was strong support for service users contributing to interview questions and criteria for rating interviews. However, there was less support for service users being involved in the short-listing process due to the possibility that their mental and physical health may affect their ability to contribute and their limited knowledge of clinical psychology issues.

A recently appointed Clinical Psychologist described to me her own personal experience of service user involvement in her interview. She described the interview process as consisting of an interview with professionals and a subsequent “lunch” with service users, other candidates and professionals. During the lunch, service users asked the candidates various questions such as, “Why did you chose to do clinical psychology?” and, “Do you have any personal mental health problems?” She said that the questions were more direct and personal in comparison to those asked by the professionals. She also stated that she was not sure whether the service users’ views would be taken into account when making the final decision on selecting a candidate. In my opinion, if service users are to be involved in selection, it should be made clear how they would be involved and whether their views would be used to make a decision on selection. From my own personal experience of being interviewed for clinical training, it is already extremely anxiety provoking for trainees and having service users in the process could increase anxiety levels. However, at the same time I can appreciate the benefits of such involvement, such as increased self-esteem and empowerment for service users and creating an interview experience, which includes more direct and personal questions.
Direct teaching

Involving service users and carers in teaching could be in the form of direct teaching to groups of students or in indirect ways such as video or written pieces of work. Another way could be for service users to be involved in the Case Discussion Groups. This may be more appealing to service users and carers as it would be to a smaller audience and therefore less stressful for the service users.

Service users could also teach in groups as opposed to individually; again this may be more attractive to them. Tew et al. (2004) highlight that teaching can be stressful, particularly if the service users and carers’ views are not supported by the rest of the teaching team. Therefore, it would be useful for the teaching staff at Surrey to have training on service user involvement, particularly with regards to the reasons and values of the involvement.

Linda Steen described two examples of user involvement in teaching sessions at Manchester University: a husband of someone with Alzheimer’s talked about services from his perspective; two people who have used clinical psychology services gave their perspective on the services they have received (personal communication, 5th December 2004).

A further example of service user involvement in teaching was presented by Hayward (n.d.). This paper describes the planning and delivery of Psychosis Revisited workshop, which involved service users. Hayward described how CAPITAL, a service user organisation was responsible for facilitating the service user sessions. This organisation specialises in preparing and training service users for public speaking. A specialised organisation such as this could be used at Surrey, in order to reduce potential anxieties in service users.

Placement

The involvement of service users and carers on placement is currently variable. One example is that of a first year trainee who has been allocated two mentors who are service users on her Adult placement. She stated that it was a useful opportunity to discuss what was helpful and unhelpful in relation to clinical psychology services. She explained that it worked better when the mentor
was well briefed about the role. She described a few uncertainties relating to boundaries and confidentiality issues. She also explained that it was difficult to phrase personal questions when she did not know the mentor and when she was not in a therapist’s role. Therefore, it seems that defining roles and clarifying these uncertainties would be helpful for the future. Other possibilities could include service users and carers observing trainees at work and sitting in on supervision.

**Research**

Possible ways of involving service users and carers in the research component of the course could be as follows: consultation, user led or collaborative research. Rose (2003) states that user led research involves service users controlling all stages of the research process, whereas collaborative research involves a partnership between the researchers and service users. Kirby (2004) suggests that the level of involvement in research may be affected by the individual’s choice and availability, nature of the research and availability of resources.

Trivedi & Wykes (2002) describe the process of user involvement in a study investigating the effects of group medication education sessions on in-patients. The authors stated that the process was challenging at times. For example, service users disagreed with outcome measures of ‘compliance’ and ‘insight,’ and stated a preference for ‘self-esteem’, ‘alliance’ and ‘empowerment.’ However, benefits were reported in terms of service users raising new research questions, and ensuring all interventions were ‘user friendly.’ Trivedi & Wykes (2002) also highlight that certain research projects (e.g. projects arising in response to users requests) may be more appealing for service user involvement than others. This could relate to the Surrey training Programme and whether service users would be involved with certain types of research projects. In addition, Allott et al. (2004) suggest that service user involvement could be particularly relevant to the Service Related Research Project.

**Student assessment**

Christine Curle (personal communication, 17th December 2004) stated that at Exeter the User Advisory Group participated in trainee assessment through consulting with the course team over
its clinical module. She added that it is hoped that supervisors consult with clients about trainee performance. In contrast, Allot et al. (n.d.) report that service users had less support for the idea that service user organisations should be involved in evaluation of trainee’s performance on placement. Reasons for this lack of support included possible conflict between the service users’ and Programmes’ views about the trainee. One possible solution would be for service users and carers to be involved in student assessment once they have been involved in other aspects of the course, such as teaching and course/module planning. This would allow the service users and carers to develop their knowledge and expectations about the role of the clinical psychologist before evaluating a trainee.

Course evaluation

The current system of course evaluation at Surrey is for each session to be evaluated using a student satisfaction questionnaire. Tew et al. (2004) state that a similar system of satisfaction questionnaires could be used to evaluate service user involvement. Furthermore, they propose the idea of evaluating students’ values, attitudes, and people skills in order to explore the impact of service user involvement on the students.

Masters et al. (2002) employed a questionnaire to evaluate service user and carer involvement on the Diploma of Higher Education in Nursing at Napier University. The authors stated that the questionnaire was comprised of both closed and open-ended questions assessing satisfaction and the importance of practical aspects of project, representativeness and the overall experience of project. At Surrey, it may be helpful to evaluate the views of the course team, service users and carers, and students in order to gain a wide perspective of service user involvement.

Service users and carers as trainee clinical psychologists

Harper et al. (2003) stress that clinical psychology training courses should not discriminate against selection of candidates with mental health problems. Tew et al. (2004) highlight that courses should encourage applications from service users and carers and that ‘reasonable’ adjustments should be made for such students, including access to student counselling services and minimising stress during assessment process. Tew et al. (2004) also comment on the
potential discrimination of the occupational health checks. Having gone through the application process myself, I think it would be helpful for the letter (requesting trainees to complete the Occupational Health questionnaire) to include a statement about how the course encourages individuals with mental health problems to apply.

**Issues and dilemmas**
The following section describes some of the many issues and dilemmas to consider when involving service users and their carers.

**Power and empowerment**
An important issue in the area of service user and carer involvement is power and empowerment. Despite the statutory duty of service user involvement, Campbell (2001) states that not enough is being done and that involvement is influence rather than power. He states that the Care Programme Approach aims to facilitate service users to make choices, but simultaneously it can be “arduous and unpleasant” for users. Power issues should be considered when involving service users and carers in training.

Rutter et al. (2003) report on results from qualitative case studies of user involvement in two mental health provider Trusts. The study reveals that the provider managers retained control over decision-making and expected users to conform to Trust management practices. The study states that in order to achieve ‘Partnership’, more resources and powers should be provided. Rutter (2003) also highlights that service users stated that they did not feel empowered in the formal management meetings. Instead, service users expressed a preference for alternative, independent and confidential meetings to express themselves openly. However, I think ideally service users should be made to feel empowered in management meetings. This may require a change in attitudes and values of professionals.

To challenge these power issues, Harper et al. (2003) suggest that trainees could attend sessions in bases run by service users opposed to inviting service users to the course base. In addition, Harper et al. (2003) suggest inviting user groups to become involved with the course as opposed
Representativeness

A Rethink advocacy worker gave me his opinions of service user in mental health services: “Most service users want nothing to do with the system once they have left - and those that do get involved are often articulate, intelligent adults. Many people don’t have the communication skills to express themselves.”

Representativeness is a vital issue in the literature of service user and carer involvement. Ideally the course team should aim to involve service users and carers from the range of client groups. Some client groups, such as children are harder to involve than others due to issues such as consent and ensuring child’s well being. However, there are studies which have reported successful involvement of children. Tew et al. (2004) describe a study carried out at Anglia Polytechnic University, which involved children and young people in the delivery of teaching on the BSc and MSc Child and Adolescent Mental Health Programmes. This study approached a MIND local advocacy group which already had experience of involving children.

At Manchester, the course team acknowledged that the working group would not represent all service users. Therefore, the course team developed a database which acts as a consultation network and includes groups that represent service users, clinical psychologists, allied professionals and other training staff. Hence, a database could be a good starting point for Surrey when thinking about involving a representative sample of service users. I think that it will be hard to achieve a completely representative sample of service users. As a trainee, I am aware that the different cohorts of trainees are not representative of the general population. In my opinion, a little involvement is better than none at all.

Another issue is involving those people with mental health problems who do not use services or who have refused services. This could hopefully enable trainees to find out the reasons why some people do not use services or why they do not attend sessions. Linda Steen stated that the Manchester course had broadened its definition of service users/ carers to include community
members who might not easily have access to services. She added that these "community representatives" sit on the Programme's committee and advise on all aspects of the course (personal communication, 5th December 2004).

It is important to involve service users from ethnic minorities groups. In a review of service user involvement in mental health training, Livingston & Cooper (2004) stated that they were unable to find any published studies on the involvement of service users and carers from ethnic minority groups. As cultural diversity and difference is a major component of the Surrey Programme, it would be meaningful to involve service users and carers from different ethnic and cultural backgrounds.

**Tokenism**

As a first year trainee I was invited to a service user involvement discussion group, with the aim being to discuss views of user involvement in training. An important issue which was raised at this meeting, was the need to avoid tokenism and to involve service users in all aspects of the course.

Whilst on placement, I attended a meeting whereby a service user with mental health problems discussed her experiences of being a service user. Her main points were that the inpatient care was not as good as other care. However, she recognised the need for inpatient care as a way of containment and safety. With regards to receiving therapy, she stated that she preferred it when a therapist disclosed personal information. This experience could be labelled as tokenistic, as it was a one-off experience. However, I found it to be extremely valuable and memorable. It was an opportunity to think from a completely different perspective. Training courses should ideally strive for comprehensive involvement. However, this is not always possible and in my opinion, some service user involvement is better than none at all.

**Different views regarding service user and carer involvement**

Various studies have highlighted that although service users and carers are discussed collectively, they have different views, experiences and knowledge (e.g. Diamond et al., 2003; Goodbody,
2003; Perkins & Goddard, in press). Tew et al. (2004) also recognise the differences between service users and carers and state that this should be considered at the beginning via joint planning sessions. Furthermore, Tew et al. stress that there should be a balance between service users and carers joint sessions and individual sessions with the focus on asking service users and carers what they want.

**Practical problems**

Soffe (2004) stresses that clinical psychologists today are driven by clinical work and research activities, which leaves little time for service user involvement. Therefore, if Surrey is going to succeed in effective service user involvement, sufficient resources need to be made available, including money, room space, time, administration, accessibility to library, office space, etc. Harding (2004) also describes several other ideas, which may be helpful when involving service users, such as: increasing the number of staff, support and transport for service users in meetings, and training to both service users and professionals.

Another practical problem could be the issue of confidentiality. If service users were involved in training on placement, there should be a policy in place which includes issues of patient anonymity and confidentiality. Training could also be provided to discuss the implications of confidentiality and anonymity with service users. It may prove useful to carry out a joint teaching session with trainees and service users to discuss the issues and implications and confidentiality and patient anonymity from both professional and service user perspectives.

There are also practical issues related with involving service users in research. With regards to involving children in research, Kirby (2004) recognises that the child's safety and well-being must be considered at all times and issues of consent must be addressed. Likewise when involving people with learning disabilities and older adults in research, it is important to consider gaining informed consent, clarifying confidentiality and other ethical issues. It may also be helpful for service users and carers to undergo some basic training in basic research methods and ethics.
Payment of involvement is a practical issue, which must be considered when involving service users and carers. Tew et al. (2004) state that service users and carers should be paid appropriately for their involvement, whilst recognising the problems with payments, such as loss of benefit entitlements.

A final practical problem is if the service users become unwell to be involved. Owen & Reay (2004) describe that if a service user tutor becomes too unwell, they have a reserve list of service users who act as stand by tutors. The authors state that service users teach in pairs, so that if one becomes unwell, the other would be familiar with the students and lesson plans.

**Why do it?**

Despite these challenges there are many benefits to involving service users and carers. During a previous job, I attended lunchtime seminars and journal clubs, which were also attended by service users. For me, having service users at these events was worthwhile as it made the topics more transparent. Speakers were encouraged to be clear and use jargon free language. I think having the opportunity to mix with service users in a setting other than assessment or therapy is useful in gaining an understanding from another perspective. Various studies have reported the advantages of involving service users and carers. Tew et al. (2004) describe the benefits for teaching staff, students and service users and carers. In addition, Walters et al. (2004) highlight the possible therapeutic effects which involvement can have on service users and carers, including having time to talk and being respectfully heard, increased self esteem, validation, empowerment, and the development of a coherent “illness narrative.” Finally, there are also advantages of involving service users and carers in research activities. Kirby (2004) highlights the benefits of involving children such as: ensuring questionnaires and interview schedules are worded in a language that is clear to their peers; young people may help participants feel at ease and it may help young people become more aware of issues affecting their peers.

**Conclusion**

This essay has shown that service user and carer involvement is an ambiguous term and that clinical psychology is lagging behind other professions in terms of service user involvement. In
addition, different Clinical Psychology Programmes across the UK have different ideas and approaches to service user involvement.

I have shown that other individuals’ and organisations’ experiences of service user involvement can be used to help guide the process at Surrey. For example, Hayward’s use of CAPITAL, an organisation which specialises in preparing and training service users for public speaking or using groups of service users and carers to be involved with programme management as opposed to individuals. In addition, a change in values and attitudes of professionals needs to be achieved, so that service users will be empowered and confident. One such way could be through having meetings in the bases of service users as opposed to university-based meetings.

Transparency is important when initiating service user and carer involvement. For example, it would be helpful to trainees, users and the course team, if the roles of the service users and carers were clearly defined. In my opinion, having a policy and contract with defined roles and responsibilities will help reduce fears about confidentiality, boundaries and other practical issues.

I also think it would be useful to consider involving service users in some aspects before they are involved in other aspects of the Training Programme. For example, it may be helpful for service users and carers to be familiar with teaching and planning of training before evaluating trainees on placement. Furthermore, this essay has shown the need to graduate service user and carer involvement, so that ‘Partnership’ level is reached carefully.

As well as policy changes and transparency, another important aspect in involving service users in the Training Programme is relationships. Coleman & Harding (2004) point out that partnerships occur due to relationships and not policy or procedure. The paper emphasises that person centredness, trust, dignity and respect are all essential when aiming for ‘Partnership.’

This essay has highlighted that planning, preparation, support, resources and relationships are needed if service user and carer involvement is to be effective. There are both benefits and difficulties with involving service users and carers in clinical psychology training. I believe that
the benefits outweigh the problems. My own experiences of service user involvement, such as being interviewed by a service user in a previous job have been extremely valuable. In my view, the prospect of involving service users and carers in clinical psychology training is an exciting idea. As trainees, we need to learn about psychological theory, assessment and intervention techniques but we would also benefit from the inclusion of service users and carers, in sharing and learning from their input.

The next steps at Surrey could be to obtain funding to achieve effective service user involvement and to further develop relationships between the course team and service users and carers.

Future considerations could be diversity and involving service users and carers from different ethnic minority backgrounds, educational and socio-economic backgrounds. As service user involvement grows, perhaps the course will endeavour to involve children, families, people with learning disabilities and older people. It will also be important to evaluate service user and carer involvement in training.
References


Supervision is seen as an important part of a psychologist’s personal and professional development, yet mental health professions are somewhat ambivalent. Critically discuss your own supervision experiences against two theoretical supervision frameworks of your choice, focusing on supervision and learning, and ethical issues including working with difference.
Supervision is an integral part of a clinical psychologist's personal and professional development. With the emergence of clinical governance and accountability, supervision serves to protect the client and the professional through promoting ethical and competent practice. In addition, the Division of Clinical Psychology’s (DCP) Professional Practice Guidelines advocate clinical psychologists to have supervision regardless of their experience and training. Despite these guidelines, there appears to be a lack of research into supervision and clinical psychology, Milne and James (2002).

In an attempt to rectify the lack of guidance on supervision in clinical psychology, the DCP produced some supervision guidelines (DCP, 2003). These guidelines highlight that supervision is a core part of all clinical psychologists’ work and requires its own training. However, these supervision guidelines do not provide much information about how supervision should be carried out – rather they indicate that there is not one approach which suits all.

From my own experience of working as an assistant psychologist, research assistant and trainee clinical psychologist I have observed how supervisors’ styles differ enormously. On reflection, their approach depended on many factors, such as the tasks of the job, the supervisor’s personality and experience and the organisational context.

I have chosen to do this essay as I wanted to gain a better understanding of the processes and issues involved in supervision. I hope that by critically discussing previous supervision experiences I will be able to gain the most out of my own future supervision. I also think it will help me for when I become a supervisor myself.

This essay will firstly define supervision. It will then discuss the title’s comment about mental health professions being 'somewhat ambivalent' about supervision. The main theoretical supervision frameworks will be briefly described. The essay will then critically discuss three different supervisors approaches against two chosen frameworks. I will focus upon the supervision, learning and ethical issues. Finally, the main points and limitations of the frameworks will be summarised and future work will be recommended.
What is supervision?

There is no single definition of supervision. The meaning of supervision varies between professions. Fleming and Steen (2004) highlight that the British Association of Counselling and Psychotherapy (BACP) refer to supervision as protecting the best interests of the client. Similarly, Campbell (2000) states that the main aim of supervision is to ensure the quality of client care while the trainee is learning. Whilst recognising the importance of supervision the DCP supervision guidelines do not attempt to define it. Instead they indicate that there are two stages of supervision. The first stage is identifying learning needs. The second stage involves facilitating learning through finding out the learning preferences of trainees, based on Kolb’s (1984) learning styles. The guidelines do not however, provide a prescriptive format of how supervision should be.

As well as finding out the learning preferences of trainees, a number of authors indicate that supervision frameworks are a useful way to guide practice (Scaif, 2001; Flemming and Steen, 2004). Despite these guidelines, from my own experience some supervisors have been somewhat ambivalent about supervision.

Ambivalence towards supervision?

As stated above, my own experiences of supervision have been variable. This connects with the lack of literature on clinical psychology and supervision in the UK. Other mental health professions seem more advanced in terms of thinking about supervision. Fleming and Steen (2004) highlight that most supervision literature has focussed on counselling, social work and psychotherapy. They state that other professions such as counsellors have mandatory requirements concerning all aspects of supervision. In contrast there is no statutory requirement for clinical psychologists to receive supervision once qualified. Perhaps this explains why there are different attitudes towards supervision in clinical practice?

In my opinion, supervisors’ ambivalence is also partially indicative of the contexts, which they work in. Hawkins & Shohet (2001) present the ‘double matrix’ model of supervision, which considers the context in which the supervision happens. They describe several ‘cultural dynamics’ which can lead to problems in supervision including: the ‘strive or bureaucratic
efficiency' culture which is high on task orientation and low on personal relatedness. The authors explain how this particular culture can lead to supervision, which is mainly concerned with checking tasks have been done correctly and less time spent on understanding. This suggests that ambivalence in supervision could also be partially accounted for by certain cultural dynamics of the organisation in which supervision is taking place. Hawkins & Shohet (2001) describe how supervision flourishes best in a 'learning developmental culture', whereby supervision is valued for people in training as well as those who are qualified. Otherwise supervision could be seen as only for those who are inexperienced and most needy. This 'learning developmental culture' also relies on the trainee being motivated and valuing supervision. A good starting point of thinking about it is to consider the various supervision frameworks.

Supervision Frameworks

The terms 'framework' and 'model' are used interchangeably in the literature on supervision. I will also use both terms in this essay whilst recognising they represent the same thing. There are many frameworks of supervision. Scaif (2001) states that frameworks can help with the development of a supervisory alliance and they can help meet the needs of the trainees, supervisors and institution of higher education. A useful way to conceptualise the different frameworks is described by Beinart (2004). She states that models can be divided into two broad categories: 'those based on psychotherapy theories and those developed specifically for supervision.' Using Beinart's description, I have created a diagram to illustrate how the different models can be categorised (Figure 1). I will now briefly describe several of the main supervision frameworks.

Psychotherapy-based models

Campbell (2000) states that psychotherapy-based models use the assumptions, methods and techniques of a particular theory to train the supervisee. Matthews and Treacher (2004) describe three therapy-based models: cognitive behavioural, psychodynamic, systemic and integrative model. Beinart (2004) indicates that there are limitations with the psychotherapy-based models as supervision is essentially a different process to supervision.
Developmental models

There are a number of different types of developmental models. Within this approach, the supervisee is seen to grow as a result of the supervisory process. One well known model is the Integrated Developmental Model (IDM) (Stoltenberg and Delworth, 1987; Stoltenberg et al., 1998). These approaches are seen to be particularly useful in understanding the supervision of trainees.

Social role models

Social role models focus on the tasks and roles in supervision. For example, in Hawkins and Shohet’s (2000) double matrix model describes seven processes, which the supervisor should pay attention to. The processes relate to the relationships between the client, the supervisee and supervisor. The model suggests that the supervisor needs to pay attention to seven modes of supervision.

Systems approach to supervision

The Systems Approach to Supervision (SAS) by Holloway (1995) evolved from the social role models. The model consists of six factors, which are all connected to the body of supervision, (the supervisory relationship). Holloway (1995) describes how the six factors are the tasks and functions (which are represented in the foreground of the interaction) and the more covert influences of supervisor, trainee, client and institution are in the background.
My choice of supervision frameworks

My first choice is the Integrated Developmental Model (IDM), Stoltenberg and Delworth, (1987), Stoltenberg et al., (1998). The IDM describes the role of the supervisor during each developmental level and the competencies needed by both. The model proposes that there are three overriding structures to monitor trainee development over the four developmental levels. The three structures are self and other-awareness (cognitive and affective), motivation and autonomy. Within each developmental stage a number of domains have been identified: intervention skill competence, assessment techniques, interpersonal assessment, ethics, client conceptualisation, individual differences, theoretical orientation, treatment goals and plans and professional ethics. The model stipulates that the trainee may be at different developmental leaves for each different domain.

The main reason for choosing this model is because I think it fits well with me at this current stage in training. That is, I feel that I have developed as a trainee in certain ways and hence it will be useful to understand how my experiences of supervision have facilitated this development.

The second model that I will discuss is the ‘double matrix’ model, Hawkins & Shohet (2000). As
described above this model focuses on seven processes of supervision. It pays attention to the process matrix and the therapy matrix as it is reflected in the supervision matrix. I have decided to focus on this model, as I am now considering process issues more during supervision. This model also appeals as it considers the organisational culture, which I believe can partially contribute to the ambivalence of supervisors. I hope that by choosing two models I will highlight the different strengths and weaknesses of my supervision experiences.

**Three different supervisors**

I have decided to focus upon three different supervisors whom I have worked with since beginning training. The supervisors will be known as Supervisor A, Supervisor B and Supervisor C. In my view, it is better to discuss in depth these three supervisors’ approaches rather than talking about many different supervisors. Anonymity and confidentiality will be maintained throughout this essay, as no identifying information will be given. The following section will present a critical discussion of the three supervisors against my two chosen frameworks.

**Integrated Developmental Model (IDM)**

**Stage 1**

Stoltenberg and Delworth, (1987), Stoltenberg et al., (1998) state that in stage 1 (‘self-centred’) trainees are viewed as dependent, highly anxious and focussing on discreet aspects of a client’s history or current situation rather than having an overview. The authors recommend that supervisors offer a lot of structure and support for trainees in the first developmental stage.

In accordance to this, Supervisor A provided me with a great deal of structure during the initial months of my first placement. For example, she gave me handouts to use during assessments and treatments and also provided me with relevant literature on presenting problems as they came up. I recall Supervisor A giving me lots of positive feedback and encouragement. This helped in reducing my anxiety levels around being evaluated. My confidence in using cognitive behavioural therapy gradually increased as my supervisor suggested that I begin by using thought records with clients, then moving onto think about underlying assumptions and finally considering core beliefs. Furthermore her approach to the supervision sessions themselves was
also highly structured. At the time I found this very helpful in containing my anxieties. Even though she did not explicitly discuss using this framework I think that she was following it to some extent.

In contrast with Supervisor A, Supervisor B did not change her approach throughout the whole of my placement with her. From the onset, she tended to adopt an unstructured approach. I recall finding this quite anxiety-provoking, particularly at the beginning as I was unsure what to talk about. She also tended to be rather vague and non-specific and I found this difficult in terms of making theory-practice links. She did not seem to consider that I had not yet developed certain specific therapeutic skills. In addition, she took a more collegial approach from the onset rather than a didactic/teacher role. Even though this made me feel comfortable I do not think it was the best way to teach me the various core competencies. Therefore I do not think that she followed Stoltenberg and Delworth (1987)'s recommendations about adapting her approach to suit my developmental level.

Stoltenberg and Delworth (1987) highlight the importance of considering different learning styles of trainees. That is, supervisors should be more structured with those trainees who have a lower conceptual level. The authors suggest that some trainees learn better vicariously while others learn better by doing. I did not have a conversation about my learning style with any of the three supervisors.

In order to facilitate learning, Stoltenberg and Delworth (1987) state that the supervisor should provide trainees with opportunities for observing supervisors conducting therapy and role-plays. Whilst I was in the early stage of training Supervisors A and C allowed me to observe them on many occasions doing assessments and therapy sessions. Supervisor A suggested that we carry out role-plays when I was unsure about how to progress with a client. For example, I recall being uncertain about what to say to a client who was felt that he was “inadequate”. I carried out a role-play whereby my supervisor pretended to be the client and I was the therapist and then we swapped roles. This was a valuable experience in terms of teaching me about socratic questioning.
Stage 2

Stoltenberg and Delworth, (1987) and Stoltenberg et al., (1998) indicate that at stage 2 (‘client centred’) trainees are characterised as experiencing conflict between their dependency and autonomy. They fluctuate between being overconfident and being overwhelmed and the focus of the work is likely to move from themselves to their clients. The supervisor needs to provide containment and be less structured.

As the placement progressed with Supervisor A, I grew more confident. I recall Supervisor A becoming less structured and more sharing. For example, she would tell me about difficulties she was having with clients.

During the pre-placement visit, Supervisor C asked me about my previous experiences in terms of supervision and clinical work. She also asked me about my expectations of supervision. We discussed my strengths and learning needs and what I hoped to gain from the placement. During this meeting we established that I was feeling confident about carrying out assessments, CBT techniques and formulations. With respect to these particular domains, I think that Supervisor C adapted her supervisory approach to meet my developmental needs as she used a more unstructured approach.

Stage 3

Stage 3 (‘process-centred’) trainees become much more self confident, stable and aware of process issues. Stoltenberg and Delworth, (1987), Stoltenberg et al., (1998) describe how the supervisor should be more sharing and collegial and able to confront appropriately.

In relation to the eight domains identified by Stoltenberg and Delworth (1987), I became more confident in terms of assessment techniques, interpersonal assessment, client conceptualisation and treatment goals and plans. For example, Supervisor C encouraged me to carry out assessments without my structured format of questions. In addition, I became much more aware of process issues, such as the therapeutic relationship. In addition, Supervisor’s C approach was
more collegial. For example, I tended to lead the supervision sessions and my supervisor would share information about what was happening in her work.

**Stage 4**

Stoltenberg and Delworth, (1987), Stoltenberg et al., (1998) state that stage 4 is the 'master-professional' stage whereby the trainee becomes more autonomous, insightful and secure and has a stable motivation. The supervisory relationship should become more collegial. I have not yet reached this stage, as I still feel somewhat reliant on the supervisor for direction in all domains – particularly in terms of process issues.

**IDM and ethical issues**

Stoltenberg and Delworth (1987) indicate that early training concerning professional guidelines on ethical issues around therapy is very important. *Supervisors A, B and C* directed me to relevant policies, e.g. BPS (2001), DCP (1995b). *Supervisor A* specifically taught me the importance of careful note keeping whilst preserving confidentiality where necessary. As my confidence grew, more time was spent discussing ethical issues with *Supervisor A* in a slightly less structured way. For example, one client told me that he had stopped taking his anti-psychotic medication. I discussed this with *Supervisor A* and we explored my own beliefs about medication, the issues involved with not taking medication, the need to explain to him about the risks involved and the effect that this disclosure had on the therapeutic relationship. I found these discussions valuable in terms of clarifying my thoughts around the ethical dilemma.

*Supervisor C* also discussed ethical issues during supervision as they came up with clients. For example we discussed the issue of consent to treatment, which arose whilst working with a 16-year-old girl. She wanted to work on one issue whilst her mother wanted her to work on something else.
The Double Matrix model

Mode 1: The content of the supervision session

Hawkins & Shohet (2000) state that this mode is concerned with the actual phenomena of supervision sessions. Even though I discussed my clients with Supervisor A, little time was spent on assessment. Looking back, there was a sense to move quickly onto formulation and intervention with Supervisors A and B rather than fully making sense of what was happening with the clients. Matthews and Treacher (2004) highlight that clinical psychologists too often focus on formulating and intervening rather than reflecting upon the relationships clients have with those around them.

In contrast, Supervisor C encouraged me to adopt a curious stance towards my clients. She explained that sometimes trainees might want to rush through the assessment towards formulation and intervention as they are keen to help the client and this might about meeting their own needs of wanting to help the client. This discussion has helped me to learn about the importance of self-restraint and not jumping into the formulation too quickly.

With regards to working with difference, Hawkins & Shohet (2000) state that the supervisor can focus on the culture specific behaviours during the sessions. I did not discuss these during supervision with Supervisors A, B or C.

Mode 2: Focusing on strategies and interventions

Hawkins & Shohet (2000) emphasise that the main goal of this mode is to increase the therapist’s choices and skill in interventions. This was not something, which was done by Supervisor A as she typically adopted a cognitive behavioural approach. Similarly, Supervisor B did not explore different techniques, which I could use with clients. She tended to let me use what I thought was best. I found this quite difficult especially during the early stages as I was unsure what to do.

In contrast Supervisor C provided me with new reading material on different theoretical orientations and we discussed clients from differing approaches. For example, I worked with a
client with a diagnosis of 'obsessional compulsive disorder.' As well as using cognitive behavioural techniques, Supervisor C taught me the value of narrative therapy, such as externalising the problem.

Mode 3: Focussing on the therapy process

Hawkins & Shohet (2000) state that in this mode, the supervisor focuses on the interaction between the therapist and client and what is happening consciously and unconsciously. This was not something which I tended to focus upon with Supervisor A.

I occasionally discussed the interactions between the therapist and client with Supervisor B. For example, I reflected on how one particular client was of a similar age to myself and how I thought she was similar to one of my friends. We discussed the implications of this and the need to consider maintaining boundaries.

I often discussed the interactions between the client and myself with Supervisor C. For example, we explored about how a client might have been trying to please me and how I therefore needed to praise her when she told me something, which was not going well for her.

Mode 4: Focus on the therapist’s process

Hawkins & Shohet (2000) state this mode is concerned with the internal processes of the trainee and how these affect therapy. In addition, the authors state that the supervisor should explore the way the trainee views the client through their own belief-and-value system, including prejudice, racism, sexism and other assumptions.

Supervisors A and B rarely asked how clients made me feel inside. I occasionally discussed how my own beliefs-and-value system impacted on clients with Supervisor A. For example, I discussed how my age and educational background were very different to my client who was a 60-year-old woman who had worked in a factory from the age of 15. We discussed how these
issues of difference might affect the therapeutic relationship.

Supervisor C was keen to explore how clients made me feel. I recall one situation where we discussed how a client made me feel anxious, as I felt he was sarcastic towards me. We suggested one hypothesis for his behaviour was that he did not want to be in the session and he may have felt threatened by the shift in attention from his son to himself.

In addition, I discussed with Supervisor C how my own family patterns and background have impacted on working with the clients. For example, I worked with a family who had a child with a disability. The father of the family was very much of the opinion that his wife should stay at home looking after the child whilst he socialised with his friends. I explored with Supervisor C how this family’s patterns and values were different to my own values and how I had to be careful not to impose my values onto the client.

Mode 5: Focussing on the supervisory relationship

Hawkins & Shohet (2000) suggest that the supervisor should focus more on herself rather than the client or trainee. They suggest that the supervisor should consider the similarities between supervision and therapy. Supervisors A, B and C did not explicitly state that they were considering the dynamics of our supervisory sessions. However, there were similarities between the therapy and supervision as Supervisor A adopted a cognitive behavioural approach and she encouraged a similar process during supervision (e.g. we set a supervision agenda, we worked collaboratively and we were open and direct). I do recall one conversation with Supervisor A about how supervision sessions were becoming quicker and there were fewer discussions about clients. She said that she thought this was a good thing as it demonstrated that I was learning what to do quicker. However, on reflection I wonder whether it was such a good thing, as I now believe that the process of therapy is much more complex than I first realised and that not discussing clients in detail can be unhelpful.
Mode 6: Focus on the supervisors’ own process

This is not something which I have discussed with any of the three supervisors.

Mode 7: Focusing on the wider context

Hawkins & Shohet (2000) indicate that this mode is concerned with focusing on the context in which both the therapy work and the supervision are taking place. They highlight that for trainees in particular the dynamics will be influenced not just by the case presented but also by the assessment context. I mainly discussed client work with Supervisor A rather than the organisational context. I observed that other professionals (e.g. nurses, occupational therapists) had less supervision than myself. I wonder whether supervision was seen as more important for psychologists in training.

Supervisor B discussed the organisation in which we were working. For example, at the beginning of placement she explained to me how the organisation was having certain difficulties and she described that the staff team may therefore be stressed. Hawkins and Shohet (2000) describe various cultural dynamics. One such dynamic is ‘driven by crisis’ whereby there is never time to reflect on the work – the focus is always on the intensity of the moment. Supervision is rarely a high priority in this culture. I think that this was the case for Supervisor B as supervision was not a priority particularly in the early stages of the placement.

Supervisor C often discussed organisational factors. I learnt how the organisation related with other agencies. I think that the organisation was a ‘learning and developmental culture’ as there was an emphasis on supervision for all professionals irrespective of their profession. In addition, there were many resources available and training was encouraged.

Summary of the critical discussion of my supervision experiences

The IDM and ‘double matrix’ model have shown the strengths and weaknesses of my different supervision experiences. The developmental model highlighted that Supervisors A and C were
able to adapt their approaches to suit my developmental needs. However, Supervisor B did not appear to change her approach throughout the placement.

The developmental model also showed that Supervisor A focused more on content and the teaching of techniques rather than focussing on the process of therapy. Supervisor C on the other hand managed to focus on both the content and process depending on the situation.

Hawkins & Shohet (2000) state that the ‘double matrix’ model can be linked to the developmental model. That is, in most situations the supervisor should be aware of the developmental stage of the trainee and focus on modes 1 and 2 before 3, 4, 5, 6 and 7. I think this is apparent through my discussion of the three supervisors. That is, the ‘double matrix’ model demonstrates that Supervisor A was more focussed on modes 1 and 2 and less so on the process orientated modes (3, 4, 5, and 6). Supervisor B also tended not to focus on the process focussed modes. In contrast Supervisor C taught me to think more about the process of sessions – however this was only when I was more competent in certain domains.

Finally, the ‘double matrix’ model is better at considering the organisational culture and cultural factors in supervision in comparison with the IDM. Even though there are obvious benefits of using the models to help clarify the content and processes involved in supervision, there are several limitations of both models.

**Limitations of the developmental model**

It is important to recognise that there are limitations of the developmental model. Carroll (1987) questions whether the model can be applied to the UK as it was developed in the USA. However, I found that the developmental level made sense to me and I applied it readily to my own supervision experiences.

Holloway (1987) states that the empirical evidence for the developmental model is ‘disappointing.’ She argues that the lack of development-specific methodology, the sole focus on
supervisory experience and the reliance on measures are not enough to support the distinct sequential stages of growth. Furthermore, Fleming & Steen (2004) state that there is little research evidence for the developmental models. Instead, they argue that the trainee develops in a supervisory relationship, which provides a learning context.

Holloway (1987) also criticises the developmental model by questioning how supervision can be responsible for a trainee's development when training is only one aspect of a trainee's life. In defence, Stoltenberg and Delworth (1988) state that training is a novel and anxiety provoking process for most trainees and hence at the beginning of training trainees conceptualise at a lower level than more experienced trainees. Personally, even though supervision is only one aspect of my life it has had a powerful effect on my own self-awareness and professional development.

Despite these limitations I think that the developmental model makes intuitive sense and is useful in matching the supervisor to the trainee.

Limitations of the 'double matrix' model

The main limitation of the 'double matrix' model is that it does not consider the developmental level of the trainee. However, as stated earlier the 'double matrix' model can be linked to the developmental model.

Likewise, this model does not consider the context of the trainee. Instead it focuses on the processes involved in therapy and supervision. Holloway's (1995) SAS model is advantageous in some ways as it considers the context of the trainee and context of the institution.

A second drawback of using the double matrix model was that it was not possible for me to comment on certain modes (e.g. mode 6), as my supervisors did not discuss these. Therefore I wonder how transparent a supervisor can be with their trainee when using such an approach.
Conclusion

In summary this essay has shown the value of considering different supervision frameworks. I agree with Scaif’s (2000) argument that it is does not matter which framework is used as long as one is familiar with the models in order to help reflection. Ideally it is helpful to be aware of the different frameworks and take something from each one.

This essay confirms that ‘supervision’ can have various meanings to different supervisors. The lack of an agreed definition of ‘supervision’ is confusing. However, I also think this variation in meanings is positive as well. That is, each supervisor has taught me something different. In the future it will be good for supervisors to know about the different models. However I do not think that they should have to adopt a particular framework. Instead supervisors should be aware of the different frameworks and in turn they can develop their own idiosyncratic style.

This essay has also shown that the approach to ethical issues and professional practice guidelines varied between supervisors. Having said that the three supervisors directed me towards to relevant policy documents and were willing to discuss ethical issues when they arose (e.g. consent issues, diversity, power issues, note keeping and confidentiality). The factor, which tended to vary, was the amount of time that was spent discussing ethical issues and implications.

This essay has shown me the importance of the first meeting and agreeing upon the contract. I think it is helpful to explore models of supervision, strengths, learning needs and expectations. In addition, I recognise the benefits of working in a ‘learning developmental culture’ which values supervision. Having said that I think it is good to be realistic and realise that not all organisations within the NHS have a ‘learning developmental culture.’ However, maybe clinical psychologists can help aid the development of such a culture?

Finally whist it is important for supervisors to know about the supervision models, it is equally important for the trainee to understand the models and value supervision. Therefore, perhaps as Holloway’s (1995) model suggests the supervisory relationship is the most important element in supervision as the supervision is dependent on the reciprocal relationship between the supervisor
and trainee? After completing this essay, I now feel that I am in a better position to make the best use of my own supervision and I am sure that this knowledge will help me when I become a supervisor myself.
References


Problem Based Learning Reflective Accounts

Problem Based Learning Reflective Account 1

Problem Based Learning Reflective Account 2

Problem Based Learning Reflective Account 3
Problem Based Learning Reflective Account 1

March 2005

Year 1
I will firstly describe how our Case Discussion Group (CDG) approached the Problem Based Learning (PBL) exercise and presentation. I will then reflect on the strengths and limitations of our approach whilst considering how I would have approached the task differently after gaining clinical experience on placement.

**Our Approach to the PBL Exercise**

To begin with, our approach to the PBL exercise consisted of exploring different psychological models of 'change.' We considered how these models could be applied to both our clients and ourselves. For example, we reflected on how as assistant psychologists we had changed professionally and personally after learning from our supervisors. We related this to Social Learning Theory, whereby our supervisors were our role models. A theme of our discussions was how we have changed from undergraduates to postgraduates. In particular how our learning style had changed from a passive style (listening to lecturers) to a more active approach (including PBL).

As a group, we collectively decided to focus on the transtheoretical Stages of Change Model (Prochaska & DiClemente, 1992). There was a consensus that this model was a clear way to explain changes in individuals. We discussed how the model was useful as it integrated different psychological models such as Behavioural Learning Theory, Social Learning Theory, Theory of Attitude Change and Systemic Theories. We were attracted to the model as it allowed for people not to be ready to change and to have set backs.

One CDG member described how the Stages of Change Model could be applied to her own changes in learning style from degree level to becoming a trainee clinical psychologist. She explained that 'Precontemplation' for her was sitting back and not contributing (passive learning style). Whereas ‘Action’ involved taking part in group discussions, developing own understandings and working out learning needs (a more active learning style). The other CDG members and I immediately identified with her example. Hence we chose to include this in our presentation. Therefore, we applied the Stages of Change Model to both ourselves and one of our clients. The client chosen was a lady with back pain whom one CDG member had worked with. Our presentation also discussed the major processes of change, which are highlighted in the
transtheoretical model, (e.g. helping relationships). Finally we provided a critique of the model.

**Strengths of our Approach**

I believe a major strength of our approach was that we considered both the advantages and limitations of the Stages of Change Model. Whilst we recognised that the model is useful in explaining where clients are in the cycle of change, we acknowledged that the model is flawed in terms of empirical evidence demonstrating that change occurs in discrete stages and the sequential processes.

A second strength of our approach was our support and cooperation with each other. In the group my role was minute-taker. During the first two PBL sessions I found it quite demanding to take minutes whilst thinking about contributing to the group. Other members of the group recognised this and asked me if I needed assistance. I felt extremely supported.

Another positive aspect of our presentation was our creativity and resourcefulness. For example, whilst we described each stage of change during the presentation we played one line from a popular song (on a tape recorder) to represent that stage.

**Limitations of our Approach**

A limitation related to our presentation was my anxiety about how the audience would react to our use of music. Whilst on my induction, I met a psychologist who worked for a Drug and Alcohol team. She emphasised the importance of feeling safe to take risks and that as a trainee I should feel able to take risks. I think taking risks can also relate to academic assignments and clinical work. Therefore, after being on placement I would like to think that I would feel more confident about using different media in the presentation. Looking back I think we could have pursued our more radical ideas and taken more risks. At the same time I acknowledge the need to be thoughtful and reflective. I believe it is about taking positive and safe risks and having confidence in one's own instincts.
I think a second limitation was that we did not think about why we used the music and discuss this in the presentation itself. I think my initial thoughts were that the music would help keep the audience interested and make people laugh. On reflection, I wonder whether our use of humour was a defence mechanism to act against our own anxieties of doing the presentation and appearing boring and not liked by others. Whilst on placement I listened to a tape recording of a session with a client. I noticed that I used humour quite a bit. This made me question the function of my humour - in this instance I think it helped with rapport building. Likewise I wonder whether using music in our presentation was to develop relationships with the audience. Although I would still use it, I think I would also reflect on why we used it.

A further limitation was our lack of conflict with each other during the PBL sessions. There were very few differences in opinions during our meetings. Looking back, I think I was trying to conform and be agreeable. I recall having similar thoughts whilst carrying out the PBL exercise and being on placement, such as: ‘Am I good enough?’; ‘I must say the right things’; ‘Do my clients like me?’ After being on placement, I can see how these feelings and thoughts I was experiencing could also relate to how clients feel when they embark on therapy. On reflection, I think I am becoming more aware of this thinking pattern in myself and my wish to change it. In addition, after being on placement and having academic lectures, I am aware that the role of the clinical psychologist involves both working in a team but also being able to bring different ideas to the multi-disciplinary team and even challenge other professionals. If I were to approach the PBL exercise again, I think I would make more of an effort to form my own opinions and state them even if they do not match other group members.

I think our lack consideration of process issues was also a weakness. We adopted a very task-focussed approach. A possible reason for this could have been that we were worried about not having anything to say and wasting time. For my part, I think I was keen to develop a structure and a sense of certainty. I recall when we were given the PBL exercise, we immediately began setting each other tasks, looking at the literature, setting goals and organising our time. Perhaps this need to organise time and set goals was because we were anxious about what would happen if we didn’t. I recall the task was initially uncertain and vague. This uncertainty bred anxiety. One possible reason why we adopted such an active approach to the task was that it helped us cope with our anxiety. I think it would have been interesting if we could have tried to understand
what was happening in the group and why we were behaving in such a way. It may have enabled us to think more about process issues and facilitate creative thinking. A possible way to incorporate reflection in the PBL meetings could have been to allocate one or two individual(s) who could be reflector(s). These reflectors could observe the session and make notes on process. Another way could be to designate the first and last 15 minutes of the session as reflection time (e.g. reflect on how you thought the last session went).

The way we approached the task could also relate to different therapeutic approaches. On placement, I have been mainly using Cognitive Behavioural Therapy (CBT) with clients. As with the PBL exercise, I have been predominately adopting a task orientated approach. I have been setting agendas, setting homework tasks, completing thought records and working in very structured manner. However, as I have now become more familiar with the CBT model I am aware that I am paying more attention to other issues, including process issues, the therapeutic relationship, transference and countertransference. My clinical work has taught me that structure and organisation of time are important - as well as how the therapist and client interact and relate to one another. For example, one of my clients missed two sessions with me. On his return to the sessions I found that it was important for me to listen to how depressed he felt. I felt it was inappropriate for me to launch into the CBT agenda setting. Being on placement has taught me that the therapeutic relationship is important, as is building trust and creating a safe place to encourage openness and honesty.

After working with clients I recognise some limitations of the Stages of Change Model. I am aware that it mainly focuses on how the client is changing. It neglects to consider how the therapist in the client-therapist interaction may also be changing themselves. That is, as well as my aim to help my clients change, I am aware that the interaction with my clients is changing me too. For example, my understanding of CBT has been consolidated through working with a gentleman with depression. Looking back my understandings of automatic thoughts, core beliefs, behavioural experiments are clearer after having put them into practice. I also think that certain clients change me emotionally and personally. After carrying out an initial assessment with a man who was experiencing severe agoraphobia, I reflected on my strong emotions of sadness during and after the session and thought about how depressed he must be feeling.
Change is Difficult

I also believe that the Stages of Change Model fails to account for the complexities and uncertainties of practice. For example, one client who I am working with has attended three appointments and missed four. There are occasions when he wishes to change and other times when he is not ready. It is difficult to apply the transtheoretical model to this client as he seems to alternate between 'Precontemplation' and 'Contemplation' stages. Furthermore I think the model does not consider how certain other factors influence change (such as the therapeutic relationship and the therapist's professional and personal experiences). Therefore, if I were to approach the PBL exercise again I would like to discuss how change is difficult in the reality of practice and how the therapeutic relationship and therapist’s own experiences can also influence change. Looking back, I remember how during our initial PBL session, our group acknowledged that 'change is difficult' – although we did not pursue this. After having worked on placement, I would like to explore this further.

In approaching the PBL exercise again I think it would be fascinating to talk about how we have each changed personally and professionally. We could explore how everyone has unique past experiences which enable different knowledge and skills to develop. Professional changes for myself include feeling more confident about my knowledge of CBT and conducting an initial assessment. I believe this confidence helps build a rapport and trust with my clients and as a consequence increases therapeutic change.

In summary, I think this account has shown me how the Stages of Change Model makes good common sense. However, my experience on placement has shown me that the model fails to consider the complexities of practice and how the therapeutic relationship is important. It also does not show how the therapist’s personal and professional experiences influence change. I think the main differences in how I would approach the PBL task would be to have more time for reflection in the sessions and presentation and to think about how we have each changed personally and professionally since being on placement – recognising our unique achievements and learning needs.
References
Problem Based Learning Reflective Account 2

March 2006

Year 2
I will firstly describe how our Case Discussion Group (CDG) approached the Problem Based Learning (PBL) task and presentation. I will then reflect on the strengths and limitations of our approach whilst considering how I would have approached the task differently after gaining clinical experience on my child placement.

**Our Approach to the PBL Exercise**

The PBL task involved considering a scenario about three year old twins who were placed in foster care following a child protection conference. Their parents were Mrs Stride who had a diagnosis of learning disabilities and Mr Stride who attended a school for children with special educational needs. The twins were on the child protection register under categories of emotional abuse and neglect. Background information about the Stride family included: they lived in deep poverty; the parents could not read or write and Mr Stride physically assaulted Mrs Stride during disagreements – although they were passionate to keep their children. The scenario raised questions about child protection, domestic violence and the ability to parent if you have a diagnosis of a learning disability. Specifically the scenario posed the question: “Whose problem is it?”

In our first session, our group decided to change our way of working from a task orientated to a more creative and reflective approach. The rationale for this change was that in the previous PBL task we had been particularly task orientated and focussed on preparing the presentation, rather than paying attention to process issues. We also felt in the previous PBL exercise that our approach was somewhat unoriginal, perhaps reflecting a concern with taking risks.

With this in mind we spent the first few PBL sessions discussing the issues and deliberately delayed planning the presentation. Initially we brainstormed ideas and then identified common themes including: power; social construction of learning disabilities; the use of narrative; societal attitudes towards people with learning disabilities and no one person having an overall picture.

As a group we had difficulty coming up with an idea for our presentation which we were all happy with. A sticking point was whether we should focus on a practical approach involving a...
risk assessment or whether we should take a broader view and consider how this is society's problem, in the sense that the parents have been labelled by society as having learning disabilities. We decided to focus on the latter approach. In response to the posed question: we decided that it was *Joe Bloggs's problem – the ordinary man in the street.*

Our presentation consisted of an introduction explaining why we did what we did. We then performed two role-plays showing two different interviews of Joe Bloggs being interviewed by a newspaper reporter. In each interview the reporter described some background information about the Stride family to Joe Bloggs whilst using different 'stories' for each interview. The first background story was more problem-saturated and was based on the scenario that the children were removed from Mr and Mrs Stride: emphasising the risk to the children. The second interview was based on the scenario that the children stayed with the Strides, highlighting the resilience of the family and how they had coped despite adversity. The aim was to show how Joe Bloggs's reaction changed depending on the way the background information was presented. That is, how language can affect what we think and say.

After the two interviews, we discussed the main themes arising from the interviews including myths about parents with learning disabilities and process issues. An example process issue was how we were initially confused about which professionals were doing what and defining our role. We discussed how this confusion might be reflective of how professionals might feel when they work on similar cases. The conclusion of our presentation was that we were attempting to show the dilemmas of balancing our aspirations of considering society and being idealistic with being practical and delivering a service.

**Strengths of our approach**

A main strength of our approach was that there was less groupthink in our sessions. I think this is reflected in the increased confidence of our group as a whole and as individuals. I noticed that my own confidence in speaking up developed throughout the task, e.g. I expressed my wish to consider the role of society. We worked well together as a group. I personally became more aware of members' particular strengths. For example, two members had a particular expertise in critical psychology and another brought her knowledge of working with organisations.
Another advantage of our approach was that we took a risk to do something different rather than playing it safe. We considered the weaknesses from the previous PBL task and developed our approach. Occasionally we had doubts about our way of working. However, we challenged these doubts. I was pleased that we stayed with our ideas as our approach was unique in comparison with other groups and it felt as though we had an identity. This was also reflected in the feedback given at the end of our presentation: that our approach was innovative.

A further strength of our approach is that we talked about our own personal experiences and how these influence our own views and assumptions. For example, one member talked about her personal experience of working in stressful environments and the difficulties of trying to speak up in a team. I talked about having a relative with learning disabilities. I was aware of how this was affecting my contributions to the group – I felt very passionate about voicing my views on how people with learning disabilities are devalued in today’s society. Interestingly, I did not talk about this in front of our CDG facilitator – I think that this was because I did not know her very well at the time and I was concerned about what she might think of me. Perhaps, this is how clients might feel when they are deciding whether they can trust someone to disclose something or not?

Limitations and changes to our approach

Despite these strengths I would have approached the task differently now after my experience on my child placement. The main difference would have been to consider the family as well as thinking about society. This change has been influenced by various experiences on my child placement, such as a day visit to a children’s assessment social services team. I observed a duty social worker for the day. He explained that when he first sees a family he often carries out a “Framework for the Assessment of Need” (DoH, 2000), which provides a systematic way of understanding what is happening to a child within their families and the wider context of the community. The social worker explained that his department aims to always “try and keep the family together.” He said this is done by thorough assessments, including interviewing parents, relatives and teachers and agency checks with school and the GP. He said that it was a difficult job but he liked it very much – he liked the “rewards in terms of protecting children.” He then told me that the job was extremely challenging at times and described how a child had recently
died as they had “slipped through the net” as their family had moved areas.

This experience highlighted the importance of considering the effects of domestic violence on the children. I think this is something we neglected in our presentation. Vetere and Dallos (2003) highlight the need to carry out an assessment of risk and to assess whether the perpetrators of violence can take responsibility for their actions and the need to set a no-violence contract. In my view, these principles would be important in the case of Mr Stride’s violence towards Mrs Stride.

With the benefit of hindsight, I would like to take a more practical approach whilst also considering society’s influence. I would consider the family and in particular explicitly assess the risks to the children. My placement has also taught me the need to create a good rapport with families and appear non-threatening and non-judgemental. This is something we neglected to talk about in our presentation.

After working in children’s services I have seen the importance of asking difficult questions and staying in difficult situations rather than avoiding them. Perhaps in a way our approach to the problem was our way of dealing with the uncomfortable feelings? Another possible explanation for our reluctance to consider the family situation may have come from not wanting to blame, scrutinise and further pathologise the Stride family. However, I have discovered on my current placement that there are direct ways to work with families which are non-pathologising. For example, I have used narrative therapy (White and Epston, 1990) to work with a young child who had “OCD” and his family to create an alternative story whereby the child used his “power” to “boss back the OCD demon” and regain control of his life. This showed me that there are practical ways to work with families, which do not blame or threaten.

Since being on placement I have become more aware of this tension between following one’s ideals and working practically within a multi-disciplinary team. For example, I have had discussions with my placement supervisor about the issue of whether children would be labelled with ADHD. My initial thoughts were that ADHD is a social construct and therefore does not really exist. That is, instead of labelling children, contextual factors should be changed. However, after working in a child and adolescent mental health service (CAMHS) I understand
that a diagnosis can be helpful for some families in terms of making sense of what is happening. At the same time, I have observed that for other families a diagnosis of ADHD is unhelpful. For example, I recently contributed to a multi-agency assessment of a child who had complex health and family issues. I attended a professional network meeting at the school and it was decided that a label of ADHD would be unhelpful for this child as his inattention and restlessness could be explained by both family issues and by a deficit in his executive functioning. I became aware of how a label of ADHD may not actually change anything for this child: other professionals were working together to meet his individual set of needs regardless. My supervisor pointed out that having a label of ADHD might actually be detrimental to this child as it may further pathologise him and stick with him as he grows up. In working with this family, I have learnt about the importance of being a cautious practitioner when considering possible ADHD and the importance of treating each case individually.

Similar ideas about labelling can be applied to the Stride family. It is important to consider the meaning of the label ‘learning disabilities’ and what affect this may have had on the Strides. However, it is also important to treat the case individually and consider practical ways to help them. That is, rather than standing outside of the system and blaming society it would be better to work within the system. Therefore, I propose that my approach to the PBL task and presentation would contain elements of the scientist practitioner (e.g. to integrate scientific and professional knowledge), the reflective practitioner (e.g. self-awareness and personal knowledge) and the critical practitioner (e.g. consider the wider effects of the social and political context).

In summary, my new PBL task would emphasise the need to develop a good rapport with the Stride family, whilst being transparent and open. My aim would be to give the family an opportunity to make sense of what is happening. I would also highlight the necessity of doing a risk assessment, which specifically addresses the domestic violence. Finally I would talk about the need to remind or inform others of how political and historical factors have affected people with learning disabilities – although rather than blaming society or other professionals I would want to work alongside them to create safer and improved lives.
References


I will firstly give some background information to the Problem Based Learning (PBL) task and then describe how our group approached the task and presentation. I will then reflect on the strengths and limitations of our approach whilst considering how I would have approached the task differently after gaining clinical experience on my older adult placement.

The scenario was based on Mr Khan and his family. Figure 1. shows a genogram of his family. Mr. Khan’s daughter, Maya was concerned about her father. She noticed that his physical health was deteriorating and that he was forgetting things and neglecting himself. Hence, she contacted social services. In addition, to the information shown in the genogram we were informed that Mr and Mrs Khan were both religious and had links with the Muslim community. However, Mr Khan fell out with the mosque about the way they responded to his wife’s death.

**Figure 1.**

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**Our approach**

Our group began by thinking about what might be going on in the Khan family. We thought
about how we would wish to find out whether Mr Khan’s symptoms could be due to a complicated grief reaction, depression, dementia or normal ageing. We agreed that we would need to gather more information before we could decide upon a plan of action.

Our conversations then turned to how the family’s culture might be an influential factor. We noted that we are all White, British young females and Mr Khan is male, he is originally from Pakistan and he is ‘old.’ However, we then talked about how these factors might not have had an effect and that we might be making assumptions and that we did not really know what was going on in this family.

Subsequently, we thought about talking to a person who was a Muslim. For example, we thought that it would helpful to talk to a Pakistani community group to gain some ‘expert’ advice on what they thought about the scenario. The rationale for this was that we did not feel in a position to make assumptions on the case, as we did not know enough information. However, we then talked about this some more and again came back to the fact that being Muslim or from Pakistan was not only the issue here – some of the problems highlighted in this scenario also raised issues for ourselves.

**Approaches to race and culture**

A useful paper, which guided our discussions, was by Hasley & Patel (2003) who critiqued four positions, which are used by clinical psychology trainees when working with people from different cultural backgrounds:

**‘Apolitical’**

The clinician focuses on the *internal* worked of the individual with a lack of *external* validity. For example, it would mean that we fail to think about cultural and social factors in the Khan case.
‘Colour blind’

The clinician says that they treat everyone the same, irrespective of the patient’s background or ethnicity. This fails to realise that people may seek help because of racial discrimination difficulties.

‘Exotic’

A clinician taking an exotic position will view individuals from different backgrounds as ‘interesting, exciting and worthy of study.’

‘Missionary’

A clinician has the desire to ‘rescue’ someone, which may interfere with the clinical work.

Our group was clear that we wanted to avoid falling into the above positions. For example, we rejected our initial idea of talking to a Pakistani community group, as we thought that we were perhaps being curious and interested in something, which was ‘different,’ which could be seen as adopting an ‘exotic’ position. Hasley & Patel (2003) recommend that clinical psychologists need to be aware of their own assumptions and motivations for working with people from different backgrounds. Therefore we realised that it was important not to impose our own beliefs on the Khans.

A personal and reflective approach

We talked about the issues, which this scenario raised for ourselves, such as our parents ageing and our grandparents having dementia. We all identified with how the PBL scenario and our experiences on the older adult placement were making us think more about mortality of people close to us and of ourselves. Looking back, I found it very supportive to share experiences with my fellow group members.
‘Universality in diversity’

We decided to think about the scenario in terms of how it made us reflect on own personal experiences and the strong feelings it evoked in us. That is, we deliberately took a different approach and rather than drawing on theory, we drew mainly on our personal experiences and feelings. For the presentation we decided that we would make of a video of each of us interviewing someone from our own personal life about tensions and loyalties in their lives. We wanted to show how there were relative tensions and difficulties in everyone’s lives: ‘universality in diversity.’ Therefore we each chose someone from our own personal lives and we deliberately selected people from different backgrounds. That is, we made a video about the experiences of a woman in her fifties whose mother had a diagnosis of dementia, an elderly gentleman from Pakistan, and three young women from different cultural and social backgrounds.

We all contributed to making the video and we all shared our own personal experiences. I noticed that I adopted more of a role of questioner, which stems from my increased confidence. For example, I remember asking people whether we should have talked about the difference of being from Pakistan more.

Strengths

A positive point of our approach was that the process highlighted the importance of taking a personal approach with clients. This has affected how I work with clients. For example, I have recently been thinking about how to personalise individuals’ rooms on a ward in a hospital setting for older people who have mental health problems. In particular, working with my fellow PBL group members has made me more aware of the experience of listening to a person’s experience rather than making assumptions based on their social identities (e.g. ethnicity, age, gender, class and sexual orientation).

In addition, our approach of thinking about the ‘universality in diversity’ meant that we were thinking about avoiding the positions, which Hasley & Patel highlighted – instead we were thinking about our own beliefs and moving towards cultural competent practice.
We worked well as a group and I felt proud to be in my group. I realised the importance of cooperation and joint working rather than competition. This is similar to my experience of being on placement whereby it is important to work effectively in multi-disciplinary teams. Looking back over the past three years of clinical psychology training, my experience in MDTs has been variable. The PBL task highlighted the importance of listening to others' opinions and respecting all views (even if they differ from yours), compromising and equally contributing to process. I think these processes can be difficult in NHS practice, where time and resources are lacking – it is also important for decisions to be made. There is a need for a balance between listening to everyone's opinions and effective leadership and decision-making. During our PBL meetings, we had an allocated chairperson, which was helpful in managing decision making and hearing multiple perspectives.

Finally, an advantage of our approach was that it was original. After the presentation, one of the audience commented that we were 'brave' to do something so different. I recalled feeling anxious when the video was being shown to the audience – it felt risky. However, I realised afterwards the importance of being able to take risks and be creative. I hope I will be able to continue to do this when I am a clinical psychologist.

Weaknesses

During the presentations, another PBL group highlighted a paper by Karim (2004), which highlighted the lack of mental health resources in Pakistan. They spoke about how Pakistan has a population, which is double that of the UK but has far fewer psychologists and less money for the health care. Our group had considered 'universality in diversity.' However, on reflection I wondered whether my group had thought enough about 'difference within diversity' and how the Pakistani culture is different from our culture. As a trainee clinical psychologist I am in a privileged position as I am higher earning professional with more choice and autonomy than many other people. Hence, perhaps we neglected to raise the issue that we are privileged to be in this country in comparison with other people from around the world. That is, we only showed a video of British citizens and had not thought about people who were living in developing countries.
Another weakness could have been that we were not explicit enough in the message, which we wanted to put across. Prior to showing the video we discussed whether to give an introduction or whether just to put the video on. In the end, we decided to just put the video on, without any explanation – to make people think. After the video was shown, some members of the audience seemed confused by it and even shocked. Perhaps we could have been more explicit in our take home message. However, I think that the fact that we provoked thought is good. Thinking back over training, the lectures, which I found were the most memorable were those which provoked some emotion in myself.

One final criticism of our approach could be that we did not directly consider what we would do if we were referred this case in real life. After being on my older adult placement I realise that it would be necessary to gather more information, which might include an interview with Mr Khan, blood tests, neuropsychological assessments and self-rating scales for depression. During my placement, I worked with a man whom was referred for query dementia and I carried out a series of cognitive assessments to ascertain whether he was showing shows of cognitive impairment. The battery of assessments included: neuropsychological tests to assess cognitive impairments, (e.g. CAMCOG - the cognitive and self-contained part of the Cambridge Examination for Mental Disorders of the Elderly, WAIS III, WMS-III - Wechsler Memory Scale: Third Edition), physical health assessments (e.g. blood tests to rule out any physical causes of his symptoms) and with the client’s consent I also interviewed his wife. Having said that, I noticed that other PBL groups consisted more of this information and I was pleased that we did not go down that route, as it was helpful to have a range of presentations.

Summary

After working on my older adult placement, I realise that I would not have changed our approach to the PBL task. A main reason for not changing our approach is that, it was different from other PBL presentations and I think having different perspectives allows for a richer and more stimulating experience for the audience. This also fits with my belief that it is important to considering multiple perspectives when working within systems in clinical practice. For example, in a family situation or a multi-disciplinary team meeting, I have learnt that it is beneficial to hear everyone’s perspective as opposed to simply identifying one person’s view as
the 'right' view and discounting others' opinions. Another reason for not changing our approach is that it has been helpful to think about how to work with individuals from different cultural backgrounds. That is, rather than adopting one of the four positions which are critiqued by Hasley & Patel (2003), it is preferable to take a position which ensures that clinicians are aware of their own motivations and assumptions and how these impact on their practice. This exercise has also taught me about being able to manage the contradictions and complexity, such as being able to recognise that we all experience tensions in our lives (universality in diversity) but at the same time there is also difference in diversity.
References


Summaries of Process Accounts of Case Discussion Group

Process Account 1

Process Account 2
Summary of Process Account of Case Discussion Group 1

September 2005

Year 1
Summary of Case Discussion Process Account 1

Our approach

Initially, our approach to CDG was often unstructured and our individual roles were unclear. The sessions began with one person presenting a case. There was no real structure and it tended to be led by our tutor. For example, she suggested that we take it in turns to ask a question. This approach worked well at first. However, it soon became confused as we were doing other things in the group (e.g. talking about presenting papers). As a group we realised that we wanted more structure so that everyone got a chance to both present a case and discuss other cases.

My role

I contributed more to the group as time went by. I found it harder to give suggestions to those who presented cases and easier to present my own case. This difficulty stemmed from worrying about saying the wrong thing and my need to conform. However, overtime I became more confident to make suggestions. From the perspectives of other members, I was someone who was able to validate others' feelings and my confidence in presenting developed.

Limitations

The main limitation was that process issues were not discussed. In addition, the group could have been said to be too cohesive. This could be explained using Janis's (1972; 1982) concept of groupthink and how the group cohesion might have meant that alternative viewpoints were considered as much as could have done. I recall wanting to make a decision but worrying about coming across as autocratic.

Strengths

Strengths included ensuring that everyone felt empowered to express themselves, talking about cases from different theoretical orientations and creating a supportive environment. These strengths enabled me to become aware of forming my own opinions, speaking up more in CDG and work settings and being professional but human at the same time.
Summary of Process Account of Case Discussion Group 2

July 2006

Year 2
Summary of Case Discussion Process Account 2

Over the last year, our Case Discussion Group (CDG) discovered common interests, including narrative therapy (White & Epston, 1990), critical and reflective approaches to our practice. A key concept in narrative therapy is that stories are made up of rich detailed descriptions. With this in mind, I applied a narrative approach to this process account and told a Group Story about how our group formed an identity. To begin with our group identity was partly influenced by historical and contextual factors (e.g. PBL exercise and our first year CDG experience). Our group spent a long time having philosophical debates covering many areas of practice including whether certain diagnostic categories such as “ADHD” are social constructs and therefore truly exist. I found these ideas interesting but I also felt quite helpless after we had had these discussions. I sometimes came away from the group with a headache. At one point, it felt like the group was stuck, as there were no answers to these big questions. Smith and Berg (1987) state that stuckness is like a non-moving group are due to unexpressed contradictions. I realised that on the one hand I felt most comfortable when I know that I have considered systemic contextual factors in a formulation (e.g. political, historical factors). However, I also liked to take a pragmatic approach. That is, rather than always criticising the system I am keen to work within the system and help improve peoples’ lives. The main strength of our group was its supportive nature, e.g. we wrote down what we appreciated about each other on cards - as a way of celebrating strengths. In contrast, the main limitation was the lack of reflection on group processes. However, overall this group enabled me to expand my mind in terms of considering broader societal issues.
Clinical Dossier

Adult Mental Health Placement
Children and Young People
People with Learning Disabilities
Older People
Children with Learning Disabilities and Mental Health Problems

This section contains summaries of the five clinical placements of the course and short summaries of the four clinical case reports. The full details of the clinical placement experience, including contracts, logbooks and evaluation forms can be found in Volume II of the portfolio. This is held in the Psychology Department of the University of Surrey for reasons of confidentiality. To preserve anonymity and confidentiality, clients' names have been changed and all potentially identifying details have been omitted. Written and verbal informed consent was obtained from all of the clients to use them as case reports.
Adult Mental Health Placement
Adult Mental Health Placement Summary

Placement details

Dates: September 2004 – November 2005

Supervisor(s): Amanda Edireweera, Clinical Psychologist; Jean Eley, Clinical Psychologist; Michelle Sowden, Consultant Clinical Psychologist.

NHS Trusts: Surrey and Borders Partnership NHS Trust

Base(s): Willow House Day Treatment Centre, Aldershot.

Conifers Community Mental Health Team, Cove, Farnborough.

Pain Clinic, Frimley Park Hospital.

Summary of Clinical Experience

This placement provided me with the experience of working in a Day Treatment Centre and in a Community Mental Health Team for adults with mental health problems. The placement also enabled me to have the opportunity to work in a Specialist Pain Clinic in a hospital setting.

I worked with a range of clients from diverse cultural, social and educational backgrounds. In addition, I worked with clients of different ages, ranging from 20 – 75 years old. I also worked with a variety of different clinical presentations, including clients with diagnoses of depression, agoraphobia, psychosis, anxiety and obsessive-compulsive disorder. These experiences enabled me to develop my knowledge and skills of assessment, formulation, intervention and evaluation using cognitive behavioural approach (CBT). These skills included: assessing and formulating with a CBT model; identifying and monitoring automatic negative thoughts/assumptions/ beliefs; the downward arrow technique; Socratic questioning; challenging thoughts/assumptions/ beliefs; and identifying and consolidating new core beliefs/ assumptions.

I also carried out a small-scale service related research project: An audit of referrers’ views of the day treatment centre. This involved designed and piloting a questionnaire, collating and
analysing the data, writing up a report and disseminating the findings back to the day treatment centre staff. I also attended a team meeting at the local family therapy team.

Finally, this placement enabled me to develop my understanding of governmental policies, such as NSF for Mental Health and Nice guidelines, e.g. for depression. Overall this placement gave me an excellent grounding in the use of CBT, the opportunity to work in a variety of settings with different presenting problems.

**Meetings, Seminars, Visits and Training**

I attended daily multidisciplinary team meetings in the day treatment centre. In addition, I attended a number of MDT team meetings in the CMHT. Training events included: Integrative formulation by Rudi Dallos. I also gave a presentation to the Day Treatment Centre whereby I discussed a debate, which I attended at the Institute of Psychiatry entitled, ‘CBT is the new coca cola: superficial and tasteless.’
Adult Mental Health Case Report 1 Summary

Cognitive therapy with a 57-year-old woman presenting with symptoms of anxiety

Presenting problem
Helen, a 57-year-old White British woman was referred by her General Practitioner. She reported excessive worrying, physical bodily symptoms (thumping head; palpitations), sleep difficulties and cognitive difficulties (e.g. decision-making and concentration problems). Helen was also experiencing symptoms of social anxiety, e.g. fear of blushing in public. Her difficulties were having an impact on her ability to lead a normal life, as she was not going out as much as she used to.

Assessment
Helen was assessed via interview, whereby information on her childhood, educational, employment and health was gathered. The administration of standardized measures, including: Beck Depression Inventory II (BDI-II), Beck et al. (1996); Beck Anxiety Inventory (BAI), Beck & Steer (1993); Fear Questionnaire, Marks & Matthews (1979); The Fear of Negative Evaluation scale (FNE) and the Social Avoidance and Distress scale (SAD) Watson & Friend (1969). The risk of self-harm was also assessed. From these assessments, her main difficulties related to her fear of people and fear of negative evaluation. Furthermore, Helen’s foremost goal was to leave the house without make-up on.

Formulation
I adopted a specific cognitive model of social anxiety by Clark & Wells (1995) – as this appeared to fit well with Helen. Hence, Helen’s problems could be accounted for by living with her grandmother who was critical towards her. Her experience at school of being a “shy, reserved child who did not confront others” could have had an effect on her problems. These early experiences could have led to the development of core beliefs of “I am inferior” and certain dysfunctional assumptions such as a “If people see me going red they will think I am inferior”; “I
can’t cope.” Helen’s experience of an anxiety management group and realising that the group did not address the underlying issues of the anxiety was identified as a possible precipitating factor. This could have led to the activation of her core beliefs and dysfunctional assumptions, which in turn may have generated a vicious cycle of negative automatic thoughts related to perceived social threat and symptoms of anxiety (e.g. “everyone is staring at me”; “my mind is going like a mouse on a wheel”; “I am out of control”). Helen’s negative automatic thought patterns could have been maintained by her feelings of anxiety and safety behaviours (e.g. wearing make-up). In addition, I observed Helen’s self-processing as a social object (e.g. she believed she was as “red as a pillar box” and she imagined herself “losing control and looking a state.” Helen also explicitly recognised that she was extremely self-conscious. Protective factors were: her motivation to change; her supportive relationship with her husband and her ability to self reflect.

**Intervention**

The intervention involved the following steps, based on the cognitive approach to anxiety disorders Wells (1997):

- Problem list and goal setting
- Formulation with Helen.
- Socialisation to the cognitive model

Identification of negative automatic thoughts, e.g. using techniques by Wells (1997) including: worst-case scenario; recounting specific episodes and Thought Records.

Exposure to a graded hierarchy of anxiety provoking situations. Helen’s main goal was to leave her house without wearing any make-up. To help her achieve this, I aimed to use a graded hierarchy, based on systematic desensitisation by Wolpe (1961).

Behavioural experiments. For example we worked to test Helen’s thought: “My face is bright red.” For this experiment, I used imagery and asked Helen to imagine that she was going red in our session. She stated that she felt 90% red – I then asked Helen to look in a mirror to see how red she actually was. She said she was not as red as she thought she was (70% redness). This technique helped Helen realise that she was not going as red as she thought she was.

Core belief work. Helen’s core belief of “I’m inferior” was identified through observing themes and using the downward arrow technique Greenberger & Padesky (1995). Helen completed a
positive log diary, which recorded evidence to support her new core belief of “I am as good as everyone else.”

Outcome

Her anxiety rating on the BAI has remained at the moderate level. Her BDI-II reduced slightly from mild to minimal level. The Fear Questionnaire showed that Helen’s avoidance from certain situations has improved. After treatment, Helen was able to go to the local post office without wearing make-up. She also showed great determination as she spontaneously bought her make-up remover with her and took her make-up off during session 12 and left the session without make-up on. In addition, I regularly used a subjective measure of 0 – 100% anxious (with zero being not at all anxious and 100% being the most anxious you have ever been). I observed that this rating fluctuated quite significantly over the sessions. For example, in the initial session Helen rated her anxiety as 80% anxious, 60% on session 5, 70% anxious on session 9 and on session 10 she rated herself as 60% anxious.
Adult Mental Health Case Report 2 Summary

Cognitive therapy with a 25-year-old woman presenting with symptoms of depression

Presenting problem

Joanne, a 25-year-old White British woman was referred by her care coordinator in the Community Mental Health Team. Joanne identified that her main problems were feeling low in mood, loss of interest and feeling guilty. She also described feeling “walked over by others.” Joanne admitted to binge eating when she was feeling particularly bad about herself. She identified having negative automatic thoughts such as, “I can’t be bothered.” She also reported having panic attacks and described how her difficulties have had a significant effect on her life. During a typical day she stayed at home and reported having no social life and no energy to do anything. Joanne is unemployed. Her sleep pattern was good.

Assessments

Joanne was assessed via interview and questionnaires. The administration of standardized measures, including: Beck Depression Inventory II (BDI-II), Beck et al. (1996) and Beck Anxiety Inventory (BAI), Beck & Steer (1993). Joanne’s initial score on the BDI-II was 33 indicating severe levels of depression and her initial BAI score was 36 indicating severe levels of anxiety.

Formulation

A cognitive formulation was used to consider Joanne’s presenting symptoms of depression and anxiety. In Joanne’s situation, her problems could be accounted for by the loss of her father and stepfather when she was four and ten respectively and then being bullied at school. These early experiences could have led to the development of core beliefs. (“I am not as good as anyone else” “I am needy/ vulnerable.”) The precipitating factor, which led to Joanne seeking help, was her relationship ending with her ex-boyfriend. This led to the activation of her core beliefs, which led to a vicious cycle of negative automatic thoughts (e.g. “I can’t cope”; “I am useless”) related to failure and symptoms of depression. In accordance with the cognitive model, Joanne’s
negative automatic thought patterns could have been maintained by her low mood, feelings of anxiety and guilt and her avoidance of people and tasks. Protective factors included her ability to reflect on her situation, the supportive relationships with her mother and sister, her sense of humour and good listening skills.

**Intervention**

The intervention was based on the cognitive approach to depression implementing strategies from both Fennell (1989) and Greenberger & Padesky (1995).

This action plan included the following stages:

- Problem list and goal setting.
- Formulation with Joanne.
- Socialisation to the cognitive model.

Activity planning and scheduling: Using guidelines set out in Fennell (1989), I asked Joanne to complete a Daily Activity Schedule.

Identification of negative automatic thoughts, based on Greenberger & Padesky (1995) during and outside of the session (Appendix C). Outside of the session Joanne found it initially difficult to find alternative perspectives to her negative automatic thoughts. However as our sessions progressed she was able to acquire this skill and stated that she felt better for doing so.

Behavioural experiments were used to test out Joanne’s underlying assumptions. Using guidelines based on Greenberger & Padesky (1995) we designed an experiment to test the specific thought (see Appendix C): “If someone talks to me - I will have nothing to say.”

Core belief work. I used common themes and the downward arrow technique, (Greenberger & Padesky, 1995) and Beck’s (1995) technique a positive log diary.

Motivational interviewing techniques. To assist with engagement and goal identification, I considered Prochaska & Diclemente’s (1992) Contemplation Stage in the Stages of Change model and I used some motivational interviewing techniques by Miller & Rodnick, (2002). These techniques included: being collaborative; allowing Joanne to identify her own goals; expressing empathy; developing discrepancies (between where Joanne was and where she wanted
to be) and affirming and supporting Joanne.

Outcome

It was not possible to gain any objective measures as Joanne failed to attend her final appointment as she was stated that she was unwell. However, I regularly used a subjective measure of 0 – 100% low mood (with 100% being the most low you have ever felt). I observed that this rating gradually reduced from 99% during our initial session to 70% in session 6. Her conviction in her new core belief of, “I am just as good as everyone else” increased from 20% in session 4 to 70% in session 6. In addition, during our penultimate session, I noticed that Joanne appeared more confident. Her body language had changed from shoulders forward to a more open body posture. She was talking about the future more and what she wanted to do – that is, get a job and move out of her mother’s house. In the end Joanne was discharged from the service as she stated that she was feeling better.
Children and Young People Placement
Children and Young People Placement Summary

Placement details
Dates: Oct '05 – March '06.
Supervisor(s): Bruce Holroyd, Consultant Clinical Psychologist; Lisa Haagen, Clinical Psychologist.
NHS Trusts: Surrey and Borders Partnership NHS Trust
Base(s): Child and Adolescent Mental Health Service, Chertsey

Summary of Clinical Experience
This placement provided me with the experience of working in a Child and Adolescent Mental Health service. I worked with a range of clients from diverse cultural, social and educational backgrounds. In addition, I worked with clients of different ages, ranging from five to seventeen years old. I also worked with a variety of different presenting issues including: low self-esteem, depression, anxiety, obsessional and compulsive behaviours, separation difficulties, attention and hyperactivity problems. These experiences enabled me to develop my knowledge and skills of assessment, formulation, intervention and evaluation using both cognitive behavioural approach (CBT) and narrative therapy. I also worked with families and professionals, including teachers and other professionals in the team. In addition, I carried out a direct observation in a school. Finally, this placement enabled me to develop my understanding of governmental policies, such as NSF-children, young people and maternity services (DoH, 2004); Children Act (2004); Framework for the assessment of children in need and their families (2000) and Every Child Matters (1999).

Meetings, Seminars, Visits and Training
As part of my induction, I visited social services assessment team and spent a morning with the duty social worker, mental health worker and art therapist in the CAMHS and discussed their different roles in the team. I visited the family therapy service and observed a family of nine, whereby I took notes and was part of the reflecting team. In addition, I visited the Child
Assessment Service and observed a multi-disciplinary assessment of a two-year old and I contributed to a Professional Network Meeting in a primary school as part of a multi-disciplinary approach to a six year old who was having difficulties at school and home. Finally, I attended fortnightly psychology meetings in the CAMHS and in one of those meetings I also carried out a presentation on two websites aimed at teenagers who have mental health problems.
Children and Young People Case Report Summary

A narrative approach with a thirteen-year-old boy presenting with symptoms of ‘obsessive-compulsive disorder’ (OCD)

Presenting Problems

Ben Smith, a thirteen-year-old boy was referred by his General Practitioner with regards to his symptoms of obsessive-compulsive disorder (OCD). The main presenting problems were Ben’s compulsive behaviours including, tapping and having certain ritualized behaviours. Ben also had obsessional thoughts around having had to do some of the behaviours to make ‘things feel right’ and ‘perfect.’ The compulsive behaviours tended to occur mainly in the home environment and occasionally at school. Ben described having ‘urges’ to ask for reassurance from his family. Ben also reported that he frequently had doubts and worries. For example, he often had thoughts that he could have done. He explained how his problems have had a significant impact on his life, as he no longer felt in control of himself or his compulsive behaviours.

Assessments

The initial assessment consisted of an interview with Ben and his parents by a clinical psychologist and a second assessment session carried out by my supervisor and myself.

Sources of information used for the assessment were:

- Unstructured face-to-face interviews.
- Questionnaire.
- Control Continuum.

Ben completed the Clark-Beck Obsessive Compulsive Inventory (CBOCI) to identify his obsessive and compulsive symptoms. His total score was showed that in comparison with a normal sample Ben had “mild-moderate” symptoms. A control continuum was used to measure how much Ben thought that he was control of his life versus ‘OCD’ being in control.
Formulation

From the assessment report and my initial meeting with Ben and his family, Ben’s presenting problems could be partially formulated in terms of DSM-IV diagnostic criteria for obsessive-compulsive behaviour (OCD). This was useful in terms of providing the family with an explanation about what was happening and normalising the experience. However, I felt that this diagnostic category risked pathologising Ben. Therefore, I based my formulation on a narrative approach based on White and Epston (1990). Narrative therapy is a non-blaming and non-pathologising approach, which treats the client as the ‘expert.’ Another reason for choosing this approach was that there were no obvious obsessional thoughts or images apart from ‘getting things right’ and being ‘perfect.’ Ben stated that generally the compulsive behaviours occurred on their own without being precipitated by anxiety. Hence, rather than only using a CBT approach (which focuses on identifying the intrusive thoughts), it seemed more helpful to use a narrative approach. A final reason for using narrative therapy was that Ben readily engaged with initial externalising conversations: he quickly took hold of the idea that ‘OCD’ was the problem rather than himself.

Thin descriptions

Using White & Epston’s (1990) metaphors of ‘thin’ and ‘thick descriptions’, it could be hypothesised that the following descriptions: ‘urges’; ‘unaware’ and ‘nervous’ are all thin descriptions. They are thin descriptions as they have been mostly been generated by others (e.g. parents, GP) and they do not allow space for Ben to generate his own particular meanings to his actions and think about the context within which they occurred.

Problem-saturated stories

Morgan states that once thin conclusions are in place it is difficult for the person to seek evidence against these dominant problem-saturated stories. That is, the problematic stories about Ben’s ‘urges’, ‘compulsive behaviours’ and ‘nervous’ had grown to the extent that his home life and school were being affected. I noticed this in the sense that there was little information on Ben’s skills, abilities, interests and knowledge. These competencies had become hidden by the problem story.
Alternative stories

The aim of narrative therapy is to use Jacque Derrida’s idea of ‘deconstruction’ to externalize the dominant problem-saturated descriptions or stories of a person’s life. That is, to listen for spaces, gaps, hidden meanings or conflicting stories and to explore the influence those problems have in a person’s life.

Intervention

I adopted a curious approach and used externalising conversations, which involved naming the problem and then tracing how the problem has affected Ben’s life and relationships. Ben recalled how he cried, felt scared and confused on his first day of school when he was six. He described feeling ‘alone’ and not really ‘belonging.’ He remembered feeling pressurised and worried about losing things. By tracing the history of the problem, Ben discovered that he felt a lot stronger now in comparison with when he was six. It was useful to deconstruct these beliefs and ideas of the broader culture in which a person lives that are supporting the problem. Ben recognised that the ‘OCD demon’s’ ideas, (such as ‘having to be perfect’) had been supported by the rules and expectations of his new school. We also explored unique outcomes (White, 1988). For example, Ben spoke about how he had gained control of the ‘OCD demon’ as he was not checking things over and over. Finally, we created an alternative story (Morgan, 2000) about how: Ben had regained control over ‘OCD’ using his ‘strength’ and ‘power’ and how he felt more in control of his life and more confident now. Again using landscape of action and landscape of identity questions I worked to connect the story with events in the past, present and future. For example, Ben told me how he used his ‘strength’ when he had done a presentation to the whole school when he was eleven. He said that his mum noticed and she told him that he was good at speaking in front of other people.

I also used March & Mulle (1998) protocol for exposure and response prevention (ERP), which fitted well with narrative ideas such as externalising the problem, fighting back the ‘OCD demon’ and regaining control. I explained to Ben that in order to ‘boss back his OCD demon,’ he would need ‘allies’ and a ‘battle strategy.’
Outcome

Ben’s scores on the Clark-Beck Obsessive Compulsive Inventory reduced significantly from 23 (pre-intervention) to 6 (post-intervention). This indicated that the symptoms of OCD had reduced significantly (from “mild-moderate” to “minimal”).
People with Learning Disabilities Placement
People with Learning Disabilities Placement Summary

Placement details

Supervisor(s): Heinz Kobler, Clinical Psychologist.
NHS Trusts: Surrey and Borders Partnership NHS Trust
Base(s): Community Team for People with Learning Disabilities, Frimley.

Summary of Clinical Experience
This placement provided me with the opportunity to work in a multi-disciplinary community team for people with learning disabilities. During this placement I worked with arrange of clients of different ages and different levels of need. I worked in different settings including residential homes, family homes, outpatient clinics and day centers. The placement enabled me to gain experience of various assessments, such as WAIS-III, Hampshire Assessment for Living with Others, BPVS-II, ABC charts, functional analysis interviews, BDI-II adapted version for people with learning disabilities.

I worked with a variety of presenting problems including: depression; ‘challenging behaviour’; difficulties relating to others; ‘obsessional slowness’ and dementia. I also carried out a Relationship/Friendship Skills group for people with learning disabilities who were having difficulties relating to others.

I developed my formulation and intervention skills using an integrative approach, whereby I draw from various psychological theories including developmental and attachment theories, behavioural and cognitive behavioural approaches. I also considered wider social and political factors, including the social construction of a ‘learning disability’ and attitudes of others towards people with learning disabilities. My interventions involved working at different levels, including direct face-to-face work with clients, indirect work with other professionals including staff...
training and indirect work with family members.

Meetings, observations and seminars
I met with several members of the CTPLD including the CPN, SALT, Physiotherapist and Team Coordinator to discuss their roles. I attended several CTPLD meetings and psychology meetings, whereby I gave several clinical case presentations.
People with Learning Disabilities Case Report

Summary

An integrative approach with a woman presenting with bereavement issues and “challenging behaviour.”

Presenting Problem

Emma is a 34-year-old White British woman who had a diagnosis of Asperger syndrome. She was referred by her support workers for her ‘challenging behaviour.’ The referrer’s main concerns were as follows: keeping her support workers waiting at her door for up to 20 minutes and being verbally abusive towards them; bottling up her feelings and being low in mood.

Assessment

Information was obtained via carrying out an interview with Emma, reading the case file at the Community Team for People with Learning Disabilities. With Emma’s consent I also spoke to her support worker. In addition, I asked Emma to complete the Beck Depression Inventory – Adapted Version for people with learning disabilities. A risk assessment was also carried out, particularly paying attention to the risk of self-harm and her vulnerability. The assessment information showed that Emma’s behaviour had worsened after the death of her Grandmother. During the assessment, Emma was keen to present herself as a capable young woman, with few limitations. She admitted to feeling lonely at times and annoyed when she support workers were not on time. In addition, Emma was not clear what Asperger syndrome meant and she stated that she would like some information. Emma admitted to having suicidal thoughts although stated she would not act on them because of her family.

With Emma’s consent, I spoke to her support workers, who informed me that they were concerned that her “Asperger’s syndrome might cause her to deteriorate as she gets older.” They also admitted to being a few minutes late sometimes with Emma, and how this would cause her to lock them out of her flat. The support workers also stated that Emma would be verbally abusive towards them when she thought they were “interfering” and Emma could spend long periods of
time on the toilet. Emma scored 9 on the BDI, showing minimal signs of depression.

**Formulation**

I formulated Emma’s case using an integrative approach whereby I considered possible vulnerability factors (imPAIRment of intellectual functioning; socio-communicAtion difficulties and difficulties in her childhood with her father who was an alcoholic). In addition, there was a theme of loss in her story. For example, she said that the family moved around a lot when she was a child and she lost touch with friends. The death of both sets of grandparents was a significant loss in her life, as was the loss of friendships when she left boarding school. Emma could also be grieving for the loss of a “normal” life. It was hypothesised that the death of her grandmother may have precipitated Emma’s difficulties. The maintaining factors were hypothesised to be related to both herself and support workers lack of understanding of “Asperger syndrome.” Her problems were also likely to be maintained by her negative automatic thoughts e.g. “No one cares about me.” Finally, Emma’s behaviours of avoiding people, hiding and keeping people waiting were likely to be keeping the problems going.

Her difficulties could also be understood in terms of Attachment theory (Bowlby, 1969). I wondered about the quality of Emma’s attachments in her life, as she could not talk openly with her parents, she had a difficult relationship with her father and she was bullied at boarding school. In relation to Bowlby’s (1969) concept of Internal Working Models, one hypothesis could be that Emma’s insecure attachment style as a child has led her to be insecure in her adult relationships (e.g. with housemates, support workers and her partner).

**Intervention**

Using Worden’s theory of tasks of mourning, I worked with Emma to normalize her feelings. I also carried out a life story book with Emma, which involved discussed how she saw herself and considering ‘What is Asperger syndrome?’ With Emma’s consent I carried out some psychoeduction on Asperger syndrome with her support workers and I developed a formulation of Emma’s difficulties, whereby I showed them how to use social stories as a way of drawing up contracts, so that both Emma and her support workers were clear on who was doing what.
Outcome

Emma completed the BDI (Adapted Version) again (see appendix B), which showed that her BDI score remained the same (9) as it was on the pre-intervention administration. However, we examined the questionnaires during the session and observed that there were a few changes. For example, Emma said that she now felt happy most of the time rather than feeling sad. In addition, she had put that she felt, “weaker with more difficulties than other people” as opposed to feeling, “the same as everyone else.” She said, “...we can’t all be perfect can we?” I agreed and explained that everyone can feel weak at times and that we cannot always feel good about ourselves. It seemed that Emma was more accepting of her limitations. I asked Emma what she had found helpful and unhelpful about the therapy and whether there was anything she would change. Emma said that what was helpful was that I had talked directly to her and given her information on Asperger syndrome rather than talking to people around her. When she was younger, she remembered professionals talking over her or asking her to leave the room and they would talk to her parents instead of talking directly to her.
Older People Placement
Older People Placement Summary

Placement details

Dates: September 2006 – March 2007

Supervisor(s): Ingalice Jensen, Clinical Psychologist.

NHS Trusts: South West London and St George's Mental Health NHS Trust

Base(s): Community Mental Health Team for Older People, St John’s Hospital, Twickenham.

Summary of Clinical Experience
I was based in a Community Mental Health Team for older people. This placement enabled me to work with clients with a variety of presenting problems including memory problems, obsessive and compulsive behaviours and symptoms of depression and anxiety. I also worked with clients who had experienced many losses, including loss of roles and significant others. I mainly worked using a cognitive behavioural approach. This placement also gave me the chance to develop my neuropsychological skills. I carried out comprehensive assessments with three clients, including the following psychometric tests: WAIS-III, WMS-III, CAMCOG, FAS, Hayling & Brixton, NART, Clock drawing and Rey Complex Figure. I also learnt about risk assessment procedures with older people. I carried out work with individuals, couples and with other professionals. In addition I attended CPA reviews. This placement also enabled me to working in different settings, including the community team, day services, client’s homes and in an acute psychiatric inpatient setting.

Meetings, Seminars, Visits and Training
I attended multidisciplinary team meetings. Training events included: risk assessment of older people with mental health problems and Mental Capacity Act (2005) training. In addition, I attended fortnightly psychology meetings (local and Trust wide). I gave three presentations as part of this placement to a variety of audiences, (e.g. ‘Challenging Behaviour and Dementia’
presentation to a variety of professionals and I gave a presentation on Risk Assessment and Problem Based Learning in the psychology meetings).
Older People Case Report Summary

A neuropsychological assessment of a man referred for memory problems and behavioural difficulties

Presenting Problem

Mr Simon Davis was referred for to the Community Mental Health Team for Older People by his GP as his wife had informed her GP that she was becoming increasingly concerned over Simon’s memory and behaviour. Simon reported that his memory had worsened and that he is more forgetful (e.g., difficulty recalling conversations, people’s names, misplacing items). He added that he also has word-finding difficulties. He added that he had noticed that his eyesight had worsened (as he cannot read the newspaper anymore). He also stated that his mobility was poorer. In addition, Simon reported that his wife who is also his main carer was having to do more things for him now, such as doing up his buttons on his shirts. Simon denied any unusual side effects from his medication such as perceptual disturbances. His wife stated that her husband was damaging her possessions (e.g. clothes) and that he was moving objects around the house (e.g. her toiletries). She added that he was “compulsively buying” items such as sewing kits, scissors and keys. Katherine explained that she had never actually seen her husband do any of these things although she has tried to catch him in the act. Simon’s response to these allegations was that he could not recall having done any of them. He did not offer any explanation as to what was occurring in his home and described feeling apprehensive when his wife talked about these difficulties.

Assessment

The assessment involved interviews with Katherine and David and then a comprehensive psychometric assessment. The following assessments were administered:

- The Logical Memory I and II from the Weschler Memory Scale – third edition (WMS-III; Weschler, 1997b) were used to measure verbal recall.
- Rey Complex Figure (Rey, 1941) to measure visual perception, problem solving approaches,
and capacity to process the whole versus the detail.

- Hopkins Verbal Learning Test (HVLT; Benedict, Schretlen, Groninger, & Brandt, 1998) is a 12-item list learning and memory test

- The National Adult Reading Test (NART; Nelson, 1982) provides an estimate of premorbid intellectual functioning.

- Letter fluency was assessed using the FAS/Controlled Oral Word Association test (COWAT; Benton & Hamsler, 1976, 1989).

- Semantic fluency was assessed using Category Naming test, whereby a person was required to name as many animals as they could in a set time.

- Hayling and Brixton tests (Burgess & Shallice, 1997) were used to assess task initiation and response suppression (Hayling test) and rule detection, rule following and perservation (Brixton test).

- The Geriatric Depression Rating Scale (Brink et al., 1982) was administered, as recommended by Synder & Nussbaum (1998).

**Formulation**

There was no evidence from the assessment to suggest that Simon’s reported memory difficulties were indicative of dementia. It was more likely that the difficulties represented forgetfulness associated with normal ageing. Any mild subjective difficulties that Simon did experience were most likely to be related to his Parkinson’s disease.

**Outcome**

In the end, it was discovered after interviewing Katherine that she was very preoccupied with talking about how her possessions were going missing or being damaged. She also talked about how she had one friend who knew her very well and who believed what was happening. Therefore, with Katherine’s consent, my supervisor spoke to her friend, Beth. Beth stated that she thought that Simon was not causing the damage reported by Katherine and she believed that the damage was likely to be caused by ‘wear and tear.’ Beth added that she thought that Katherine was struggling to cope with her husband’s deterioration and that she felt Katherine’s
stress was worsening as she had noticed that she had lost weight, had poor sleep, was tearful and was becoming more forgetful. This conversation with Beth suggested that Katherine was likely to be experiencing difficulties herself. Therefore, it was decided that it would be good for Katherine to be seen by someone in the team and for Simon to be monitored in terms of his potential vulnerability in relation to living with Katherine.
Children with Learning Disabilities and Mental Health Difficulties Placement
Children with Learning Disabilities and Mental Health Difficulties Placement Summary

Placement details


Supervisor(s): Maria Callias, Consultant Clinical Psychologist.

NHS Trusts: South West And St George’s Mental Health Trust NHS.

Base(s): Child and Adolescent Mental Health services for children with learning disabilities and mental health problems, Clare House, St George’s Hospital Medical School.

Summary of Clinical Experience

This placement provided me with the opportunity to work in a multi-disciplinary specialist team for children and young people with learning disabilities and mental health difficulties. The main presenting problems included: behavioural difficulties, emotional difficulties, attention and hyperactivity problems. The work involved working with both the children and the parents. I worked on my own and I carried out joint work with other professionals including a trainee family therapist and an SHO. I carried out assessments (including psychometrics), formulations and interventions. In terms of the interventions, I adopted an integrative approach, whereby I integrated different psychological models, including behavioural theories, attachment theory, systemic theories and cognitive behavioural theory. I did not manage to complete this placement due to having a personal crisis.

Meetings, observations and seminars

I attended weekly team meetings and some fortnightly psychology meetings.
Family Therapy Placement
Family Therapy Placement Summary

Placement details
Supervisor(s): Annette Lumsden, Consultant Clinical Psychologist/Family Therapist and Lorna Atkins, Family Therapist.
NHS Trusts: Surrey and Borders Partnership NHS Trust.
Base(s): Horizon Centre, Farnham Road Hospital, Guildford.

Summary of Clinical Experience
This placement provided me with the opportunity to work in a family therapy service for adults who have mental health difficulties and their families. The main presenting problems included, relationship difficulties, depression and eating disorders. The work involved working with both children and parents. I gained experience of working alongside family therapists and took on different roles, including the observer, the co-worker and the key worker. The work involved gathering information from a variety of sources, assessing the level of risk, carrying out systemic formulations and interventions. I gained experience of using various systemic interventions, including hypothesising, reflecting teams, enactments and circular questions. In addition, I also contributed to two research projects within the family therapy service. The first was developing a Carers’ Strategy for the Specialist Psychological Services and the second was carrying out an audit of health visitors’ views regarding the services available for women with postnatal depression.

Meetings, observations and seminars
I participated in weekly referral meetings within the family therapy service. I also attended monthly multi-disciplinary meetings and I attended two family therapy forum meetings. In addition, I went on a conference, which was about the new government document ‘Keeping the Family in Mind’ by the Barnardo’s Trust.
Research Dossier

Small Scale Research Project

Abstract of Qualitative Project

Major Research Project
An Audit of Referrers’ Views of a Day Treatment Centre, which offers Psychological Therapeutic Interventions for Adults with Mental Health Problems

Small Scale Research Project

July 2005

Year 1
Abstract

Title: An audit of referrers' views of a Day Treatment Centre (DTC), which offers psychological therapeutic interventions for adults with mental health problems.

Objectives: The main objectives were to measure referrers' views on: awareness and understanding of what the DTC offers; the information brochure; waiting times and admission process; staff liaison; the range of psychological interventions available and the summary reports.

Design: A survey of referrers to the DTC was carried out.

Participants: Forty five (63%) participants responded to the questionnaire.

Outcome measures: A semi-structured questionnaire was designed and used in this study.

Results: The sample comprised of a range of professionals from a variety of settings. Fewer responses were received from ward staff and consultant psychiatrists. Referrers seemed to have a good awareness of the DTC and were very satisfied with the service. Most participants found the information brochure very useful, although 37% of the sample had not received the brochure. Sixty percent gave examples of other groups, which are not currently offered by the DTC. Anger management, men's group, sports and exercise group and survivors of sexual abuse were the most commonly asked for groups.

Conclusions: Most referrers were satisfied with the DTC. Limitations of the study are presented and future recommendations are suggested.
Acknowledgements
I would like to thank the following people for their assistance and support with the project: all the referrers who took part in the project; Dr. Amanda Ediriweera; Dr. Martin Carroll and everyone at the day treatment centre.
Introduction

This study focussed on an acute day treatment centre (DTC) for adults with mental health problems. The centre offers support groups (e.g. women’s groups), psychoeducational groups (e.g. living with psychosis) and psychotherapeutic groups (e.g. art therapy) and also individual psychology sessions.

In line with Department of Health guidelines and standards regarding Clinical Governance and improving the quality of NHS services (DoH, 1997; DoH, 1999a; DoH 1999b), two comprehensive audits of the DTC were carried out in 1997-98 (Clinical Audit Department, 1998) and 2003 (Ediriweera et al., 2004). It should be noted that these two audits were very detailed and included evaluations of service users’ views and a detailed analysis of the attending population. However, one limitation was that they did not consider referrers’ views. The 2003 report made several recommendations including: “Follow on survey including a survey of referrers views,” Ediriweera et al. (2004).

In addition, the DTC team were particularly keen to find out what referrers thought about an information brochure (see appendix A), which was sent out to referrers one year prior to the evaluation. The aim of this brochure was to increase knowledge and awareness of referrers and their clients about the day treatment centre. The brochure was sent out to the managers of each service with a covering letter asking the managers to distribute the brochures to the rest of the team members.

In addition to evaluating the brochure, the DTC team were motivated to find out what referrers thought about the summary reports, written after closed group. Therefore, the study aimed to
gain the views of actual and potential referrers’ to the DTC.

The objectives of the present study were to measure referrers’ views on:

- Awareness and understanding of what the day treatment centre offers.
- Information brochure.
- Waiting times and admission process.
- Staff liaison.
- Range of psychological interventions available (group and individual).
- Summary reports, which are sent to the referrers once their clients have completed a group.
Method

Procedure

A list of potential and actual referrers was compiled through discussions with different teams across the Trust. I aimed to gain a representative sample of different professionals from a variety of settings. I attended the DTC team meeting to discuss the project and I visited the ward manager at the acute psychiatric ward. Different team members at the DTC supplied names of other people of the same profession as themselves who might refer to the DTC.

Letters explaining the purpose and details of the project (see appendix B) were then sent out to all actual and potential referrers. A copy of the semi-structured questionnaire (see appendix C) was included. In the letter the participants were informed that if they did not return the semi-structured questionnaire within two weeks, I would contact them to find out if they wanted to do one of the following options:

1. Answer the questions over the telephone there and then.
2. Arrange a time to complete the telephone interview.
3. Choose not to take part.

Questionnaire development

Kitchen et al. (2002) describe a standardised assessment tool to evaluate mental health day hospitals for older people: the World Health Organisation (WHO) – Quality Assurance Audit Tool. This was used to help design the questionnaire in the present study. Additional questions were also added after consulting the DTC team. A draft questionnaire was sent to all DTC team members for their comments. Several minor alterations were made, such as including a question on five-day support and shortening the questions relating to the brochure. The final questionnaire included both quantitative and qualitative items.

Ethical considerations

Referrers were informed that their responses would be treated as strictly confidential and no names would be used (in the letters sent out to them). All responses were made anonymous and the questionnaires had a research number on them to identify who took part. All raw data was stored in a locked filing cabinet and information on the computer was anonymised. Finally, no
comments were used in the written report that could identify the referrers concerned.
**Results**

**Sample characteristics**

Forty-five individuals responded to the questionnaire out of a total of 72 (63% response rate). Telephone calls were made to 27 individuals who did not reply. From these calls it was discovered that four people were on holiday, four people were absent and one person was working nights, one person was on a training course, one person was sick, two people had left the job and one person was too busy to take part in the study. It was not possible to get hold of the remaining 13 people. Further telephone calls were not attempted due to time constraints.

Table 1 shows the professions of the participants and table 2 shows where the participants worked. It can be seen that the sample comprised of a range of professionals from a variety of settings. Table 2 also shows that the least responses came from the consultant psychiatrists/senior house officers and staff working in the ward setting. This is perhaps reflective of the workloads facing these two groups of people.

**Table 1. Professions of participants of study.**

<table>
<thead>
<tr>
<th>Professions</th>
<th>Frequency of those who responded (response rates of each profession)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ward manager</td>
<td></td>
</tr>
<tr>
<td>Deputy ward manager</td>
<td></td>
</tr>
<tr>
<td>Community team leader</td>
<td></td>
</tr>
<tr>
<td>CMHT Team managers</td>
<td>4 (100%)</td>
</tr>
<tr>
<td>Community psychiatric nurse</td>
<td>17 (68%)</td>
</tr>
<tr>
<td>Approved social worker</td>
<td></td>
</tr>
<tr>
<td>Social worker</td>
<td>5 (50%)</td>
</tr>
<tr>
<td>Occupational therapist</td>
<td>6 (86%)</td>
</tr>
<tr>
<td>Occupational therapist technical assistant</td>
<td></td>
</tr>
<tr>
<td>Community support worker</td>
<td></td>
</tr>
<tr>
<td>Carers support worker</td>
<td>1 (100%)</td>
</tr>
<tr>
<td>Health care assistant</td>
<td>1 (100%)</td>
</tr>
<tr>
<td>Counselling psychologist</td>
<td>1 (100%)</td>
</tr>
<tr>
<td>Clinical psychologist</td>
<td>3 (100%)</td>
</tr>
<tr>
<td>Family therapist</td>
<td>1 (100%)</td>
</tr>
</tbody>
</table>
Table 2. Number of participants from different locations

<table>
<thead>
<tr>
<th>Service</th>
<th>Frequency of participants, (response rates)</th>
</tr>
</thead>
<tbody>
<tr>
<td>CMHT 1</td>
<td>8 (62%)</td>
</tr>
<tr>
<td>CMHT 2</td>
<td>11 (79%)</td>
</tr>
<tr>
<td>CMHT 3</td>
<td>7 (100%)</td>
</tr>
<tr>
<td>CMHT 4</td>
<td>2 (67%)</td>
</tr>
<tr>
<td>Elderly Team</td>
<td>9 (100%)</td>
</tr>
<tr>
<td>Adult acute in patient psychiatric ward</td>
<td>4 (27%)</td>
</tr>
<tr>
<td>Consultant psychiatrists/ SHOs</td>
<td>4 (36%)</td>
</tr>
<tr>
<td>Total</td>
<td>45</td>
</tr>
</tbody>
</table>

**Frequency of referrals to the DTC**

Figure 1. is a pie chart showing how often people refer to the DTC. The majority of people refer clients to the DTC between one and six months. Fewer people refer clients once a year or more than once a month.

**Reasons for not referring clients**

Thirty-nine (87%) participants referred the DTC and 6 (13%) did not. Reasons for not referring clients were included:

- Clients were not suitable for service, e.g. did not like groups, live far away (n = 3).
- Not in job role (new staff member; health care assistant; limited hours of work).
- Elderly clients have different needs and have transport problems
Opinions of the function of the DTC

When asked to talk about the services the DTC provides using their own words, most participants gave a fairly detailed response and included examples of the types of groups offered. For example,

“Daily support for patients in the community e.g. anxiety management, relaxation group and coping with depression.”

“Psycho-education in group setting; forum for shared experiences; forum for social inclusion; low key art and relaxation groups.”

This suggests that participants had a good understanding and awareness of the DTC. Most of the responses were descriptive apart from a couple of participants who gave more evaluative opinions about how the services are delivered. These responses appeared to capture some of the feelings surrounding the DTC. For example,

“Very calm and supportive environment.”

“Group therapy provides altruism which increases self esteem. Overall the DTC empowers clients to use their coping skills.”
Awareness of the DTC

With regards to the information brochure which was sent out in October 2003, 24 individuals had received it and 17 had not. Figure 2. shows that the majority of these 24 people found it very useful.

Figure 2.

A variety of different ways were suggested to increase the awareness of the DTC. These included: sending out emails to indicate when the new groups are starting; sending out a Newsletter via email; DTC team to do a presentation to explain what they do; attend team meetings and Care Programme Approach meetings; presentation as part of SHO induction; presentation to staff on the acute in patient ward and open days.

Summary reports

Out of the 39 participants who referred clients to the DTC, 20 (51%) participants stated that they liked the summary reports. Sixteen people (41%) gave no comments and three people stated that they had not seen a summary report as yet. Likes included: content, length and timing of report.

Ten participants (25%) had some dislikes about the summary reports. These included: the length being too brief (3); length being too long (1); “not very individual – too clinical” (1).
Several improvements to the summary reports were suggested. These included: more needed on recommendations/ further work; more detail on clients’ progress; the reports should include information on medication; verbal liaison as well as written report would be useful.

**Satisfaction ratings**

Figure 3 shows the satisfaction of staff liaison, waiting times, admission process and the range of therapeutic interventions. It indicates that the majority of participants were very satisfied with all aspects of the service.

In the any other comments section, three participants from the elderly team commented that there were not enough services available to the older person and their needs were not always met (e.g. transport problems, sensory deprivation).

Table 3 shows how helpful the participants found each different intervention. The majority of participants found each group helpful. Only four participants found some groups (art therapy, coping with depression and living with psychosis) not at all helpful. Nine participants (23%) did not know how helpful the individual psychology sessions were.

![Satisfaction ratings of the DTC.](image)

Figure 3.
**Small Scale Research Project**

Table 3.

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Missing</th>
<th>Extremely helpful</th>
<th>Very helpful</th>
<th>Helpful</th>
<th>A bit helpful</th>
<th>Not at all helpful</th>
<th>Don’t know</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety management</td>
<td>1 (3%)</td>
<td>11 (28%)</td>
<td>19 (48%)</td>
<td>6 (15%)</td>
<td>1 (3%)</td>
<td>0 (0%)</td>
<td>2 (5%)</td>
<td>40</td>
</tr>
<tr>
<td>Art and craft</td>
<td>1 (3%)</td>
<td>5 (13%)</td>
<td>9 (23%)</td>
<td>17 (43%)</td>
<td>4 (10%)</td>
<td>0 (0%)</td>
<td>4 (10%)</td>
<td>40</td>
</tr>
<tr>
<td>Art therapy</td>
<td>1 (3%)</td>
<td>8 (20%)</td>
<td>13 (33%)</td>
<td>11 (28%)</td>
<td>2 (5%)</td>
<td>1 (3%)</td>
<td>4 (10%)</td>
<td>40</td>
</tr>
<tr>
<td>Confidence building</td>
<td>1 (2%)</td>
<td>12 (29%)</td>
<td>13 (32%)</td>
<td>8 (20%)</td>
<td>1 (2%)</td>
<td>0 (0%)</td>
<td>6 (15%)</td>
<td>41</td>
</tr>
<tr>
<td>Coping with depression</td>
<td>1 (2%)</td>
<td>13 (32%)</td>
<td>17 (41%)</td>
<td>7 (17%)</td>
<td>0 (0%)</td>
<td>1 (2%)</td>
<td>2 (5%)</td>
<td>41</td>
</tr>
<tr>
<td>Creative art</td>
<td>1 (3%)</td>
<td>4 (10%)</td>
<td>8 (21%)</td>
<td>18 (46%)</td>
<td>3 (8%)</td>
<td>0 (0%)</td>
<td>5 (13%)</td>
<td>39</td>
</tr>
<tr>
<td>Mixed support</td>
<td>1 (2%)</td>
<td>4 (10%)</td>
<td>8 (20%)</td>
<td>17 (41%)</td>
<td>4 (10%)</td>
<td>0 (0%)</td>
<td>7 (17%)</td>
<td>41</td>
</tr>
<tr>
<td>Relaxation</td>
<td>1 (2%)</td>
<td>6 (15%)</td>
<td>16 (39%)</td>
<td>13 (32%)</td>
<td>1 (2%)</td>
<td>0 (0%)</td>
<td>4 (10%)</td>
<td>41</td>
</tr>
<tr>
<td>Positive living</td>
<td>2 (5%)</td>
<td>6 (16%)</td>
<td>9 (24%)</td>
<td>12 (32%)</td>
<td>2 (5%)</td>
<td>0 (0%)</td>
<td>7 (18%)</td>
<td>38</td>
</tr>
<tr>
<td>Women’s support</td>
<td>2 (5%)</td>
<td>5 (13%)</td>
<td>10 (25%)</td>
<td>13 (33%)</td>
<td>3 (8%)</td>
<td>0 (0%)</td>
<td>7 (18%)</td>
<td>40</td>
</tr>
<tr>
<td>Coping with voices</td>
<td>0 (0%)</td>
<td>9 (23%)</td>
<td>15 (38%)</td>
<td>6 (15%)</td>
<td>2 (5%)</td>
<td>0 (0%)</td>
<td>8 (20%)</td>
<td>40</td>
</tr>
<tr>
<td>Living with psychosis</td>
<td>1 (3%)</td>
<td>8 (20%)</td>
<td>15 (38%)</td>
<td>6 (15%)</td>
<td>1 (3%)</td>
<td>2 (5%)</td>
<td>7 (18%)</td>
<td>40</td>
</tr>
<tr>
<td>Individual psychology work</td>
<td>1 (3%)</td>
<td>9 (23%)</td>
<td>12 (30%)</td>
<td>9 (23%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>9 (23%)</td>
<td>40</td>
</tr>
<tr>
<td>Five day support</td>
<td>1 (3%)</td>
<td>15 (39%)</td>
<td>11 (29%)</td>
<td>5 (13%)</td>
<td>1 (3%)</td>
<td>0 (0%)</td>
<td>5 (13%)</td>
<td>38</td>
</tr>
</tbody>
</table>

**Other groups which may be useful**

Many participants (n=27, 60%) gave examples of groups, which are not currently offered by the DTC, but which they thought would be useful. Anger management (n=12, 27%), men’s group (n=3, 7%), sports and exercise group and survivors of sexual abuse (n = 2, 4%) were the most commonly asked for groups.

**A comparison of views across different teams**

Crosstabulations were created to explore the differences between teams with regards to the frequency of referrals to the DTC and the information brochure. Tables 4, 5, 6, and 7 show the
results from these crosstabulations. Due to the low frequencies statistics were not possible. Visual inspection of the data was carried out instead.

It was hypothesised that certain teams may find the brochure more useful than other teams and that certain teams may be more aware of the DTC than others and refer clients more frequently. For example, teams members from the CMHT located in the same building as the DTC were predicted to refer clients of the DTC more often than those in CMHTs located further away.

Table 5. shows that most participants were referring clients between one and six months. As predicted, participants in CMHT 1 (which was located in the same building as the DTC) were referring clients more frequently (more than once a month) than other teams.

Table 6. shows that the highest number of participants who received the brochure were from CMHTs 2 and 3. It also shows that participants from the acute psychiatric ward and consultant psychiatrists/ SHOs were least likely to have received the brochure.

Table 7 shows the opinions regarding the usefulness of the brochure across teams. It indicates that it is difficult to draw conclusions, as the frequencies are particularly low for certain teams.

Table 4. Referrals to DTC by each team

<table>
<thead>
<tr>
<th>Team</th>
<th>Ever referred</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
<td>Total</td>
</tr>
<tr>
<td>CMHT1</td>
<td>6</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>Elderly</td>
<td>6</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td>CMHT2</td>
<td>10</td>
<td>1</td>
<td>11</td>
</tr>
<tr>
<td>CMHT3</td>
<td>7</td>
<td>0</td>
<td>7</td>
</tr>
<tr>
<td>CMHT4</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Consultants/SHOs</td>
<td>4</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Acute Psychiatric ward</td>
<td>4</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Total</td>
<td>39</td>
<td>6</td>
<td>45</td>
</tr>
</tbody>
</table>
Table 5. Frequency of referrals by different teams to the DTC.

<table>
<thead>
<tr>
<th>Team</th>
<th>Less than once a year</th>
<th>Once a year</th>
<th>Once every six months</th>
<th>Once a month</th>
<th>More than once a month</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>CMHT1</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>Elderly</td>
<td>1</td>
<td>1</td>
<td>4</td>
<td>0</td>
<td>0</td>
<td>6</td>
</tr>
<tr>
<td>CMHT2</td>
<td>0</td>
<td>1</td>
<td>6</td>
<td>3</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>CMHT3</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>CMHT4</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Consultants/SHO’s</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Acute Psychiatric ward</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Total</td>
<td>2</td>
<td>5</td>
<td>14</td>
<td>13</td>
<td>5</td>
<td>39</td>
</tr>
</tbody>
</table>

Table 6. Frequency of people who received information brochure.

<table>
<thead>
<tr>
<th>Team (with total number of people who were included in study shown in brackets).</th>
<th>Received brochure?</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes (with percentage score as a percentage of total number in team).</td>
<td>No (with percentage score as a percentage of total number in team).</td>
</tr>
<tr>
<td>CMHT1 (13)</td>
<td>3 (23%)</td>
<td>4 (31%)</td>
</tr>
<tr>
<td>Elderly (9)</td>
<td>3 (33%)</td>
<td>3 (33%)</td>
</tr>
<tr>
<td>CMHT2 (14)</td>
<td>9 (64%)</td>
<td>2 (14%)</td>
</tr>
<tr>
<td>CMHT3 (7)</td>
<td>5 (71%)</td>
<td>2 (29%)</td>
</tr>
<tr>
<td>CMHT4 (3)</td>
<td>1 (33%)</td>
<td>1 (33%)</td>
</tr>
<tr>
<td>Consultants/SHOs (11)</td>
<td>2 (18%)</td>
<td>2 (18%)</td>
</tr>
<tr>
<td>Acute Psychiatric ward (15)</td>
<td>1 (7%)</td>
<td>3 (20%)</td>
</tr>
<tr>
<td>Total (45)</td>
<td>24 (53%)</td>
<td>17 (32%)</td>
</tr>
</tbody>
</table>
Table 7. Opinions regarding usefulness of brochure across different teams.

<table>
<thead>
<tr>
<th>Team</th>
<th>Usefulness of brochure</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Missing</td>
<td>Extremely useful</td>
<td>Very useful</td>
<td>Useful</td>
<td>Somewhat useful</td>
<td></td>
</tr>
<tr>
<td>CMHT1</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Elderly</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>CMHT2</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td>CMHT3</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>3</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>CMHT4</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Consultants/ SHOs</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Acute Psychiatric ward</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>1</td>
<td>2</td>
<td>11</td>
<td>9</td>
<td>1</td>
<td>24</td>
</tr>
</tbody>
</table>
Discussion

A main finding from this study was that the majority of participants seemed to have a general good understanding and awareness of the DTC.

The sample was comprised of a broad range of professionals from a variety of settings. There were fewer responses from staff on the acute psychiatric ward and consultant psychiatrists/SHOs, which perhaps reflects the time pressures of these two groups of people. Another reason for the lack of responses could be due to these two groups having less contact or knowledge of the services, which the DTC provides. Table 7 indicates that only one person on the ward received the information brochure. Therefore, perhaps more work could be carried out to increase the profile and awareness of the DTC to the ward staff and consultants/SHOs. One SHO had an idea of “presentations as a part of induction course to new SHOs.”

Most participants reported each intervention to be helpful, although 23% did not know how helpful the individual psychology sessions were. This could suggest that these participants did not know that the DTC offers individual psychology sessions as well as groups. This may be due to individual psychology work being a relatively new service in comparison with the groups. Therefore perhaps more work needs to be carried out to increase the awareness of individual psychology work.

The results also suggested that the elderly team felt that there were not enough services available to older people. Perhaps further liaison between the DTC and the elderly services needs to be carried out to investigate this in more detail.

With regards to the information brochure, the results indicated that a large proportion of participants had not seen it (n=17, 32%). Therefore, if brochures or other correspondence are to be sent out in the future, better methods of communications need to be explored (such as emailing all referrers and potential referrers as opposed to posting to managers).

An additional finding was the request for other groups which are not currently on the programme.
such as anger management and men’s groups. Therefore, perhaps the programme needs to be revisited in order to assess whether the groups on offer are appropriate to the needs of the clients.

Overall the summary reports appear to be meeting the needs of the referrers.

There are several limitations of this study. The first main problem was that not all potential and actual referrers were included, due to time constraints. For example, it was discovered towards the end of the study there was a second elderly team who were not included who referred clients to the DTC.

A further limitation of this study was the lack of qualitative information. It may have been beneficial to follow-up participants’ responses. This could have led to more meaningful detailed information such as understanding the meaning of peoples’ request for anger management groups. It also would have been valuable to establish reasons as to why some groups were considered helpful or not at all helpful.

The third drawback is that diversity and cultural issues were not considered in the questionnaire. On reflection, it would have been useful to explore whether the DTC referrers believed that clients from different backgrounds and cultures were having their needs met. The reason for asking this question could be that there may be an issue about accessibility of services for clients from ethnic minority backgrounds.

In a study of service users who had not attended a DTC, McGonagle et al. (1996) found that common reasons for non attendance included: not having their needs listened to when expressed; there was a lack of choice of therapeutic approaches and that individual needs were not met. Therefore a future recommendation of this study would be to present the study in conjunction with the audits carried out by Ediriweera et al., (1998, 2004) which included service user perspectives.

A final future recommendation would be to carry out a follow up study, which would aim to
include all referrers and aim to gain more qualitative information.
References


Appendices

Appendix A: Information brochure

Day Treatment Centre

Current Therapeutic Groups

Information for Referrers
TREATMENT CENTRE
UPDATE ON GROUPS AVAILABLE AT OCTOBER 2003
INFORMATION FOR REFERRERS

Treatment Centre runs a variety of therapeutic groups using different approaches & theoretical frameworks. There are both 'open' groups (ongoing, clients can join when place available) and 'closed' groups (time limited, no new people can join once the group has commenced). The following information is intended to give referrers and their clients a better understanding of the groups available. Referrers may indicate which group their clients may benefit from, however, the MDT evaluate which group is most appropriate for each individual after assessment.

OPEN GROUPS:

These groups are ongoing & clients are usually reviewed with a member of staff after 6 weeks attendance to evaluate their experience of the group and whether it would be beneficial to continue or consider another group.

WOMENS SUPPORT GROUP:

A supportive talking group where clients can discuss their difficulties and work towards making changes. The group provides a supportive environment for people to reflect on and explore their feelings.

MIXED SUPPORT GROUP:

A supportive talking group for both men & women where clients can discuss their difficulties and work towards making changes. The group provides a supportive environment for people to reflect on and explore their feelings.

ART & CRAFT GROUP:

An activity based group where clients work on their own individual art & craft projects. The activities enable clients to build their confidence through the art, develop interpersonal skills and gain support from staff and clients. Art & craft hobbies may be continued as a leisure interest or a distraction technique outside of Willow House.

CREATIVE ART GROUP:

This differs from the art & craft group in that clients work together on a particular art project & plan future sessions together e.g. candle making, clay work, group paintings etc. This provides more opportunity for developing communication and social skills and gaining support.
POSITIVE LIVING GROUP:

This group is aimed at clients with longer term mental health needs. The group is primarily about lifestyle and improving clients' quality of life in terms of their productivity, self care and leisure. The facilitators adopt a client-centred approach & sessions are planned with group members. However, there is always space for people to share their thoughts & feelings and gain support as well as engage in some form of activity. Outside speakers are sometimes invited & links within the community developed.

ART THERAPY:

Through art therapy people can express and process their feelings and personal issues. Unresolved childhood issues, including abuse, can be worked on. Each session consists of art-making time followed by group discussion about the work. People do not need to be good at art but must be willing to use the materials.

Two art therapy groups are facilitated by an art therapist and co-worker utilising a psychodynamic approach. One of the sessions is open and one is 'slow-open' (commitment to attend is necessary & new members are announced in advance so that a safe, cohesive group may be developed).

RESOURCING GROUP:

This group focuses on identifying, enhancing & expanding client's personal resources & coping strategies to prepare them for the more specific exploration that is required in the closed groups. It is primarily designed to introduce clients to the group work process & can also be used for practical assessment purposes.

SENIOR CITIZENS SUPPORT GROUP:

A supportive talking group aimed at clients over 65 years. It is particularly useful for clients to meet other functional elderly people with mental health problems to provide social interaction & support. Facilitators encourage general discussion and an opportunity to share specific problems & difficulties.

RELAXATION:

This is a practical session where clients are given an opportunity to try different relaxation & breathing exercises. There is also some time in the session for people to share their feelings & discuss how they can apply techniques in their own life.
CLOSED GROUPS:

Clients are individually assessed prior to the group to ascertain their suitability, motivation & commitment to attend. The closed groups usually run for 8 weeks and group members are expected to attend every session and have some motivation to make changes in their life. The course outlines, described below, are flexible and tailored to meet the needs of each particular group of clients.

COPING WITH DEPRESSION:

8 week course outline as follows:
- Introduction, what is depression, symptoms and causes
- Activity and depression, pleasant events, activity scheduling
- Introduction to thought distortions and negative thoughts
- Challenging negative thoughts and behavioural experiments
- Introduction to core beliefs/schemas, underlying assumptions, coping with painful feelings
- Problem solving strategies; alternative beliefs
- Relapse prevention
- Summary, evaluation and what next?

The course draws on principles of cognitive behavioural therapy and requires clients to have basic literacy skills and ability to reflect and talk about their thoughts & feelings.

CONFIDENCE BUILDING:

8 week course outline as follows:
- Course introduction; what is confidence? How would you like to change?
- Introduction to assertiveness; knowing our rights
- Non-verbal communications; saying no; factors that knock our confidence
- What is self-esteem, its development & impact on daily life
- Introduction to negative automatic thoughts, self critical thoughts, thought distortions & challenges
- Core beliefs & underlying assumptions (what you believe/your rules for living)
- New core beliefs; giving & receiving criticism, dealing with social situations, overcoming shyness
- Summary & evaluation; looking ahead

The course draws on principles of cognitive behavioural therapy and requires clients to have basic literacy skills and ability to reflect and talk about their thoughts & feelings.

ANXIETY MANAGEMENT:

8 week course outline as follows:
- Getting to know each other; what is anxiety? causes, misconceptions and three systems of anxiety (physiological, thoughts, behaviour)
- Physical signs and symptoms of anxiety; coping strategies - breathing and relaxation exercises
• Coping with panic attacks; how thoughts can increase anxiety
• Identifying and challenging negative thoughts - breaking the spiral
• Behaviours in response to anxiety; distraction techniques
• Goal setting and facing our fears
• Anxiety and self care; managing the stresses of modern day living
• Summary & evaluation; coping with setbacks & looking ahead

The course draws on principles of cognitive behavioural therapy and requires clients to have basic literacy skills and an ability to reflect and talk about their thoughts & feelings.

COPING WITH VOICES:

This group is an opportunity for clients who hear voices (& who are distressed by them) to learn additional ways of coping & explore possible explanations for their voices. Clients are initially seen individually for a number of sessions in order to obtain detailed information about the voices and help with rapport and engagement.

8 week course outline:
• Introduction to course; voice hearers through history; rating scales
• Triggers to voices, current coping strategies, diary keeping
• New coping strategies, onset & characteristics of voices
• Unhelpful coping strategies, voice content, power of voices
• Challenging power & content of voices; evidence for beliefs
• Explanations of voices: medical/psychological/telepathic
• Life events exercise, evidence for & against psychological explanation; intrusive thoughts & auditory hallucinations (Morrison 1995)
• Summary & evaluation of course

LIVING WITH PSYCHOSES:

This group is primarily about giving clients information about psychoses and offering a supportive environment to discuss specific difficulties with their illness. The group is currently in its planning stage but referrals are now welcome.

Possible 8 week course outline:
• Introduction to course; participants' knowledge about psychoses, common symptoms associated with psychoses e.g. hearing voices, unusual beliefs; normalise experience of psychoses
• Causes of psychoses, identify problem symptoms & current coping strategies
• Current treatment/management for psychoses
• Coping strategies, self monitoring
• Factors that influence coping strategies e.g. anger, depression, signs of relapse
• Finance, accommodation, employment, identify goals for future
• Society/family/carers/loneliness/relationships/advocacy/stigma
• Summary of group, evaluation
OTHER SERVICES AT

SELF-SUPPORT GROUP:

This group is for individuals who have been discharged from and no longer need therapeutic input from staff, but would benefit from some continued support. Group members organise how they run this group themselves. Staff are not directly involved in the sessions but monitor attendance and are available should clients need assistance. Clients’ attendance and suitability for the group will be informally reviewed after a 3 month period.

5 DAY SUPPORT PROGRAMME:

Also provides an emergency 5 day support programme. This aims to provide an alternative to hospital admission, maintaining clients in the community. Individuals are assessed and if appropriate, invited to attend one group every day for a two week period. Should they feel the need to stay longer than one session, they are welcome to use the waiting lounge and kitchen during the hours of 10am to 3pm.

During the initial two week period, clients are regularly reviewed by the MDT and their programme adjusted according to their needs. The team then offer a reduced number of groups for clients to attend for six weeks until their next review.

CARERS’ SUPPORT GROUP:

We are currently planning to set up a carers’ support group for the carers and relatives of clients who attend . This is likely to meet during the evening on a monthly basis. The group aims to provide an opportunity for carers to reflect, share and discuss any issues related to mental health and gain support and information. Outside speakers may be invited to provide specific information according to the needs of the group.

New groups are developed according to the needs of our clients. The team are open to suggestions of other groups or services, which could meet the needs of referrer’s clients. Also, please feel free to contact staff should you wish to discuss a possible referral.
Appendix B: Letter sent out to referrers

2nd February 2005

Dear………………………………………………

I am a first year trainee clinical psychologist, based at X Day Treatment Centre and X CMHT. As part of my course, I am required to undertake a Service Related Research Project. I have chosen to carry out my research project at X DTC. The project title is "An audit of referrers’ views of X Day Treatment Centre for adults with mental health problems." The reason for carrying out such a study is to find out what people think about X DTC in terms of awareness, satisfaction with the admission process, treatment and discharge processes and to explore whether referrers believe that the clients’ needs are being met with the current services offered.

Furthermore, in line with Department of Health guidelines regarding Clinical Governance (DoH, 1997) and improving the quality of NHS services, two comprehensive audits of X Day Treatment Centre were carried out in 1997-98 and 2003. The 2003 report made several recommendations including, “A follow on survey including a survey of referrers views” Ediriweera et al (2004). Therefore, the current project aims to assess referrers’ views of the day treatment centre.

As you are a referrer or potential referrer to X DTC, I would like to ask you to take part in my study. The study will involve you completing the short questionnaire which is enclosed and returning it to me in the internal mail envelope to Jennifer Alcock, X DTC. The questionnaire should take no longer than 10 minutes to complete. It should be noted that any information which you provide will be treated as strictly confidential. All questionnaires will be anonymised and no identifiable information about you will be used in verbal or written format.

If I do not receive a reply from you within the next two weeks, I will telephone you and with your consent, I will carry out the interview over the telephone.

I hope you can see the value of such a study and I look forward to receiving your reply. If you have any concerns or questions, please feel free to contact me at THE DTC (Wednesdays only) or email: (anyday).

I would like to thank you for your time.

Yours sincerely,

Supervised by

Trainee Clinical Psychologist       Clinical Psychologist

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Appendix C: Questionnaire

REFERRERS' VIEWS OF X DAY TREATMENT CENTRE

Research Number: Date:

Have you ever referred clients to X day treatment centre?

Please circle your response?

YES NO

If yes, please answer questions 2 – 17. If you circled no, please tick why not?

☐ Not aware of X DTC

☐ Clients are not suitable. Please state why you think this

☐ Location – too far away.

☐ Location – inaccessible for clients.

☐ Other reason. Please state

How often do you refer clients to X DTC(approximately)?

☐ Less than once a year

☐ Once a year

☐ Once every six months

☐ Once a month

☐ More than once a month

In your own words, what services do you think X DTC provides?

........................................................................................................................................

........................................................................................................................................

How satisfied are you with your liaison with the staff at X DTC?

1 Extremely Satisfied 

2 3 4 5 Not at all Satisfied

Any Comments (problems, improvements):

........................................................................................................................................

........................................................................................................................................

How satisfied are you with the waiting times at X DTC?
How satisfied are you with the admission process (initial assessment and subsequent correspondence) at X DTC?

<table>
<thead>
<tr>
<th>1</th>
<th>Extremely Satisfied</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>Not at all Satisfied</th>
</tr>
</thead>
</table>

Any Comments (problems, improvements):

____________________________________________________________________________________

____________________________________________________________________________________

How satisfied are you with the range of therapeutic interventions offered at X DTC?

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<thead>
<tr>
<th>1</th>
<th>Extremely Satisfied</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>Not at all Satisfied</th>
</tr>
</thead>
</table>

Any Comments (problems, improvements):

____________________________________________________________________________________

____________________________________________________________________________________

Please rate how helpful you think each different service is to clients:

<table>
<thead>
<tr>
<th>Service</th>
<th>Extremely helpful</th>
<th>Very helpful</th>
<th>Helpful</th>
<th>A bit helpful</th>
<th>Not at all helpful</th>
<th>Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety Management</td>
<td></td>
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<td></td>
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<tr>
<td>Art and Craft</td>
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<td>Art Therapy</td>
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<td>Confidence Building</td>
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<tr>
<td>Coping with Depression</td>
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<tr>
<td>Creative Art</td>
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<tr>
<td>Mixed support</td>
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<tr>
<td>Relaxation</td>
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<tr>
<td>Positive Living</td>
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</tr>
</tbody>
</table>
Are there any groups, which X DTC does not currently offer, which you think would be useful? (Do you think clients’ needs are being addressed?)

We sent out an information brochure to referrers about 12 months ago (with a picture of a tree on the front, dated Oct 2003. It contained detailed information about the referral criteria and the groups we offer at X DTC).

Did you receive the information brochure about X DTC? (Please circle).

YES NO

Are there any other ways, which you think, would be helpful in raising the awareness of X DTC?

If you read the information brochure, please answer the following questions:

How useful was the brochure?

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Extremely useful</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>Not at all useful</td>
</tr>
</tbody>
</table>

What aspects of the brochure did you find useful/ not useful?

How could the brochure be improved?
Finally, we currently routinely send out SUMMARY REPORTS to referrers about the clients once they have completed a closed group.

What aspects of the summary reports do you like? (Length, content, etc).

What aspects of the summary reports do you dislike? How do you think these summary reports could be improved?

Any other comments?

Please return to XXXXX at X DTC in the internal mail envelope provided. Thank you.
05 June 2007

Dear Jen

Re: An Audit of Referrers Views of a Day Treatment Centre, which offers Psychological Therapeutic Interventions for Adults with Mental Health Problems.

I am writing to thank you for the excellent presentation that you gave to the Willow House team in June 2005 on the above audit that you conducted here whilst on an adult mental health placement between November 2004 – September 2005.

Yours sincerely

Clinical Psychologist
Ethics Approval from University

University of Surrey
PSYCHD CLINICAL PSYCHOLOGY
Service Related Research Project
Ethical Scrutiny Form

The nature of the proposed project is such that I am satisfied that it will not require scrutiny by the trust's ethical committee.

Name of Supervisor: ........................................
Signature of Supervisor: ...................................

Name of Trainee: ..........................................
Title of SRRP: .............................................

Date: 5/1/05 ..............................................
Abstract of Qualitative Project

May 2006

Year 2
Summary of Group Qualitative Research Project

Newspaper constructions of risk following protests about the publication of cartoons depicting the Prophet Mohamed ... A discourse analysis.

Objectives: The current study focussed on the media response to the “cartoon” incident of March 2006 during which a Danish newspaper published “cartoons” depicting the Islamic prophet Muhammad. Specifically, the study aimed to explore media representations of Muslims and Islam in response to this incident, focussing on the depictions of risk and threat conveyed within British newspapers.

Method: In exploring these aims, a qualitative research methodology was employed. Specifically, newspaper extracts (including text and images) relating to the depiction of threat and risk were selected from papers of varying political affiliations, before being subjected to a detailed discourse analysis, exploring the text’s discursive organisation and possible functional orientations. Here, a critical discursive psychology approach was undertaken, integrating elements of previously distinct discursive and Foucauldian discourse analytic traditions, within a social constructionist framework.

Results: Extracts of texts and images were discussed in relation to the following two predominant themes: ‘the separation of the majority Muslim community from the ‘extremists’” and ‘the protestors as wild men bringing Armageddon on the West’.

Conclusions: The study concluded by considering the way in which the British media generally portrayed Muslims in a negative light, reinforcing notions of risk/danger through use of simplistic text and imagery supporting these positions. In doing so the current findings were contrasted alongside wider literature from the field with regard to the study’s potential limitations.
Major Research Project

July 2007

Year 3

WORD COUNT: 19,980 (abstract 247)
Acknowledgements

I would firstly like to thank my research supervisors Karen Dodd and Arlene Vetere for their support and encouragement throughout the project. Then I would like to thank the people in the study who spoke so openly about their lives.

Finally, would also like to thank my husband-to-be, my family, friends and fellow trainees for their continued support.

For my sister, Jude.
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1 Abstract

This study is a narrative analysis of the accounts of six people who could be described as being older, who have Down's syndrome and who spent part of their childhood in institutional environments. The main research aims were to empower the participants to talk about their lives in their own words and then to explore their sense of themselves. The study drew on different types of narrative analysis including those of Murray (2003), Gergen & Gergen (1984) and Labov (1984). Semi-structured ethnomethodological interviewing was used to create six life stories, whereby all of the people spoke about their childhood, current lives and their future. One of these accounts is presented in full. The narrative analysis highlighted the main commonalities across all of the accounts, including loss, abuse, health, significant others, transition and resilience. The different narrative forms within the accounts were interpreted, such as 'tragedy' and 'heroic.' Significantly, none of the participants identified themselves as having 'Down's syndrome' or a 'learning disability' and nor did they identify with being 'older.' Instead, individuals identified themselves in relation to gender and social roles. Most participants were able to reflect upon their strengths, limitations and hopes. The structure, coherence and reflective nature of the accounts varied and this was related to the development of narrative skill. The main findings were discussed in relation to attachment theory, resilience and social roles. Subsequently, the clinical implications, limitations and finally the influence of myself on the research process and vice versa were explored.
2 Introduction

2.1 Living longer - older people with Down’s syndrome

Down’s syndrome is a genetic condition, which affects one in every one thousand babies born. People who have Down’s syndrome have some degree of learning disability\(^1\). In addition, some health problems are more common, such as eye and hearing problems, heart and thyroid difficulties, DSA, (2002). However, advances in healthcare technology and changes in societal attitudes have meant that people with Down’s syndrome are living longer. The average life expectancy of an individual who has Down’s syndrome has increased from 9.9 years in 1931-35 to 55.3 years in 1976-80, Carter & Jancar, (1983).

Changing times have also led to a shift in positivist approaches towards carrying out research with people with learning disabilities; in particular there has been an increase in the use of qualitative methodologies to explore subjective experiences. Hence, as people with Down’s syndrome are living longer it seems timely to find out from them about their experiences. There are no studies exploring how older people who have Down’s syndrome who once lived in long stay hospitals talk about themselves and their lives. In some ways this is a fairly exceptional group of people as they have lived through the experience of institutionalised care, which no longer occurs today. They are in the unique position to talk about how their lives have changed since leaving the long stay hospitals. This might be helpful for them and us in terms of understanding how historical, social and cultural factors have influenced people’s sense of themselves. Hence, this study aims to explore how older people with Down’s syndrome see themselves in the context of changing societal attitudes, shifts in government policy and advances in technology.

The current chapter will consider the literature that has already explored relevant issues such as: institutionalisation; deinstitutionalisation; the current situation for people with Down’s syndrome; identity; social identity theory; social comparison theory; narrative analysis and narrative development.

\(^1\) The term ‘learning disability’ will be used in this study as it is in accordance with accepted British terminology.
2.2 **Down’s syndrome – an historical overview**

2.2.1 **Institutions**

In the past, it was common for people with learning disabilities, including Down’s syndrome, to live in institutions\(^2\). Institutionalisation arose in the early nineteenth century with the industrial revolution. This revolution led to a mass migration to the cities and as a consequence the government set up the Poor Laws (1834) and built institutions for the ‘feebleminded,’ (www.mencap.org.uk). The original idea behind the institutions was to provide better living conditions than people would receive elsewhere and this was achieved in their early years of establishment (Merriman, 2007). However, in the end institutions meant that people were often segregated from the rest of society and frequently not valued or treated with respect. In 1948 the National Health Service (NHS) was set up and as a result institutions became ‘hospitals.’ In the classic study, ‘Asylums,’ Goffman (1961) highlighted the oppressive regimes of living in mental institutions and suggested that a person’s self-concept alters when they enter an institution due to the changes in social roles (e.g. losing one’s name, separation of oneself from one’s belongings and the denial of sexuality).

2.2.2 **Deinstitutionalisation**

The growing awareness of the oppressive practices of the institutions led to a change in society’s attitude and a rise in new ideas, such as ‘normalisation’ and ‘social role valorisation.’ (Nirje, 1969; Wolfensberger, 1972, 1983). These ideas were behind the closure of long stay hospitals and a resettlement of people with learning disabilities into smaller community-based homes. The main premise behind ‘normalisation’ was that people with learning disabilities should be treated the same as everyone else. Normalisation was operationalised in terms of O’Brien & Lyle’s (1987) five service accomplishments, e.g. ensuring that service users could make choices and be respected in the community.

The reported effects of the closure of the institutions are mixed. Emerson & Hatton (1994) reviewed the research on deinstitutionalisation in the UK between 1980 and 1994 and reported several positive effects (e.g. smaller community homes often resulted in an increase in engagement in activities and more choice). However, they also found no differences with respect

\(^2\) The terms ‘institution’ and ‘hospital’ will be used interchangeably throughout this study.
to ‘reported challenging behaviour’ 3. An additional criticism of normalisation was how does one define ‘normal?’ Klotz (2004) argues that normalisation does not accept people with learning disabilities as they are. Brown and Smith (1992) argue that normalisation neglects gender, race and class.

2.2.3 Current situation of older people with Down’s syndrome

Currently older people with Down’s syndrome tend to live in smaller community-based homes or with their parents. Many studies have investigated the major health problems which are common in this population. For example, Prasher (1995) reported a 54% prevalence rate of Alzheimer’s disease in people over 60 years old. Several authors argue that most research on older people in general is negatively biased. For example, Bond et al. (1993) discuss how policy makers are preoccupied with the sickness, poverty and mental deterioration of older people. They advocate that research needs to consider also the pleasures and achievements that growing older brings. Likewise, there is a need to study the lives of people who have Down’s syndrome as people are living longer nowadays and there is a lack of research into their lived experiences and from their point of view.

2.3 Down’s syndrome and identity

Today, there appears to be a move towards recommending that parents help their children to understand ‘Down’s syndrome’ and what it means. For example, the Down’s Syndrome Association (DSA) recommend books for children about what it means to have Down’s syndrome, e.g. Bryan (2000). However, DSA do not have any books explaining Down’s syndrome to adults. Furthermore, there are few studies specifically addressing how individuals with Down’s syndrome view themselves. Cunningham and Glenn (2004) investigated the self-awareness of 77 young adults with Down’s syndrome. The authors reported that only those children who were older than eight years old made social comparisons and formed social categories of Down’s syndrome and disability. From this study, the authors recommended that parents discuss topics of Down’s syndrome and disability openly within the family and be proactive in taking opportunities to inform the child that they have Down’s syndrome and learning disability according to their ability to understand. Beart (2005) points out a limitation of the Cunningham and Glenn study as she highlights that the authors used three measures of awareness

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3 In Emerson & Hatton’s study (1994) staff of the smaller community homes were asked to complete standardised rating scales to measure the ‘challenging behaviour.’
Major Research Project

of Down’s syndrome (parental report; interview with young person including direct and indirect questions; and a photo sort) and stated that awareness was present if the person reached a ‘two out of three’ of these measures. Beart (2005) states that the ‘two out of three’ criteria for awareness is flawed as it assumes that some people were aware of Down’s syndrome on a verbal level but not visual or vice versa. Beart argues that if this is true then awareness involves ‘different aspects of cognitive functioning.’

Fifty years ago things were very different with regards to disability. The Down’s syndrome Association describes how government legislation and public attitudes led to parents feeling ashamed about putting their children with Down’s syndrome in institutions, (http://www.downs-syndrome.org.uk/). It was common for people with Down’s syndrome to be stigmatised and discriminated against. Anecdotal evidence suggests that older people with Down's syndrome who lived in institutions may never have been told they had Down’s syndrome. Some may have been told they were ‘high grades’ or ‘Mongols,’ (K. Dodd, personal communication, 11th November 2006). It is therefore possible that older people with Down's syndrome, (particularly those who lived in institutions) do not identify themselves as having Down’s syndrome. Furthermore, there was anecdotal evidence that this group may not identify with being ‘old’ as they are unlikely to have gone through the typical life stages that people without Down’s syndrome go through (e.g. having children, children leaving home, retirement, becoming a grandparent) (K. Dodd, personal communication, 11th November 2006).

2.4 Definitions of self and identity

The ‘self’ and ‘identity’ are difficult concepts to define. Deaux (1992) views the ‘self’ as a more global concept and refers to ‘identity’ as being related to more specific aspects of self-definition including social roles and personal internal and external characteristics (e.g. caring and tall). There exists debate over the distinction between personal and social identity. Craib (1998) states that personal identity can be separated from social identity. In contrast, Burkitt (1991) argues that individuals derive their identities from social interaction and hence all identity is socially constructed.

There has been a shift from the modernist view of the self as a relatively stable concept, (e.g. personality theorists, such as Costa and MacRae, 1992) to the self being made up of multiple identities. That is, a person has multiple identities for the different positions they hold in society,
Stets & Burke (2005). The symbolic interactionist tradition claims that individuals adopt multiple roles and enact multiple performances in order to negotiate meanings, status, and position in everyday social life. Furthermore, this perspective states that the ways in which people interact with others in our social world are central to the development of self and the construction of social identities. From this perspective, Mead (1934) argues that the development of self is a social process. This concept of multiple identities is discussed in work by Thoits (1983, 1986) who showed that multiple role identities are better for a person’s well-being because they give lives greater meaning and offer a variety of guides for behaviours.

Another more recent perspective is the postmodern view of the self, which is concerned with a relational self whereby it is seen as the ‘self-in-action’ which is constantly created and recreated through social interaction (Flaskas, 1999). From a radical social constructionist viewpoint, Gergen (1994) states that the self is socially constructed embedded in the historical and social context. That is, there is no true reality and the world exists within the confines of language.

Several authors have highlighted the limitations of the postmodern self. For example, Flaskas (1999) suggests that the postmodern self does not take into account the experiential self, which cannot be put into words. She suggests that as well as thinking about language as a social process, it is important to think about it as an emotional process. Flaskas cites Bollas’s (1987) idea of the ‘unknown thought’ and how people also hold an awareness of unconscious attachment patterns and that during life-threatening times people have emotional experiences which ‘exist outside words.’ Hence, she argues that the narrative constructs experience but is also constructed by experience. Throughout this study, my beliefs about the ‘self’ have changed. I initially felt ambivalent as on the one hand I saw how the self is fluid, relational and exists in language. Then on the other hand, I saw Flaskas’s (1999) argument for a more autonomous self, which existed without language. I then saw the benefits of both positions.4

2.4.1 Social identity theory

One approach to studying awareness, self-perception, and discrimination is ‘social identity theory’ (Tajfel & Turner, 1986). This theory stems from Festinger’s social comparison theory

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4 The development of these ideas will be considered further in the Discussion section.
and states that our group evaluations are essentially relative in nature; we assess our own group’s worth by comparing it with that of other groups. The outcome of these social comparisons contributes to our self-esteem. If the group we belong to is perceived as superior to other groups, we will feel better about ourselves. Several researchers have applied social identity theory (SIT) to explore how people with learning disabilities see themselves and this will be discussed later. There are several criticisms of social identity theory. For example, Craib (1998) argues that sociological approaches to identity do not consider the subjective experiences, thoughts and feelings of the person sufficiently. Craib adds that social identities come and go, unlike identity which ‘overflows, adds to and transforms the social identities,’ (pp 4).

2.4.2 Social comparison theory

Social comparison theory is the process by which we evaluate ourselves through comparison of others, Festinger (1954). A ‘downward comparison’ is when individuals compare themselves to someone whom they see belongs to a group which is inferior to themselves. Downward comparisons are believed to maintain self-esteem, Swallow & Kuiper (1988). In addition, having a wide range of roles and attributes is thought to buffer against the effects of negative social comparisons, Linville (1987).

Several researchers have examined social comparison processes with people with learning disabilities. For example, Gibbons, (1985) reports that people with learning disabilities make downward comparisons with their peer group, to maintain their self-esteem. However, it is important to note that not everyone has access to a peer group or an opportunity for someone to talk to about themselves. Similarly, in a study investigating the social comparisons and perceptions of stigma in 50 people with mild learning disabilities, Szivos-Bach (1993) reported that those people with the most stigma and the lowest self esteem had the greatest discrepancy between the way they saw themselves and the way they saw others. Dagnan & Sandu (1999) found that social comparison is associated with self-esteem and depression for people with a learning disability, in the same way as people without a learning disability.

2.5 Learning disability and identity

Central to identity studies with people with disabilities is labelling theory, as a ‘learning disability’ is assumed to be a social construct, which is used to label people. Labelling theory suggests that when a person is labelled with a ‘mental illness’, they internalise society’s
assumptions about people with a 'mental illness'\(^5\) and as a result experience difficulties, (Scheff, 1966). In a critique of Scheff’s theory, Gove (1970) highlighted that people with a diagnosis of a 'mental illness' report little direct discrimination. Scheff’s theory was later developed by Links et al. (1989) who proposed the Modified Labelling Theory (MLT). The MLT posits that even if labelling does not directly cause 'mental illness', it can lead to negative outcomes, such as the development of beliefs and expectations of what it means to have a 'mental illness.' This can in turn lead to a development of 'maldapative' (self-protective) coping strategies, such as secrecy and withdrawal and hence result in people becoming isolated. Links et al. (1989) conclude that these coping strategies can also lead to an increase in unemployment and low self-esteem. On a similar note, the BPS (2000) guidelines on learning disability highlight that labelling can be socially devaluing as can the social consequences of labelling and hence *meaningful change for individuals would include the wider social and political systems.*

Many authors argue that there are a number of common consequences of the social identity of learning disabilities. For example, Beart (2005) cites studies by O’Connor (1992) and Koller et al. (1988) who argue that people with learning disabilities are less well off and are less likely to marry. Beart (2005) discusses how these negative consequences can come about through stigma and the internalization of the stigmatized identity. In addition, Beart discusses how a person may not be aware of their true sense of self and their capabilities due to being in denial or having an unawareness stemming from the protection of others (e.g. Todd & Shearn, 1999). Drawing on labelling theories, Mead’s (1934) symbolic interactionism, and Goffman’s (1974) studies of stigma, Edgerton (1967) carried out an ethnographic study (in depth interviewing and participant observation) on the perspectives of people with learning disabilities who used to live in institutions. Edgerton argued that the participants could not accept themselves as 'mentally retarded' and subsequently 'worked at seeming to be normal.' His evidence for this included that people gave excuses for being in the hospital.

There have been several criticisms to Edgerton’s study. For example, Bogdan & Taylor (1982) rejected the idea that people are ‘working at being normal’ to hide the stigma of being learning disabled. Instead, the authors concluded that people labelled as ‘mentally retarded’ have been covered in a ‘cloak of incompetence.’ The authors argued that the term ‘mental retardation’ tells us about society rather than about the individual. Furthermore, Gerber (1990) stated that

\(^5\) ‘Mental illness’ is arguably another socially constructed term. A more appropriate term is mental distress.
Edgerton's approach meant he was questioning the validity of his participants' accounts and failing to recognise the resilience of those who had been institutionalised, as he did not consider the socially constructed nature of learning disabilities.

In a literature review on social identity theory in people with learning disabilities, Beart (2005) highlights that many people do not see it as a salient identity. She suggests that this lack of salience could be explained by such people not having access to or discussion about the label. For example, Davies & Jenkins (1997) argue that the 'learning disabled' identity is the 'master status' and that this affects other identities. The authors found that 42% of the sample did not know what the terms 'learning disability' and 'mental retardation' meant and 30% gave a definition of the terms, which excluded themselves. Davies & Jenkins (1997) concluded that even though people with learning disabilities were not aware of the label at the level of discourse, they internalised the identity at an emotional level, e.g. despite not talking directly about learning disabilities, the participants often spoke about wanting to be like their siblings. Beart (2005) also discusses ideas by Sinason (1992) who from her therapeutic experience hypothesises that being labelled is an emotionally painful experience and thus people with learning disabilities use denial to deal with the pain of their social identity.

From a social constructionist view, Rapley (2004) argues that a 'learning disability' is a social and cultural construct, which is open to negotiation through social interaction. That is, when an individual encounters discourses that focus on difference and abnormality, the view that a person with a disability is outside mainstream society is reinforced. Furthermore, Rapley (2004) states that people are aware of the social identity of learning disabilities and that they manage identity construction in talk by doing 'being ordinary.' The social construction of the label is also discussed by Finlay & Lyons (2005), who argue that people do not identify with the label because it does not fit with their personal experience and social arrangements. Finlay & Lyons (2005) state that '...it would be unreasonable to expect people to represent themselves on the basis of a single, abstract label when lived experience shows that label to be partial, unclear, without standard concrete referents, temporary, and internally inconsistent.' The authors argue that other information on identity is also important, and that this can often challenge the stereotypical versions of the individual.

2.5.1 Positive aspects of labelling

As stated above, various studies have highlighted the theoretical difficulties with labelling
someone as having a ‘learning disability.’ However, Davies & Jenkins (1997) point out that these studies do not address the issue of the role of the label in establishing access to support and resources. The British Psychological Society (BPS, 2000) have produced guidelines for practitioners on definitions and concept of ‘learning disability.’ The guidelines state, ‘...given that it is a social construction and whatever one’s views are on its theoretical basis, it has to be acknowledged that the concept is enshrined within our social and legal systems. As such, the concept affects peoples’ legal and civil rights.’ The BPS document therefore advocates that practitioners should acknowledge a person’s disability as otherwise they may denying them their rights to justice or equality and access to services.

In addition, Szvios (1992) advocates that people should be labelled rather than denying that they are not different. She argued, ‘...by constantly underplaying and denying such feelings we may give an implicit message that being different is shameful.’ Szvios (1992) also reported on the findings of a consciousness-raising group, which aimed to increase self-awareness and self-esteem. The group ran for 13 weeks and offered the opportunity to share experiences, to talk openly about the meanings of their labels and experience a sense of loss for the non-disabled person they aspired to be. The group was evaluated by means of a modified Piers Harris Self-Esteem Scale and it was found that participants’ self-esteem increased significantly. Szvios explained that care is needed when selecting the label. However, she proposed that the label needs to be named before it can be explored.

Zetlin & Turner (1984) reported that people whose parents spoke openly with them about their learning disability were better adjusted as adults. Their study involved investigating the attitudes of 46 ‘mildly mentally retarded’ adults towards their disability. They carried out participant observation and interviews with the participants and their families and then identified four ways of classifying the people in terms of their attitudes on their willingness/reluctance to discuss ‘handicaps’: 1) acceptance (e.g. ‘I’m retarded’); 2) qualification (e.g. ‘I’m slow in reading but not retarded.’) 3) vacillation (e.g. ‘I may have trouble reading but I do not consider myself to be handicapped) and 4) denial (e.g. ‘I don’t have any problems’). The authors reported that the parents of ‘acceptors’ and ‘qualifiers’ believed their sons or daughters were capable of accomplishments and therefore actively promoted growth. In contrast, the authors stated that those parents who had difficulty adapting to their children’s disability either set unrealistic goals for their children or were over protective and restricted the life experiences of individuals. Hence, it was argued that the ‘vacillators’ and ‘deniers’ groups did not strive for
accomplishments or growth. A major limitation, which was discussed by the authors, was that people switched between groups. For example, moving from being a 'denier' to a 'vacillation' and that this switching was dependent on audience, setting and circumstance. Therefore the current study reported here aims to take a more naturalistic approach in terms of studying the self-perceptions, which accepts that 'self-perceptions' are more fluid, relational and situational.

2.6 Narrative and identity

One approach to studying identity is through the use of qualitative narrative research. Murray (2003) emphasises how we tell stories to ourselves and to others about our lives and how the narrative gives a structure to our sense of self. Furthermore, McAdams (1985) argues that identity is a life story and that 'identity stability' is longitudinal consistency in the life story and that 'identity transformation' is a story revision.

Narrative approaches, such as life reviews have been used with older people as an opportunity for exploring identity. For example, Coleman (1986) suggests that the life review approach maintains a person’s sense of identity, as it allows a person to understand negative experiences and draw lessons from them, and hence feel more whole and integrated. Atkinson (2004) argues that the sense of identity comes with the overview of one’s past life and achievements.

2.6.1 Narrative research and people with learning disabilities

Meininger (2006) makes a distinction between different life story approaches, which have been used with people with learning disabilities. He describes the ‘chronicle’, which is a chronologically ordered listing of facts that charts a person’s life. Then, the ‘life book’ (or memory book), which is compiled by the person with learning disabilities, often in collaboration with parents, relatives and professionals. The third type of approach highlighted by Meininger is the ‘life story’, which he states is a narrative composition based on selected experiences of the person with learning disabilities. As well as Meininger’s distinction, Atkinson & Walmsley (1999) distinguishes between research studies, which focus on oppression in the lives of people with learning disabilities, such as Booth & Booth (1994) and Flynn (1989) versus those studies, which look at the ‘ordinary lives,’ Deacon (1974).

The use of autobiographical approaches with people with learning disabilities is discussed by Atkinson & Walmsley (1999). The authors argue that the telling of a life history enables a person
to make sense of their lives and claim an identity, rather than having powerful others construct their identity. It is worth considering the reasons why people have not used autobiographical approaches in the past. Atkinson & Williams (1990) point out that people previously assumed that people with learning disabilities did not have the capacity to tell their stories. Furthermore, society has not listened to people with learning disabilities, which has led to them becoming silenced voices, Bogdan & Taylor, (1990). Booth & Booth (1996) highlight the practical challenges of carrying out narrative research with people with learning disabilities: inarticulateness; unresponsiveness; a concrete frame of reference and difficulties with the concept of time. The authors however go on to describe how through the process of interviewing ‘Danny,’ the challenges can be overcome, such as paying attention to even ‘the small particulars and happenings’ and to ‘recognise that the task of learning to communicate with subjects takes a long time.’ Narrative work aims to empower, as it treats people like ‘expert witnesses’, (Atkinson, 2004; Booth & Booth, 1998, Birren & Deutchman, 1991).

### 2.6.2 Narrative development

When considering narrative research with people with learning disabilities, it is worth paying attention to the development of narrative abilities. The time at which narrative abilities develops is under debate. In Vygotsky’s theory of moral development, the narrative or 'story-telling' function typically develops when a child is aged between two to three years, Vygotsky, (1987). Various studies have shown how young children can tell stories about their own past (Hudson, 1990; Miller & Sperry, 1988; Nelson, 1989). Another view is that the ability to narrate one’s ‘life story’ occurs later on in life. Pasupathi & Mansour (2006) report that as adults get older, they are more likely to demonstrate autobiographical reasoning when constructing personal narratives.6

### 2.6.3 Language and Narrative development

When considering narrative development, it is important to consider language. Dallos (2004) states that the ‘ability to develop stories about one’s life is a sophisticated ‘skill,’ which is shaped by the ways in which parents talk to children such that the ability can be facilitated or retarded.’ Language enables people to organize their experiences and share information with others. Even before a child is able to talk, they have the ability to temporarily sequence events, Bauer, (1997). However, researchers argue that language allows for a deeper and more complex organization of

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6 Pasupathi & Mansour (2006) base their approach to the self on Erikson & Erikson (1997) and McAdams (1993) and state that ‘the development of the self consists of the integration of autobiographical experiences into a coherent life story.’ (pp. 4).
personal memories (Bruner, 1990; Fivush & Haden, 1997). In addition, the ability to talk about an event in the context of one's life allows a child to develop an autobiography (a self with a past, present and future), (Habermans & Bluck, 2000). Labov\(^7\) (1967, 1982) suggests story telling is being able to describe an event, but also evaluate it. In addition, having language and hence having the capacity to narrate one's life enables a person to co-construct their personal experiences with others.

Research shows how adults can facilitate young children to use language to describe, organize and evaluate their experiences through the use of early parent-guided reminiscing (Nelson & Fivush, 2002; Fivush, 1991; Haden et al., 1997). The authors argue that when primary caregivers encourage children to reminisce, the children are better at telling stories of their own experiences later on in life. In contrast, when caregivers simply repeat the same questions over and over, children may develop more fragmented, disorganized memories of their past. This in turn may mean that they have more difficulty understanding who they are in relation to their own past experiences or in relation to others with whom they have shared these experiences. Fivush (2001) explains that reminiscing with others allows children to come to understand that their perspective on the event may or may not be the same as someone else’s perspective.

### 2.6.4 Attachment theory and narrative development

Narrative development is also thought to be related to early attachments. Holmes (2000) defines narrative as the capacity to link ‘raw experience to a world of meaning: this is a developmental function deriving from early attachment experience.’ In addition, Dallos (2004) highlights various research studies, which indicate that the development of a child’s narrative is connected to the emotional context of the family (Main et al. 1985; Fonagy et al. 1991).

Attachment theory was founded by Bowlby (1969; 1973), who suggested that attachment with an adult caregiver ensured the safety of children. Four styles of attachment have been developed: secure, avoidant, resistant or ambivalent, and disorganized/disoriented (Ainsworth et al. 1978; Main & Solomon, 1990). Despite these classifications, it is worth noting that these styles are seen as dynamic constructs rather than stable fixed units. Heard (1982) proposes that attachment theory provides an underlying theoretical framework that explains many aspects of everyday

\[^7\] Labov (1967) defined a ‘fully-formed narrative’ as having six common elements: abstract, orientation, complicating action, resolution, evaluation and coda.
major research project

social behaviour in families (a developmental theory of the social regulation of emotion in family groups). She argues that attachment-working models are considered as dynamic interpersonal constructs linking cognition, affect and behaviour. From a family systems perspective, Byng Hall (1999) highlights the significance of the emotional context of the family. He defines a secure family base as, ‘a family that provides a reliable and readily available network of attachment relationships, and appropriate caregivers, from which all members of the family are able to feel sufficiently secure to explore their potential’ (1999, p. 627). In the current study, I am interviewing people who once lived in long stay hospitals when they were younger. Hence, it will be important to consider that their narrative ability may have been influenced by the separation from their parents and their emotional relationships within the institution and the opportunities for consistent relating.

In addition, as I intend to interview older people who have Down’s syndrome, it is important to highlight that attachment is relevant across the lifespan. There has been a shift in paradigm from infant attachment theory (Bowlby, 1969; Ainsworth et al. 1978) to attachment patterns in adult relationships (Hazan & Shaver, 1987). Cookman (2005) highlights the need to study attachment in older people. Bradley & Cafferty (2001) highlight that attachment issues are particularly relevant for older people as there is an increased potential for separation, loss and vulnerability associated with ageing. The authors conclude that attachment patterns are associated with a variety of outcomes in later life (such as adaptation to chronic illness and caregiver burden among family members, reactions to the death of a loved one, and general well-being).

2.7 Qualitative methods

Narrative analysis was chosen as the most suitable method to address the research questions as it seeks to facilitate participants to tell their own stories in their own ways, (Dallos & Vetere, 2005). There are various forms of narrative analysis, which vary depending on the epistemological position of the researcher. For example, Crossley (2000) discusses a form of narrative analysis, which is based on a ‘realist’ position." In contrast, Gergen & Gergen (1984, 1988) suggest that there is no objective social reality ‘out there’ to be discovered and that narratives are social constructions, formed through the social interchanges. Narrative analysis seemed an appropriate method as it allowed me to be open and flexible in terms of my epistemological position. Hence, I am aware that my attitude towards research is consistent with the pragmatist view, whereby I have chosen a method, which suits the research question (Marks & Yardley, 2004). I am aware that this view has developed over the course of my clinical psychology training, whereby I
believe that human interpretation and subjective meanings construct multiple social worlds and thus a diversity of truths (the constructionist view). However, I also believe that as well as considering interpretations, intentions and values, research should be grounded in empirical, embodied experience (critical realist view), (Robson, 2002).

Lieblich et al. (1998) distinguishes between two different dimensions in Narrative Analysis: a) *holistic* versus *categorical* and b) *content* versus *form*. The holistic approach is used when the researcher is interested in the person as a whole, whereby the life story is taken as a whole and sections of the text are interpreted in the *context* of the other parts of the narrative. This holistic approach was appropriate for the present study as I was partially exploring identity. With regards to the second dimension of *content* versus *form*, Lieblich et al. (1998) explain that *content* concerns what is said, what happened, who took part, etc. In contrast *form* is concerned with the structure of the plot, the sequencing of events, its relation to time, its coherence, feelings evoked by the story and its style. Lieblich et al. stresses that the *form* orientated approach accesses deeper layers of the narrator’s identity. Hence, as I was concerned with identity, I decided to consider both the *content* and *form* in my approach to Narrative Analysis.

In terms of a specific approach, I drew from various philosophies and principles from a number of narrative researchers to enable me to engage with and understand the meanings of the participants’ stories, including (Dallos & Vetere, 2005; Michael Murray, 2003; Labov & Fanshel, 1977 and Gergen & Gergen, 1984).

Narrative analysis also seemed an appropriate method as it has a specific focus on the way individuals draw on culturally sanctioned ways of thinking and being to construct stories. This appeared to be relevant to my study, as I was interested in the historical and cultural context of older people with Down’s syndrome. In addition, narrative analysis has been used to study the concept of identity and it has been used with people with learning disabilities, as it is a non-threatening approach, which can empower individuals, (Booth & Booth, 1996; Atkinson, 2001). Story telling allows people to bring order to chaotic lives and develop their sense of selves and their lives, Murray (2003). The limitations of narrative analysis will be discussed in the Discussion section.
Another approach, which could have been used, is Interpretative Phenomenological Analysis (IPA), Smith et. al. (1999). This is a phenomenological approach coming from a critical realist epistemology, which is concerned with the subjective experience of psychological phenomena. That is, it focuses more on embodied consciousness, what it is like to live through individual experiences. An underlying assumption of IPA is that the descriptions of experience provided by participants represent their actual experiences of an event. I chose not to use IPA as it is a theme analysis and hence not designed to analyse narrative form and structure. I felt it neglected the idea that language is shaped by cultural and historical factors. I also thought that IPA does not consider the whole person, their context and their view of their lives over time, which seemed relevant to my study.

Another interpretative qualitative method is Grounded Theory (Glaser & Strauss, 1967), which is the generation of theory from data. The researcher starts with a general research subject and builds their research question as they collect data allowing the research question to emerge and develop with the collection of the data at the same time as developing theory. Grounded Theory is most commonly used when exploring a relatively new area and exploring processes and it aims to produce a new theory. Therefore, this approach did not seem ideal in my study, as there has already been a fair amount of research carried out on the identities of people with learning disabilities.

As with Narrative Analysis, Discourse Analysis (Potter & Wetherell, 1987) is another method, which focuses on language. This method involves considering the functions being performed by the language. It is concerned with the construction and negotiation of meaning and power in discourse and interaction. Epistemologically, discourse analysis takes a social constructionist position and defines a transcript as purely a text, and a text from which we should infer nothing about the psychological state or intentions of the people who produced it. This may have been a useful approach to use; yet I was reluctant to use it, as I believed that I wanted to try and represent the experiences of the participants as being ‘real’ to them, rather than representing my own reading however theoretically informed.

2.8 Theoretical rationale

The main reason for doing this study is to hear the untold stories about how older people with Down's syndrome talk about themselves. Exploring how these individuals talk about themselves
will contribute to understanding their self-concept and self-esteem. This has implications for how we organise and deliver services. Another reason for doing this study is that it will be useful in terms of suggesting to those people who have regular contact with them (staff and service providers) about how they can think about their relationships (in terms of understanding and relating to people with learning disabilities). That is, work could be carried out to help older people with Down's syndrome to develop their positive identities and maximise their potentials. Finally, this is a preliminary exploratory study, which aims to be a basis for future work in relation to older people with Down's syndrome.

2.9 Current research questions

The main research questions are:

- When invited, how do people tell their life stories?
- Do people compare themselves to others (downward/upward social comparisons) and if so, how?
- Do people have positive or negative self-concepts? Are they aware of what they can and cannot do in relation to others without a diagnosis of Down’s syndrome?

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8 This is discussed on page 195 of the Discussion section.
3 Method

3.1 Recruitment strategy

Potential participants were recruited via a local NHS Trust in the South East of England. My research field supervisor and assistant psychologist (who worked with people with Down’s Syndrome in the NHS Trust) identified potential participants by searching through a database of longitudinal information of people with Down’s syndrome, called the Down’s syndrome project. Participants were selected who met the inclusion criteria below:

1. Diagnosis of Down's syndrome
2. Men or women
3. Older than 50 years of age. (For the purposes of this study my supervisors and I decided upon 'older' being over the age of fifty years old. This was based on life expectancy data)
4. Those participants with relatively good expressive and comprehensive language skills. This was assessed using their scores on the Picture Naming subtest of the Neuropsychological Battery for Dementia in Adults with Intellectual Disabilities (NAID), (see Oliver et al., 1998, 2005; Crayton et al., 1998). Participants were selected if they scored over 10 on Picture Naming. (K. Dodd, Personal Communication, 14th May 2007)
5. Do not have a diagnosis of dementia
6. Spent some part of their childhood living in a long stay hospital
7. English as their first language. This was because English is my first language and I analysed the data. I believed that meaning and understanding may have been lost if an

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9 The Down's Syndrome Project is a project, which is being carried out by the Psychology department of the NHS Trust. It is managed by the Head of Psychology and involves a database of longitudinal information of people with Down's syndrome for the purposes of clinical work. I did not have access to the database.

10 The Picture Naming subtest involves showing a participant 14 pictures (and two practice pictures), which have been taken from the British Picture Vocabulary Scale (BPVS), ranging from number 1 (hand) to 23 (arrow). The participant is asked to name each picture. Crayton et al. report that the Picture Naming subtest of the NAI D has good reliability (Cronbach’s Alpha = 0.87; Spearman’s Brown split half reliability = 0.90, K. Dodd, Personal Communication, 14th May 2007).
interpreter was used. In addition, I did not have the resources in place to use an interpreter.

3.2 Ethical Issues

Ethical approval was obtained from the Local Research Ethics Committee and the University of Surrey Advisory Committee on Ethics (Appendix 1). The main ethical issues were:

3.2.1 Ensuring understanding and acquiring consent

My research field supervisor wrote to potential participants (who met the inclusion criteria above) asking if they wished to be telephoned by me (see Invitation Letter, Appendix 2). In addition, the letter recommended that the participant talk this decision through with their keyworker. This letter was copied to the participant's residential home manager and their keyworker. The participant was asked to send back a reply form indicating whether they would like to be telephoned to discuss the study.

I then telephoned those potential participants who indicated that they wanted to be called back and arranged a meeting, whereby I went through the Participant Information Sheet and Consent Form (Appendices 3 & 4). I initially checked whether the person had any visual, hearing or physical impairments by asking them and their keyworker. If they did, the methods were adapted accordingly (e.g. I spoke louder). The participant information sheet, consent form and interview questions were all designed using clear plain English, which was deemed suitable for people who have learning disabilities.

When going through the forms, I used Arscott’s et al. (1998) recommendation of asking questions about the study to assess whether they had understood what I was doing. If it was apparent that the person did not understand the forms on their own, it was assumed that they did not have the capacity to consent to take part in this study. All of the participants’ key workers or their home managers also signed the consent form and family members of three of the participants also all gave their consent for them to take part in the study. Once I had gone through the forms, I left the information with them and their key worker, so that they could have a think about whether they wanted to take part and then I re-visited them a week later to find out their decision. Continued verbal consent was gained throughout the study process. That is, at the beginning of each
interview, I asked the person if they wanted to carry on taking part.

3.2.2 Sensitive issues

I explained to the participants before the interviewing that this study may bring up difficult issues and that if they became upset and I was worried, I would have to tell my research supervisors and tell someone of their choice who they knew well (e.g. key worker).

3.2.3 Reducing the potential for distress

Precautions were taken to prevent participants becoming upset during the interviews. The questions in the interview schedule were carefully worded and I developed a good rapport with individuals. I used a similar approach to Finlay & Lyons (2000) & Booth and Booth (1998) who adopted an informal style of interviewing to create a relaxed atmosphere. I only carried out the interviews when I knew that there was a member of staff present in the participant’s home who knew them well. I initially focused on asking questions in the current situation, as I thought that these would be potentially less threatening than questions relating to a person’s past as participants may not have fully processed painful childhood memories on a cognitive or emotional level.

3.2.4 Anonymity and digitally recording interviews

Anonymity was maintained throughout the research process. Names and any potentially identifying details about the participants were changed. All raw data were kept in a locked filing cabinet in the researcher’s home. In addition, the interviews were digitally recorded and these recordings were kept in a secure place. Then the plan was to destroy them 12 months after project completion.

3.3 Procedure

3.3.1 Participants

Six participants took part in this study. In the first stage of recruitment, 18 participants met the inclusion criteria. I adapted a Grounded Theory approach (Glaser & Strauss, 1967), whereby I used theoretical sampling and constant comparison. That is, I selected a group who met the inclusion criteria described above (pp 167). From the analysis of the first transcript and its emerging ideas I decided that I wanted to speak to someone else (that is, I was interested in
speaking to a whole person rather than just focussing on them as having ‘Down’s syndrome’ or being a ‘Mongol’). Hence, I realised that I wanted to ask more expanding questions and to explore topics in more depth rather than jumping from topic to topic and I wanted to ask more evaluative questions in order to explore the meaning and significance of events. Thus, I developed a hypothesis that I needed to talk to participants about their lived experiences in order to answer my research questions about identity. Thus, following that I carried out the second interview and asked some different questions and then the third. Then using comparison with the first participant’s interviews, I sought a second participant who embodied certain abilities\(^\text{11}\), with certain lived experiences and this process continued as I interviewed subsequent participants.

Table 1. shows the main demographic details of the participants, without providing too much information in order to protect anonymity. The number of participants was decided upon after consultation with my supervisors. It should be noted that the sample size varies in studies employing narrative analysis. For example, Roets & Van Hove (2003) carried out a narrative analysis on the accounts of two women with learning disabilities. Whilst the sample size is small, the use of narrative analysis ensured that the descriptions and interpretations were rich.

\(^{11}\) The embodied abilities related to a person’s language and reflective abilities.
Table 1. Demographic information of the participants

<table>
<thead>
<tr>
<th>Name*</th>
<th>Age</th>
<th>Living situation</th>
<th>Ethnicity</th>
<th>Daily activities</th>
<th>Married</th>
</tr>
</thead>
<tbody>
<tr>
<td>Elliot</td>
<td>50</td>
<td>Residential home supported 24 hours a day</td>
<td>White, British</td>
<td>Workshop for people with learning disabilities.</td>
<td>No</td>
</tr>
<tr>
<td>Lily</td>
<td>50</td>
<td>Residential home</td>
<td>White, British</td>
<td>Workshop for people with learning disabilities</td>
<td>No</td>
</tr>
<tr>
<td>John</td>
<td>55</td>
<td>Residential home</td>
<td>White, British</td>
<td>Day centre</td>
<td>No</td>
</tr>
<tr>
<td>David</td>
<td>55</td>
<td>Residential home</td>
<td>White, British</td>
<td>Day centre</td>
<td>No</td>
</tr>
<tr>
<td>Christopher</td>
<td>56</td>
<td>Residential home</td>
<td>White, British</td>
<td>Day centre</td>
<td>No</td>
</tr>
<tr>
<td>George</td>
<td>53</td>
<td>Residential home</td>
<td>White, British</td>
<td>Day centre</td>
<td>No</td>
</tr>
</tbody>
</table>

* Names have been changed.

3.4 Interview Procedure

I adopted a similar ethnomethodological\(^2\) interview format to the study carried out by Booth & Booth (1994, 1997) who carried out three interviews with each participant in their own homes. I used this approach, as I wanted to create a relationship whereby the participants felt empowered to talk about their lives in the way that they wanted and I wanted to go back again, to thicken the descriptions, to ask again after they reflected and to ask questions which I did not think of at first.

The narrative interview is usually unstructured and hence does not impose a rigid set of questions, like other methods (Murray, 2003). However, in the current study I used a semi-structured approach as I assumed that the participants might not have had the opportunity to tell their life stories before and hence may have had difficulties without some prompt questions. I began each interview with more open-ended questions asking people to talk about themselves and their lives.

\(^2\) Ethnomethodology (Garfinkle, 1967) studies the ways people make sense of their worlds. It assumes that social life is chaotic and social order is constructed in the minds of social actors.
If people were unable to respond to these questions, I used more concrete questions relating to more specific aspects of a person's current life. I also used prompts to direct attention to specific areas of interest. This process of interviewing each person three times was carried out over a period of no longer than three weeks, which was similar to the Booth & Booth study (1994). The format of the interviews is shown in Appendix 5.

I also adopted Booth & Booth's (1997) suggestion of using photographs and personal objects to facilitate the interview process. During the second interview, I invited the participant to bring along any favourite personal objects, which were about them or their lives. Participants often showed me certificates of achievement, sports awards, and photo boards. In addition, after my first interview I tried drawing genograms and using Makaton pictures in future interviews, as a way to increase understanding. Finally, I used Booth & Booth's (1994) recommendation of turning off the digital recorder during the interviews so as to make the person feel more relaxed. During these mini breaks we would have a refreshment break or make small talk.

It is important to consider my impact on the research relationship and interviewing process, such as how I initially took a more tentative approach and was cautious about not wanting to upset them. However, with my supervisor's support and encouragement this changed and I related to the participants' stories. This will be considered in greater detail in the Discussion.

3.5 Interview schedule

The semi-structured interview schedule (Appendix 6) was developed following consultation with my clinical and academic supervisors. I also consulted researchers in the field who had expertise in using Life Story work with people with learning disabilities. For example, Dorothy Atkinson recommended using questions, such as 'Can you remember your first day at the hospital?' (D. Atkinson, personal communication, 18th June 2006). In addition, I used Hewitt's (2006) book on life story approaches with people with learning disabilities and adapted the schedule to suit the person's level of understanding and communication.

I aimed to ensure that my interview schedule covered the person's main significant life events. It should be noted that I was initially interested in the social identities of the participants, and specifically I wanted to explore whether individuals were aware of 'Down's syndrome' and what
this meant to them. I was also interested in the social comparisons which the individuals made, and how they compared themselves to others. However, after analysing my first interview I realised that I was specifically interested in the lived experience and embodied abilities of the participants and hence I wanted to ask more evaluative questions exploring meaning and further expanding questions. See Appendix 6. for the full interview schedule.

The interview began by asking open-ended questions about a person’s life such as, ‘Please tell me about yourself.’ I then asked questions about a person’s current life, including ‘What do you like doing here?’ I chose to ask these more concrete questions relating to a person’s current life, due to my wish to limit potential distress, as described above. The interview then moved onto asking about significant events in their past lives such as, ‘Where did you live before here?’ I incorporated Dorothy Atkinson’s questions, such as ‘Can you tell me about your first day at the hospital?’ Then, questions relating to self-concept were asked including, ‘What are you good at?’ Finally, questions about future aspirations were asked such as, ‘What are your hopes in life?’ The questions came from interview schedules from related studies, such as Finlay & Lyons (2000) and my own personal experience of people with learning disabilities. All interviews were audio-digitally recorded.

Burck (2005) emphasises that qualitative researchers often use the interview format as a guide to ensure that particular areas are covered, but that it also allows space to ‘follow feedback idiosyncratically.’ I did not always follow the questions on the schedule in the order specified, as individuals often spoke about target topics spontaneously without prompting. For example, in the first interview, Elliot spoke about his forthcoming operation after talking about his enjoyment of shopping and then this led onto us talking his previous operations in the long stay hospital and life generally in the hospital. If people did talk about topics spontaneously, I would tick them off on the schedule, so as to ensure that I covered the remaining topics in their interviews.

3.6 Analysis of data

The interviews were transcribed verbatim (see Appendix 14 for example of a transcript) and were read a number of times for the researcher to gain a sense of the person’s story, (Dallos & Vetere, 2005). The data were analysed using a narrative approach, which drew upon ideas from different writers. I adopted Michael Murray’s (2003) approach whereby I initially wrote a summary for each person’s account and then highlighted the main features in the form of a three-part story
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(beginning, middle and end), whilst grounding the analysis using example quotations from the text. In my study the ‘beginning’ reflected childhood events, the ‘middle’ was current life and the ‘end’ corresponded to identity and future hopes. Finally, I summarized my overall interpretations and reflections. I found that Murray’s approach provided structure, yet it was not too restrictive in terms of ordering peoples’ experiences in a particular way, whilst allowing for flexibility in the co-constructed narrative accounts.

Additional analyses were also carried out on the narrative accounts including considering the narrative structures (Labov & Fanshel, 1977), identifying the narrative forms (Gergen & Gergen’s, 1984) and considering how the accounts were influenced by broader societal and cultural factors. After analysing each participant’s account, a comparative analysis was carried out, whereby the main commonalities were identified. As there is no one agreed-upon methodology of doing narrative analysis, I made the decision to present one complete life story and commonalities in this study. My rationale for doing this was that I felt that the full life story would give the reader a whole sense of one person’s life and then the themes would give justice to all of the participants’ accounts in some way.

The process of identifying the commonalities initially involved writing down the overarching main features for each account, in terms of the content of the participants’ stories (e.g. significant events) and the narrative forms (e.g. the structure of the stories, the reflexive capacity and coherence of the stories) and any other interpretations of the stories (e.g. how the narratives were influenced by broader societal narratives, such as gender). These main features were transferred to Table 2 (Appendix 7), which facilitated the comparative approach to interpreting the similarities and differences among the participants’ accounts. In my analysis, a theme became a theme when it was apparent in more than two participants’ accounts. However, it should be noted that I was not solely concerned with prevalence of the information across the six accounts when deciding upon a theme. I was also concerned with other factors including the richness and detail of the information that highlighted the themes and how the theme helped to clarify other aspects of the accounts. This practice of paying attention to these others factors (e.g. richness of the information) follows that accepted by phenomenological researchers, e.g. Interpretative

13 Descriptions of Gergen & Gergen’s (1984) narrative forms can be found in Appendix 9.
14 Commonalities and themes will be used interchangeably throughout this study as they have the same meanings.
Phenomenological Analysis (Smith & Osborne, 2003). I was also mindful of connecting the findings back to the original research questions when considering the themes.

Murray (2003) emphasises that when themes are interpreted, it is important to locate them within a particular interpretative narrative framework. I adopted an integrative interpretative framework, as I paid attention to different psychological models including developmental (e.g. development of narrative as a skill), relational (e.g. attachment styles) and I also considered how the narratives seemed to be shaped by the interpersonal and societal context.

### 3.7 Research quality checks

It has been argued that qualitative research cannot be evaluated in the same way as quantitative research, such as using concepts such as reliability and validity, representativeness, generalisability and objectivity due to differing aims, Willig, (2001). However, Dallos & Vetere (2005) argue that validity can be addressed through the researcher’s need to show/persuade the reader of the trustworthiness of the findings in generating to theory. I chose to use criteria by Elliott et al. (1999) as they partially overlapped with Riessman's (1993) research quality checks, which are specific to narrative analysis, (e.g. 'persuasiveness', 'correspondence' and 'coherence').

#### 3.7.1 Owning one's perspective

Whilst I am aware that it is not possible for me to set aside my own perspective totally, I have attempted to be as self-reflexive as I can throughout this study by keeping a diary. I will now present a further reflection on my own personal and professional background and initial interest in exploring this area.

I am a White British, female aged thirty-years old and I do not have a diagnosis of 'Down’s syndrome' or 'learning disability.' I am aware of my wish to limit 'othering,' Fine (1994). Hence I tried to be as transparent as possible and use the participant’s words. In addition, I also frequently checked out how the participant was finding the process throughout the interviews. Having said that, I realise that I was not completely transparent with my participants, as I did not tell them I was specifically interested in 'social identities.'
Furthermore, this study is part of my clinical psychology doctorate course. Hence, when I met with the participants, I always explained that I was training to be a clinical psychologist and that I was separate from any services used. It is possible that the participants may have thought of me as a ‘professional’ and hence it is important to be aware of any power dynamics. I tried to maintain a relaxed and informal approach and made it clear throughout the process that people could say as much or as little as they wanted and that they could stop at anytime.

I would also like the reader to be aware of my personal and professional experiences, which are likely to influence my motivations for doing this study and my interpretations. Firstly, I have a younger sister who has learning disabilities. This has been a motivating factor to carry out the research in this area and to ultimately improve services. I am aware that this personal family experience has contributed to my assumption that generally people with learning disabilities have fewer opportunities in life than people without a label, in terms of fewer chances to marry, to own a house, to drive, to have a paid job, to make friends and to travel.

As well as my personal experience, my professional experiences have also influenced me to carry out research in this area. For example, during my first assistant psychologist’s post I recall carrying out some formal observations of some clients in an old long stay hospital. I remember feeling shocked by the barren environment. Finally, I recognise that my interpretations are likely to be affected by the current cultural and political context. For example, there is emphasis on ‘rights’, ‘inclusion’, ‘independence’ and ‘choice’ in current NHS learning disability services. My clinical training has increased my awareness of the social construction of learning disabilities and the shift towards ‘inclusive research’ Walmsley, (2001). I also considered much of the research literature to be somewhat biased towards the negative aspects of older people with Down’s syndrome, and thus I wanted the person with Down’s syndrome to tell their own story in their own words.

All of the above influenced the interview process and research analysis in different ways, including my wish to ensure that people had the choice to participate, a choice to say what they wanted throughout the interviews and an opportunity to feel empowered and to express themselves using their own words.
3.7.2 Situating the sample

Basic descriptive data (pp. 171) were provided in order to allow the reader to judge the range of persons and situations to which the findings might be relevant to their practice.

3.7.3 Grounding in examples

Also known as the ‘audit trail’ (Dallos & Vetere, 2005) I grounded the main findings of the data in the form of direct quotations from the interview transcripts. These examples allow the reader to examine the fit between the analysis of narrative form, content and themes and the reader’s understanding of it. That is, the quotes illustrate the themes.

3.7.4 Providing credibility checks

Elliott’s et al. (1999) guideline of credibility checks overlaps with Riessman’s criterion of correspondence. In order to meet this guideline, I asked my clinical and academic supervisors to look over the data and supporting analyses. Part of this involved carrying out an ‘independent audit’ (Dallos & Vetere, 2005), whereby I attended a Narrative Analysis research group, where I asked another trainee to read and interpret one transcript and found that there was correspondence between my own interpretations and hers, (Appendix 11). I decided to give the trainee only one transcript (out of the possible three per participant) to audit as I thought that this contained sufficient information for her to make some interpretations. Once she had made her interpretations, I discussed with her part of my findings and analysis so that she was able to comment on whether the analysis made sense. A limitation of not allowing her to analyse all three transcripts and the relevant sample of the analysis may have been that she was not able to gain a whole sense of a participant and their life, as I had done when I analysed the data. The main reason for not giving her all three transcripts and the analysis was that the transcripts were very lengthy. Despite this limitation, the trainee managed to make sense of my analysis and made some interpretations, which corresponded to my own. For example the trainee noticed how family is significant to Lily and how Lily positioned herself alongside her relatives. She also highlighted how Lily’s account seemed quite positive at times, (Appendix 11). In future, I would give all three transcripts and the accompanying analysis and negotiate a reciprocal research relationship with my independent auditor.

I adapted Elliott at al. (1999) suggestion of ‘member checking’ to suit the population. That is, I thought that it would not be appropriate to feedback lengthy individual narrative accounts to the
participants. Hence, I fed back the co-constructed story in the third interview with them, which was possible with my ethnomethodological interviewing approach.

3.7.5 Coherence

Riessman (1993) and Elliott et al. (1999) both highlight the need for coherence of the narrative accounts. For the findings to be coherent they need to be presented in such a way that preserves the nuances of the information, whilst also allowing the reader to get a sense of the structure of the data, (Dallos & Vetere, 2005). To achieve this, I asked my supervisors for regular feedback on my individual and overall analyses. In addition, this process was accomplished by using direct quotations in the findings, triangulating the narrative themes with the literature review and carrying out an independent audit. Finally, the reader will assess the coherence of the arguments for him or herself.

3.7.6 Accomplishing general versus specific tasks

I have specified in the Discussion, the limitation of generalisability of this study to the population, as I did not use a random sampling approach. However, as I used a theoretical sampling approach I am able to hypothesise as a basis for further research and make connections to existing theory.

3.7.7 Resonating with readers

This relates to whether the research speaks to the reader’s own experiences and practices in a way that clarifies and/or amplifies their own understanding (Dallos & Vetere, 2005). To achieve this criterion, I asked my supervisors for feedback on my individual and overall analyses.
4 Analysis

This section will present the main commonalities across all six stories, followed by a discussion on the narrative forms and the development of narrative skill. An example of the salient features of Lily’s story are shown in Appendix 8.

4.1 Commonalities

This section will highlight the commonalities across the narrative accounts.

4.1.1 Loss

A sense of loss pervaded throughout all of the narrative accounts. Most of the participants spoke about the sadness of losing their parents. Speaking about his mother’s cremation, Elliot said, ‘It was very very sad... I was crying. I was crying. My mum. My brother. Everybody was crying. Crying all the time.’ Similarly, David and John reflected on their sadness over the death of their parents. David stated, ‘And my mum and dad died as well...Gone to heaven.... I was sad.’ John said, ‘Mummy, daddy, the dog died.’ Most participants spoke about this sadness, although not Lily. Instead she spoke about how her mother was living in a ‘different world.’

The theme of loss was noticeable in Christopher’s story. After he spoke about the death of his parents, he talked about his sadness over the loss of an old family friend. He said, ‘He was next-door neighbour at my house...He died. I was upset... It’s a shame...He had cancer...I’m alright now. Before I was crying...’ Christopher described an incident, whereby a car hit him and he spoke about how this affected his mobility. He said, ‘I used to walk down to church on my own and right...Now I got a cramp and they take me down...The staff take me down... It’s much better now I used to walk down. No not anymore but I used to...Um 2006, I used to walk down on my own... I saw a car spin around, at my house up to my leg...Yeah. I don’t know if you know Pauline, hold on, she put the brake up and hit my legs...I think she put the brakes down...Yeah and now I got my cramp...I used to walk at first...But I saw a car coming round too fast... At the footpath.’ A third significant loss, which Christopher seemed to be trying to come to terms with, was the loss of his job as a cleaner at the long stay hospital. Despite telling me that he was the ‘best cleaner’ he was reluctant to talk about it. It seemed his way of coping with this loss was to avoid talking about it.
4.1.2 The experience of abuse

Many participants spoke about how they had experienced physical abuse whilst living in the long stay hospitals. When Elliot began talking about the hospital, there was initially a sense that things were ‘alright’ and ‘fine.’ However, the narrative then took a downward turn, as he repeatedly spoke about some negative events, such as when one man ‘took his clothes off’ and when he was ‘teased’ by another man in the hospital. He said, ‘When I was Garden ward, I had, I had, er...I had that done. (shows me a scar on his wrist)... I broke a window. Wind me, teased me. Trying to wind me up...And I went smashed a window a long time... and I get blame for it....I had my arm done up (inaudible). I was in bandage like that, in Dart Ward. (Demonstrates arm in sling).’ As a consequence of being teased, he described how he smashed a window with his arm.

David frequently mentioned being assaulted whilst he lived in the hospital. He said, ‘Someone hit me once... Big Mick... He whacked me in the face. (He demonstrates being punched in the face)... Bite my ear once. (Points to his ear)... I was really frightened...He was after me once...He bit me in the arm. (He demonstrates being bitten on the arm)... With his teeth. (He demonstrates by biting his own arm)... I don’t want to go back there again.’ On another occasion, David said, ‘He pulled my ear all the away around...I hate him. I don’t like him...Too big for me...Hurts...He gave me one black eye once.’

When John talked about his life in the hospital, he described being ‘sick’ and losing weight and finally he stated ‘I died.’ He repeatedly talked about the ‘bad’ events, how he was ‘sick’ and finally how he ‘died.’ I felt confused about what had happened to John. In contrast, Christopher did not mention any such violence.

George could not recall his life in the hospital. However, he spoke in detail about being physically abused by his father. He said, ‘And my dad (…) I went under big, I would hide under the (he stutters) table... Because he hit me (stutters) was sick...I was cry out my tears...He be nasty with me...Bad that did. Really hurt my back...I was frightened of my dad...I do not like him. Dad go mad with a hard stick... Um he go mad... I don’t know why I get that.’ George explained that he found it difficult to talk about. He said, ‘I’ve still emotion saying that...Every time I say it, you know what I am like...Well, you know what I get, it’s the emotion...Yeah, it comes out...I won’t do it. I won’t do it in here with you in here...I won’t do it with you here in my room...Cry a lot...’ It sounded like he did not want to cry in front of me or worry Debbie, his manager. He
seemed to want to maintain a brave face saying, 'I'm not crying here.' As we spoke about it, he said, 'They might hear me in here... You know what Debbie's like, she'll run out here she will like Flash Flash Gordon... She does, she'll say Paul 'what's the matter?' You know like that... ' When I asked him whether he had spoken to his manager, he said 'you will.' Hence, with his consent I spoke with his manager about the matter.

4.1.3 Transitions

All of the participants spoke about moving homes and living in different places. For example, Lily and Elliot both spoke about living on many different wards in the hospital. The majority of participants preferred their current way of life as opposed to living in the institution. Lily explained about liking her current 'freedom' and having her own possessions. Elliot talked about liking the surroundings of the hospital, 'They had some lovely fields over there.' However, overall Elliot stated that he preferred his current home to the hospital. He said, 'It is nicer here.' Having said that, Christopher seemed to miss his old job as a cleaner at the old hospital.

4.1.4 Physical health

Several of the participants emphasised their physical health during the interviews. They either mentioned it in relation to their own particular health problems or to how their bodies were injured. At the beginning of the first interview, when Elliot was asked to describe himself, he talked about how he 'looks after himself.' He repeatedly spoke about his forthcoming operation on his toenail and he talked about how he would be 'brave' for it. He also spoke about his special cream for his chapped hands and how he was 'poorly' with 'headaches and everything' in the Kings Estate hospital. Elliot talked about his medication and it makes him feel 'drowsy.' However, he also stated, 'Tablet helps me get better' and 'Makes me feel happy, for my life' and 'If I didn't take the tablet, I'll be ill... I would fall down and hurt myself and that sort of thing.'

A significant feature of George's story was his 'heart trouble.' He said, 'For my heart trouble. You know what I got... My back you know, my back gets sore...' He described an incident whereby he collapsed. He said, 'I was in ...bed. I was in (Inaudible) Debbie take me that's in know you or she take me to see the lady to talk about me, about my heart trouble...I was standing on the chair... Go in another room... with another lady that is where I shake like this (he shakes his body) flat down you know, I pass out I sweating... I was I was I was collapse. My knees shake like this... Yes Debbie. One of the girls there she phone her to tell the hos (stutters)
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...hospital...All came out to see I was on floor they take me in (stutters) ... in Hospital...Yes, it was very very painful...’ George expressed his distress about talking about his heart trouble. He stated, ‘I (stutters) I can’t you know (stutters) help it...And every time I say it, it make me cry more. I won’t do that here... (Sigh) Yeah yeah it is hard. That’s right...I won’t do that here with you here. I must calm down...’

John also spoke about his physical health. He described how he was ‘sick’ when he lived in the long stay hospital. He said, ‘I was ill...I was dead...’ There was also a focus on health in David’s account, particularly when he spoke about his life in the old hospital. As he described how he lived through abusive experiences, he frequently pointed to the parts of the body where he was attacked and scarred. In addition, David talked about an incident whereby he was hit by a hockey stick. He said, ‘Last time I played hockey, look...(He points to his eye)... Whacked me with a hockey stick...Oh it hurts, hurts up there. I was in hospital as well...I come back very late...I’m alright now...It’s cleared up, cleared up.’

4.1.5 Attachment figures

All of the participants spoke about significant people in their lives. For example, Elliot recalled living in Malaysia when he was very young, as his father was in the army. At one point he spoke about being cared for as a baby. He said, ‘When I was a little tiny baby. Me. My mum...My mum look after me when I was baby... Feed me in the bosom and all that. When I was a boy, I was a little boy, a little baby with my mum, then she feed me the drink me the milk the breast and that sort of thing... And a bottle like that (He demonstrates putting a bottle in his mouth). And a dummy. Yeah, like that. (Demonstrates having a dummy in his mouth with his thumb). I used to do that, used to do that as a baby.’ Whilst talking about being cared for as a baby, he said, ‘Because I love it so much...I like how it feels, there. (Pointing to mouth and smiling)... Like feelings. (He smiles).’ In addition, he talked about how his father taught him to swim in the sea in Malaysia. He said, ‘With my father, yeah. He had to hold me...He hold me, He teach me to swim... Yeah, I can swim on my own now. (He smiles).’ This gave a sense of pride and achievement.

Hazan and Shaver (1987) suggest that the emotional bond that develops between adult romantic partners is partly a function of the same attachment behavioural system that gives rise to the emotional bond between infants and their caregivers. When Elliot spoke about his parents there was a sense of warmth and this was also apparent when Elliot spoke about Francesca, his
'girlfriend' and when George spoke about doing the colouring with Penny, his girlfriend. Elliot met Francesca in the hospital and they now live together in the same residential home. He spoke about how they used to go horse riding together on a trailer. He said, 'I love Francesca so much...I love feels how it feels. I love her.' Elliot also talked about being physically affectionate towards her, 'I give her a kiss sometimes...and how they 'Make love.' At one point, Elliot spoke about a dream whereby he dreamt about his girlfriend getting out of her wheelchair and walking towards him. He said, 'In my dreams, yeah...Where I am going...(inaudible)...Down the hill...Somebody's walking up to me...Yeah, my girlfriend...Yeah, Francesca...And then I dreamed about. She was...walking....she got the wheelchair and er...walking down. She starts walking there. She's got bad hip. Sometimes, my girl gets a bad hip and a...er...pain in her leg pain in her leg sometimes.'

As well as adult romantic relationships, participants also spoke about significant others, such as key workers and members of staff. In Elliot's account, Simon, (his key worker) is a significant person in his life. He explained how Simon taught him to cook and how he enjoys going to the pub and going shopping with Simon. Elliot said, 'I like how it feels with Simon.' Elliot also recounted an event whereby he had to help Simon once as a fellow resident had knocked Simon over. He said, 'He had a fight this morning. And er falled Simon falled down and hurt his knee.' He described how he 'I saved his life. I saved Simon's life.' Throughout the interviews with David, he mentioned Sam, his key worker several times. He said, 'She's not here now. She's got a couple of days off...Yes, I'm going with her on (holiday) my own this year...On my own with Sam...Pontins in Bognor...Clubbing get drunk...'

A significant person in John's story was his 'mate,' Mark. He mentioned Mark several times during each of the three interviews. He described how he goes out in the car with Mark. He said, 'My mate Mark, Mark, Mark... Er (...) Go out in the car...' During the second interview, John showed me a photo of him with Mark's children.

### 4.1.6 Resilience

There was a sense of resilience throughout several of the stories. For example, a significant event in Lily's early life was moving into the long stay hospital when she was six years old. She explained that her mother had a breakdown and that this was the reason that she had to move homes. She did not talk a lot about her mother's 'breakdown.' It is also possible that Lily did not know much about what had happened and what a breakdown meant as she made the
point that, 'nobody told her.' The way Lily described not being told about what was happening to her, gave a feeling of injustice. In a qualitative study of two women with learning disabilities who spoke about their lives, Roets & Van Hove (2003) argue that power rests with the professionals and hence 'decisions, even really intrusive ones like moving houses, are taken without consultation of the person at issue.' At some points in Lily’s narrative, this seemed to be the case. However, despite this sense of injustice, Lily also put on a brave face with regards to leaving her family home when she was a young girl, as she stated that she 'did not mind.' It could also be interpreted that Lily’s family served as an important protective factor against the social oppression. Another supporting actor in Lily’s narrative who is likely to have added to the resilience of the story is Jonathan, (the manager of the advocacy meetings). Jonathan helped Lily to become reunited with her ‘old friend’ and Lily talked about how Jonathan had been there for her when she had a problem. Her story shows that she had emerged from the difficult times with a sense of humour, with an ability to talk positively about herself (‘I’m a very beautiful lady’) and with a sense of being able to stand up for herself.

For the most part, Christopher’s story was ‘regressive.’ However, when he spoke about his brother he seemed more animated and his narrative adopted a more ‘progressive’ form. Christopher described going on holiday to Hawaii with his brother. He said, ‘Hawaii... I’ve went there with my brother...Yeah, been there in a helicopter...Yeah. It’s great. (He laughs)... Yeah, it was fantastic...Er the sea...I got on a skate board or something...The sky is blue. Yeah...Oh I can do a Hawaii dance... (He dances)... I can do that. (He sits down after doing a Hawaiian dance)...’ Similarly, John’s and David’s narratives became more progressive when they spoke about going on holidays with family and members of staff.

4.1.7 Identity

Social identities

Gender

The six participants in this study talked about themselves in different ways. No one talked about themselves in terms of a having ‘Down’s syndrome’ or a ‘disability.’ Four out the six participants drew on gendered identities: ‘I am a normal man’ (Elliot); ‘I am a beautiful lady’ (Lily); ‘I am a grown man’ (George) and ‘I used to be a kitchen boy’ (Christopher). In particular, the accounts showed that many of the participants positioned themselves in line with a stereotype of what it is to be a man or a woman. For example, Elliot talked about himself as a ‘normal man’ and he
spoke about his wish to work as a ‘builder’ and his enjoyment of going to the pub, drinking Guinness, playing darts and snooker. He also spoke about doing the gardening in the old hospital. Lily described herself as a ‘beautiful lady.’ She stated that she worked in the kitchens at the Kings Estate hospital. She also described being a bridesmaid for her siblings’ weddings and how she liked having her hair in a ‘perm.’

There was some confusion regarding gender identities in George’s story. He stated that when he was younger he was a, ‘baby girl’ because he had ‘tiny fingers and toes’ and that he wore a ‘hat.’ However, George said that he is no longer a baby girl now and stated, ‘I’m a grown man.. That means happy... I’d er (...) get married. (He laughs)... Yeah with Penny.’

Social roles

The participants also identified themselves in relation to social role identities. For example, Lily described herself as a ‘Great Aunty’ and Christopher’s identity appeared to be wrapped up with his old job as a cleaner on the hospital. He stated that he cleans at the weekends and in the evenings and he reported that his main strength as cleaning. Furthermore, the loss of this job appeared to affect Christopher’s current sense of self, as there were discrepancies in his narrative regarding whether he did the cleaning in the night times. That is, he initially made the point that he did not clean the floors in his current home during the night times, as he explained that the staff get paid to do it. However, later on, he stated that he helped a member of staff called Emma with the cleaning of the floors at nights. In addition, the way Christopher spoke about being a cleaner gave the impression that he was an authoritative and responsible person. For example, he spoke confidently about his previous job as a ‘kitchen boy’ and how he had two cleaners, Doreen and Amy. He said, ‘I, Doreen she was my cleaner... Doreen she used to work at my Duke’s Hall kitchen downstairs... Yeah Doreen and Amy.’ I interpreted this as his way of maintaining a sense of dignity and identity.

Age and physical characteristics

With regards to the social identity of being ‘older’, none of the participants identified with this identity. Lily described herself as ‘young’ and ‘little.’ Christopher was not sure what I meant when I asked him about what it felt like to be fifty-five. He stated, ‘I don’t know about that one.’ George said that he was a ‘grown man.’ One participant (John) talked about himself in terms of
his physical attributes. He said, 'I have two teeth'.

Social comparisons

Half of the participants did not appear to understand when I asked whether they were the same as or different from other people. The remaining three participants did understand. For example, Elliot spoke about his siblings in terms of their age and in terms of their physical attributes. He spoke about how Trevor was 'younger' and 'very tall.' And he said, 'He was working. (...) He was working in his office and he hurt his arm. And he's got scar on his arm up there...He has got a scar now. (Shows me his upper arm).' In addition, George compared himself with his fellow resident and he said that he was not like him as his fellow resident had a hearing aid and he did not. John said that his advocate was not like him as he said his advocate was 'tall.' This shows that the participants interpreted my questions on a more concrete level, as opposed to making more abstract social comparisons.

Personal strengths and difficulties

The participants varied in how they spoke about their strengths and difficulties. As shown in Appendix 8, Lily emphasised that she can do things on her own and did not talk about any personal limitations. When talking about growing up and becoming a man, Elliot stated, 'I am a normal man.' It was as though he wanted to point out that he was not different from anyone else. With regards to his strengths, Elliot described how he enjoyed playing squash and that he was good at 'building.' When I asked Elliot about his difficulties, he said, 'Difficult. I get horses to do. Like metal stuff, metal stuff horse shoes and all that.' When this was explored further he went on to talk about falling off a horse. He said, ‘Yeah I ride a horse sometimes, I fell it once and hurt my thigh there...I fell down. My thighs bit painful. I’ve still got it. I’ve still got it.’

When Christopher was asked to describe himself, he repeatedly stated that he was ‘very good at cleaning.’ Later on he said, ‘I used to be a kitchen boy...Yeah. I am best cleaner...Yeah. Before I used to do er Duke’s Hall right...I had a t-shirt, right kitchen boy.’

David talked about how he was good at hockey, badminton, darts and cricket. When asked about his difficulties, he stated that he wore glasses and that he did not read. He said that he found reading difficult explaining that this was because of his eyes. John said that he was good at
bowling and swimming.

George said he was good at 'colouring.' During the third interview, he explained how he liked to colour, 'Do it in here. (He points to a small table by his bed). And Penny sit on my chair. I do it, watch my telly tonight.' I got a sense that George was very proud of his colourings and that this evening routine gave both him and his girlfriend pleasure. George said that he found certain household jobs difficult because of his heart and that he had to be 'careful.'

4.2 Narrative forms

Using Gergen & Gergen’s (1984)\textsuperscript{15} approach, the following section will analyse the narrative forms of all six participants’ accounts. This allows the reader to see how I engaged with the readings and shows how people are constrained when telling stories due to the limited number of narrative forms.

My overall impressions of Lily are that she lived through some difficult times but she has managed to maintain a sense of humour and courage. The way Lily talked about her life could be interpreted as a ‘heroic’ narrative. Her story was made up of both the obstacles she has faced (such as having to leave her family home, having her clothes stolen at Kings Estate) but also the ways in which these obstacles were overcome (such as her parents meeting with the boss of the hospital to help resolve the situation of Lily’s clothes being stolen and Jonathan helping her with difficulties in her current residential home). Lily recalled happy childhood memories, such as family holidays. The way Lily spoke about her reunion with Paul, her old friend, could be interpreted as a ‘happily ever after’ narrative of a ‘reunion of two long lost friends.’ Her story gave a sense of anticipation and excitement about seeing him again after all these years. In addition, there was also a ‘fantasy’ narrative in Lily’s story, such as when Lily spoke about how her mother had died and moved onto a ‘different world’ in the television. This could be Lily’s way of coping with what had happened.

In contrast, Elliot’s story seemed to take on ‘romantic’ and ‘tragic’ narrative forms. The way he spoke about Francesca, his girlfriend, was in a ‘romantic’ narrative form at times. For example, when he spoke about his dream of her walking towards him without her wheelchair. However,

\textsuperscript{15} See Appendix 9 for a description of Gergen & Gergen’s (1984) narrative forms.
there was also a sense of tragedy in Elliot’s story, such as when he spoke about not being able to marry his girlfriend. I recall thinking during the interview ‘why can’t you get married if you both want to?’ Brown (1996) argues that there will be a natural progression to partnership and marriage in people who have Down’s syndrome due to the increasing lifespan of individuals who have this diagnosis and because of the development of social models of disability. He advocates that professionals and staff should be prepared for such possibilities of partnership and marriage in people who have Down’s syndrome. Marriage did not seem to be a possibility for Elliot. From a broader societal level, it could be said that Elliot’s narrative is embedded in a Westernised ‘romantic’ narrative in terms of his dream to marry his girlfriend and look after her.

For the most part, Elliot’s story made me feel sad and was in the form of a ‘tragic’ narrative. His life seemed comprised of losses, thwarted ambitions, with few opportunities and a sense of hopelessness. He appeared happier when he was reminiscing about the past, such as when he talked about his days in Malaysia. Roets & Van Hove (2003) highlight that ‘if people who have experienced that they will have little effect on valued outcomes, they will cease trying to solve problems or to overcome barriers (learned helplessness theory).’ Elliot lived in a time, when it was normal to send people with learning disabilities to live in institutions. A consequence of this is that one is denied choice, power and control over one’s life. Therefore it could be said that because Elliot may have had little power and control over his life, he was unable to work out how to achieve his wishes and dreams (e.g. marry his girlfriend). Instead, Elliot seems to create a ‘fantasy’ story, where he lived out his dreams, such as when he ‘saves Simon’s [key worker’s] life’ and when he says that he ‘going to get a job as a builder.’ These ‘fantasy’ stories perhaps allow him to have a sense of autonomy and be a ‘normal’ man whom he aspires to be.

One of most striking aspects of John’s story was when he talked about his life at the old hospital. This particular narrative was ‘regressive’, as John repeatedly talked about the ‘bad’ events, how he was ‘sick’ and finally how he ‘died.’ This particular narrative made me feel a mixture of emotions; mainly shock and confusion. I felt confused as I was not sure what had happened to John in the hospital. Similarly, the narrative form of George’s story could also be interpreted as regressive. His account gave a sense of sadness as he spoke about the difficult events in his life, such as his experience of being physically abused as a child and his ‘heart trouble.’

David’s narrative was also mostly ‘regressive’, as whenever I asked him about the past, he tended to speak about negative events, (such as being whacked and bitten by ‘Big Mick’, being hit by a
hockey stick, being bitten by a boxer dog when he was younger and his housemate shouting and pushing his father over). David’s narratives also emphasised his bodily injuries. I wondered whether there were any positive events in his early life and his life in the hospital. David stressed that he preferred his current home and that he would not like to go back to the hospitals. His narratives about events in his current life were more ‘progressive’, (e.g. his enjoyment of holidays, dressing up as King George, his love of food and his weekend routine of going to the pub and church). Hence, it seems that when David’s life improved once he left the long stay hospital, as it enabled him to have more opportunities and choices in his life.

Christopher’s narrative could be interpreted as ‘heroic’ as he spoke at length about various losses. However, despite these losses, his story also gave a sense of fun and lightheartedness, particularly when he spoke about his holidays with his brother, hobbies and when he showed me his dance routines. Hence, there was also a theme of resilience in his narrative, whereby he has adapted to his losses in some ways. One of his main coping strategies could be the way he positions himself alongside a member of staff, as this enables him to regain an important role in life, after losing his role of being a cleaner.

4.3 Narrative as a skill

The following section will consider the variability between the accounts through a discussion of narrative structure and reflexive capacity. There was a development in my interviewing skills and this will be reflected upon in the Discussion section.

4.3.1 Narrative structure

All of the participants were able to talk about some aspects of their lives. There appeared to be a change in terms of topics being talked about in more depth as the interviews progressed. Appendix 13 shows how the number of topics reduced from the first to the last interview for Elliot. I attributed this change to a development of the participant’s narrative skill and my interviewing skills.

Some accounts were more limited in terms of their content. For example, John’s story was fairly limited, when compared with the other participants’ stories. He spoke very little about his early life. In terms of the structure of the story, John generally answered with one word or a very short
Using Labov’s¹⁶ (1967) framework to analyse structures in the narratives, I noticed that I used many prompt questions to enable the narrative to develop a sense of structure. For example, I asked ‘How did that make you feel?’ in order to address the meaning of an event. In addition, I asked ‘What happened?’ to gain more of the abstract, orientation, complicating action and resolution. However, despite using such questions, I found it difficult at times to analyse the narratives structures. Participants’ accounts often jumped from topic to topic and participants gave responses in the form of short sentences or one words. For example, a significant feature of David’s interviews was the way he jumped from topic to topic. It was difficult at times to expand on a particular topic in more depth, as David frequently spontaneously moved the conversation on. Hence, this meant that some accounts were more coherent than others.

Reflexive capacity
The ability to reflect involves evaluating an event. The majority of participants were able to evaluate the significance of events to a certain extent. For example, Lily was able to say that she felt ‘angry’ when her housemates told on her for not doing the cleaning. Likewise, George spoke about feeling ‘frightened’ when he was beaten by his father. However, there were times when some participants did not offer many evaluative comments about their life experiences. For example, Elliot and John often said, ‘it’s alright’, when he was asked to talk about the significance of something. Overall, John’s story was more concrete rather than reflexive. He did say that his experience in the hospital was ‘bad.’ However, when asked what his friend Mark was like, he said, ‘tall’ and when he asked about what the baby was like, he replied that she had an ear, a nose and a mouth.

Coherence
Some narrative accounts were more coherent than others. I was left wondering what had happened to John at certain times of his life. There were gaps in his story, such as his childhood and adolescent times. There were also discrepancies. For example, George described being a ‘grown man’ and ‘happy’ and then shortly afterwards he started to cry when he spoke about his ‘heart trouble.’ Furthermore, after George had talked about his father being abusive, he

¹⁶ Labov & Fanshel (1977) approach emphasises the different structures of the narratives, including an abstract, orientation, complicating action, evaluation, resolution and coda. These structures are detailed in Appendix 10.
explained that he found it hard to talk about because of the 'emotion.' He said, 'Yeah I know. Every time I say it, you know what I am like...Well, you know what I get, it’s the emotion... Emotion I get...I won’t do it. I won’t do it in here with you in here... I won’t cry a lot...'}
5 Discussion

The current study explored the identities of six older people who have Down's syndrome who once lived in long stay hospitals. The following section will firstly summarise the analysis and the original research questions will be addressed. Secondly, there will be a discussion on how the findings relate to previous literature and a consideration of clinical implications, limitations and ideas for future research.

5.1 Summary of analysis

This study involved using ethnomethodological interviewing to co-construct six life stories with older people who have Down's syndrome as a way of exploring their identities. All participants talked about their childhood, current life and their future. Although each person's life story was unique, there were several main commonalities, such as loss, abuse, transition and health. Participants also spoke about more positive events and people in their lives, such as childhood holidays and significant others.

Significantly, none of the participants identified themselves as having 'Down's syndrome,' being a 'Mongol' or a 'high grade' and nor did they identify with being 'older.' Instead, individuals identified themselves in relation to gender and social roles. Most participants were able to reflect upon their personal strengths, limitations and consider future hopes and wishes to a certain extent, although one person was unable to talk about their limitations.

The six participant's accounts varied in terms of their structure, coherence and reflective capacity. This could partly be due to differences in participants' narrative skills. In addition, there was evidence that the participants' narrative skills and my interviewing skills developed across the three interviews as topics were spoken about in more depth in interviews 2 and 3. Secondly, my supervisors and I noticed a difference between early and later participants' interviews, e.g. the first person's account (Elliot who longed to marry his girlfriend) was more idealised than the sixth person's account (George who talked about the abuse and his 'heart trouble'). This perhaps also relates to a change in my interviewing skills and shows that I was able to elicit their emotions more readily.
5.2 Theoretical considerations

The findings from this study make important additions to some of the areas which were discussed in the introduction. For example, the findings add to the current literature on ageing. That is, as with Coleman’s research (1986) this study aims to present a more balanced perspective in terms of highlighting the resilience, strengths and hopes of older people as well as discussing the adversities and health problems. Secondly, this study adds to the literature on identity and people with learning disabilities and more specifically Down’s syndrome and identity. That is, the current findings do not fit with some of the anecdotal evidence of people with Down’s syndrome talking about themselves as ‘Mongols,’ which was discussed in the introduction. Instead, this study corresponds with other studies, e.g. Cunningham et al. (2000); Beart (2005); Davies & Jones, (1997); Finlay & Lyons (2005) and Edgerton (1967), which found there to be a lack of salience with the disabled identity from the perspective of the person given that diagnosis, i.e. the participants see themselves as ‘people’ not ‘disabled.’ Furthermore, the findings correspond with the anecdotal evidence of older people with Down’s syndrome not identifying with the term ‘old.’ Finally, as stated in the introduction there have been relatively few studies using a narrative approach with people with learning disabilities and the current findings make a valuable addition to the existing literature (e.g. Atkinson & Walmsley (1999); Booth & Booth, (1996). Hence this study promotes the view that people with learning disabilities can narrate their life/identity forming experiences, and that the method itself can illuminate their life experiences. The following paragraphs will highlight the ways that the findings have moved forward our understanding to a consideration of different issues.

All of the participants had experienced significant losses and separations throughout their lives. Researchers have argued that if a person has been abused then it is beneficial for the person to remember, reflect and make sense of that experience rather than putting it out of their mind (e.g. Fonagy, 1994). In the current study, some participants seemed more able to remember and reflect on their difficult experiences in comparison to others. For example, Lily and Elliot were able to recall what had happened to them in detail, whereas John gave a very limited account and Christopher preferred to not talk about certain events. It could be suggested that the way the participants talked about their significant losses related to their different coping styles. For example, the way Christopher did not want to talk about his old life at the hospital could be seen as a repressive coping style. Repression is defined as the cognitive and emotional effort to ignore or divert attention from threatening stimuli, whether internal or external, Weinberger et al. (1979). Two of the participants’ accounts had fantasy narrative forms, which may connect with
the use of idealisation as a means of coping with traumatic events. For example, Lily spoke about how her dead mother was ‘on the telly’ now and stated that she did not have any personal weaknesses. In addition Elliot talked about being a builder and saving his key worker’s life. It could be suggested that these coping styles serve to protect the participants’ self-esteem and identities.

On the other hand, the way some people talked about their early childhood and family experiences seemed to serve as a protective factor. Other authors (e.g. Roets & Van Hove, 2003) also identified a sense of resilience and have shown that some people can emerge from institutionalisation as ‘survivors – with the dignity and self-respect intact.’ Kraemer (1999) highlights that resilience is about flexibility and being able to survive adversity but also know when one is not able to cope and when one needs help. With respect to recognising one’s limitations, the current study had mixed findings. Some talked openly about their difficulties and others did not. No one mentioned being a ‘Mongol’ or a ‘high grade.’ I did not interpret this lack of identification solely in relation to Edgerton’s (1967) ideas of a person with learning disabilities ‘hiding behind a cloak of competence.’ I think the situation is more complex than this and that each person is different and that some people may not have had access to the label, such as in the study by Finlay & Lyons (2001) and hence may be resisting professionals’ descriptions and so creating more positive alternative self-descriptions (‘I am a beautiful lady’) and finally some people may not want to admit that they have difficulties as the reality is too painful, according to Sinason (1992).

The above two paragraphs connect with Attachment theory (Bowlby, 1969, 1973). That is, the infant’s early experiences become internally represented to form attachment-working models. Hence, those participants who used idealization and repressive coping styles could also be said to be engaging in insecure avoidant attachment patterns, whereas those participants who spoke more coherently and reflectively about their experiences could have developed a secure attachment strategy. The use of insecure attachment strategies is perhaps not surprising considering these people were separated from their parents when they were children as they moved into institutions. In many ways, it is a testament to them that they were able to talk about their experiences so openly. Another possible consideration with regards to the incoherence and lack of reflective capacity could be related to people with learning disabilities having difficulties understanding timescales and having a notion of time, learned acquiescence and language limitations (Booth & Booth, 1997). It is therefore important to consider that the gaps in the stories may have been my
gaps rather than the participants. That is, their stories may have made sense to them with their frame of reference.

Kramer (1999) also states that individuals who overcome serious disadvantage usually have one or more supportive people in their lives or they may belong to a community, which 'gives one a second chance for mutual affection and reflection.' Hence, in this study it could be suggested that the participants' significant others and sense of community (long stay hospital community, current homes, church, advocacy, college, day centres, workshops and holidays) may have contributed to their sense of resilience.

Similarly, this study has shown the importance of having a variety of social roles. For example Lily identified with being her 'father's daughter', a worker, a 'bridesmaid', 'a Great Aunty' and a 'mate.' In contrast, Christopher did not appear to have many other roles apart from his job as a cleaner which he did not want to talk about as he seemed to find it hard to talk about and this gave a great sense of loss. This shows that having a wide range of social roles appears to buffer against the effects of negative social comparisons, Linville (1987), and increases a person's well being, Thoits (1983, 1986).

5.3 Clinical implications

This study highlighted the benefits of using life story approaches with people with learning disabilities. In particular, it has shown how the process of creating a life story in a relational context can facilitate a person to talk about themselves, their lives and their personal strengths and difficulties. This has therapeutic implications in terms of allowing a person to feel empowered, use their own words and hence be in control of their lives, which fits with one of the basic principles of Valuing People (2001). For example, Lily said, 'I like doing this' because she 'can do it on her own' and 'This is what I say, talk about this, about me.' This has implications for identifying and reducing self-protective coping strategies and attachment strategies if appropriate.

Another implication could be to carry out life stories with families who have children with learning disabilities and in particular to carry out prospective life stories with the children. This could be about creating a relational context whereby families can feel empowered to express
themselves and their feelings and then create a dynamic plan for the future, which includes what the child likes, dislikes, their strengths and weaknesses, realistic goals and their hopes. In addition, the process of exploring the child’s life story could hopefully create a space whereby the whole family could come to terms with the loss of the ‘normal’ child and express difficult feelings such as shame, sadness, anger, guilt and embarrassment. This process of dynamic prospective life stories could also be linked to Person Centred Planning, (DoH, 2002), whereby people are supported to create a plan about their future.

Furthermore, the study emphasised the importance of listening to people with learning disabilities. Lily frequently talked about how she liked people to listen to her. For example, she talked about her brothers and she said, ‘They listen to me.’ Being listened to and having people stand up for her was also highlighted when Lily spoke about the interviewing process itself. This highlights the importance of advocates and befrienders, in terms of allowing people to have different people they can talk to make sense of things.

As stated in the Introduction, certain researchers argue that people should be informed about having Down’s syndrome/learning disability (e.g. Szivos, 1992). After conducting this study, I still feel ambivalent about labelling someone. On the one hand, I can see that the process of naming the difference enables a person to consider why they are different and how there is a need to ensure people are not denied their civil rights. However, from the findings of this study I believe that care is needed in thinking about what language is used and the meanings of these labels. In my view, it seems important to adopt a label which is easily understood by professionals and hence can be explained to families. In some ways the current term ‘learning disability’ used by the Department of Health seems rather broad, vague and confusing and this seems to be further muddled by the terms used by the educational system (‘learning difficulties’). It may be better to use the term ‘intellectual disability’ which could be better understood by professionals and hence conveyed to families. As well as ‘intellectual intelligence,’ it may also be helpful to consider a person’s ‘emotional intelligence’ and this could be an area for future research.

As well as finding an appropriate label, it seems helpful to consider a person’s embodied experiences and their strengths and difficulties from their perspective. Towards the end of the research process, I read a book called ‘Where’s Chimpy?,’ which is recommended for children.
with Down's syndrome by the DSA. It shows photos of Misty, a young girl trying to search for her toy monkey. It mentions 'Down's syndrome' at the beginning and states that, 'Misty has Down's syndrome but this does not mean she acts any differently from any other child.' As I read about Misty, I thought about Lily. I imagined co-creating a book with Lily about her life and using photos, which could be about her life, such as how she goes to work, goes to advocacy meetings, how she has a photo board of all her memories and how she likes playing the guitar and being listened to. The hope of such a book would be for other older people with Down's syndrome to identify with the main character engaging in everyday situations and perhaps be then supported to create their own book with a significant other.

This study has implications for how services for people with learning disabilities are organised. From a lifespan perspective, it shows the importance of having significant others and a sense of community from infancy to later life and hence have access to social networks and significant others, such as advocates, key workers, immediate and extended family members. This could have clinical implications in relation to creating local services which provide services from infancy to old age and which are integrated in terms of health and psychological services. These local services could be local small teams, which act as secure bases providing flexible, responsive, sensitive and emotionally attuned services so that families can have somewhere to go when they need to.

Finally, this study showed the importance of enabling people with learning disabilities to be brought up in a secure emotional context of their families rather than living in institutions, in terms of enabling them to develop secure attachment patterns and healthy ways of relating to others.

It should be noted that the values of listening, empowering people and having services across the lifespan are not limited to narrative analysis approaches. These ideas also overlap with developments in other services, such as the service user involvement movement, and specific intervention approaches to people with mental health problems, e.g. the family therapy approaches and the recovery model for psychosis. That is, family therapists work with families, listening to different viewpoints in order to ensure that all members have a voice. This aims to bring about positive change (www.aft.org.uk/home/familytherapy). The recovery model consists of several main themes including: using personal narratives to enable people to develop coherent
accounts of their experiences; building a positive personal and social identity; having supportive others and hope, May (2004). Hence, both of these approaches have shared characteristics with the approach and findings discussed in this study.

5.4 Limitations

This study has been effective in exploring how older people with Down’s syndrome see themselves. However, there are several limitations.

One possible criticism is whether I could have asked more direct questions about a person’s understanding of the terms ‘learning disability’ and ‘Down’s syndrome.’ This is something I considered throughout the research process. I wondered whether my focus on using more open-ended questions to ascertain a person’s identity were suitable for people with less developed language and cognitive skills. It may have been more appropriate to ask direct questions, so that people were more able to answer the questions. Davies & Jenkins (1997) asked more direct questions using the terms ‘learning disability’, but only after they had seen participants for a number of times. Having said that, I believe that it was important to hear the participants’ own stories and then gain a sense of who they are through the research relationship.

Similarly, another criticism was that Narrative Analysis privileges language and thus there was a reliance on the verbal abilities of the participants. This may have been demanding for some participants at times. I tried to overcome this by ensuring frequent breaks and carrying out shorter sessions.

Another possible limitation is the practical constraint of the length of time to do narrative analysis. Interviewing each person three times could be seen to be at odds with the current Western model of healthcare which emphasises evidence based practice, efficiency and effectiveness in the NHS. However, this should not be a reason to not use this approach in current practice. This study demonstrates the value of taking time to listen.

The small sample size and the generalisability of the findings to population could be criticised. However, it should be noted that this study was not claiming to represent older people with Down’s syndrome in general. One of the main aims of this study was to explore the identities of
a unique group of people who have lived through experiences. Hence, the findings can be
generalised to existing theory and generate further research.

An additional limitation could be that I saw each person three times each. I realised that some of
the participants did not want the process to end. For example, Lily spoke about her wish for the
process to continue. She described that she would have to be 'very very strong' with regards to
ending the interviews. Stalker (1998) states that people with learning disabilities may be more
vulnerable to expecting friendship from researchers, as they often have fewer friends than non-
disabled people. Despite this limitation, I believe that it was better to carry out the research than
not at all, as it is helpful for people to learn to cope with separation and loss in a safe and planned
way.

5.5 Suggestions for future research

This study is the first to explore how older people who have Down's syndrome who lived in
hospitals, see themselves and hence it would be good to develop the ideas further. For example,
narrative analysis could also be used with older people who have learning disabilities in general
as this study showed that Down's syndrome was only one aspect of a person. It is a non-
threatening and empowering approach to explore identity. A specific study could focus upon
further investigating the different coping styles and attachment strategies of older people with
learning disabilities, with the aim to help people to develop more adaptive ways of relating to
others and hence recognise their strengths and limitations.

In addition, a study could evaluate the effectiveness of life stories with people with learning
disabilities, as a means of helping them make sense of themselves and significant events in their
lives. Hence, it would be useful to carry out research into the effectiveness through interviewing
the participants themselves and their significant others, including staff, family and friends.

Future research could also employ non-verbal techniques to facilitate communication. Fivush
(2002) states that autobiographical memory is also represented in multiple modalities, including
visual, auditory and kinaesthetic sensations, as well as language. Hence, it may have been useful
to incorporate other methods of communication, (e.g. drama, art), particularly as three of the
participants spoke about their enjoyment of acting.
5.6 Reflection of the research process

This study was initially about exploring the social identities of older people with Down’s syndrome who lived in long stay hospital. However, I have discovered it has been about much more than that...

The Beginning: Confusion and Self-Doubt

As stated in the method I initially felt overwhelmed about how I was going to ‘do narrative analysis.’ I wondered how to co-construct life stories and I was not sure how I was going to explore identity without asking individuals directly whether they had ‘Down’s syndrome.’ I was doubting myself and wondering whether I should be doing another project. I wanted more structure and I wanted someone to tell me what to do. I was also questioning how this was related to Clinical Psychology as I was simply listening to people tell their stories. However, my supervisor reassured me to ‘trust the process...’ so I apprehensively carried on...

The Middle: Emotions, Ethics and Epistemology

As the interviews progressed, I noticed that my interviewing skills developed, as I was asking more expanding questions to elicit detail about particular events. This change came about through the support of my supervisor who empowered me to feel confident to trust in my own abilities. Furthermore, as I listened to the stories, I began to see that the stories were moving and touching. Some were tragic, some were heartwarming and others were confusing. I remember being initially excited that in my first interview the participant had spoken about his unfulfilled wish to marry his girlfriend, and I then realised my incorrect assumption that the participants might find it difficult to answer some of my open-ended questions, such as ‘What are your dreams?’

I also felt acutely uncomfortable at times and realised that I was confronting ethical dilemmas. For example, the process raised the issue of reciprocity and how I should answer participants’ direct questions, e.g. when John asked me how many teeth I had. In the end I decided to adopt a similar approach to Vernon (1997) and in general only share information about myself, when I was asked. At the time, I believed that this study was about the six participants rather than myself. However, I also recognized that it would be wrong to ignore a person’s questions. Reciprocating information felt quite liberating at times and more like a natural conversation.

The stories about abuse and loss shocked me. I found that it was helpful to share my worries with
my supervisors, who were bound by the rules of confidentiality and their duty of care. On a similar note, Booth & Booth (1994) point out that there is also a strain arising from ethical dilemmas, such as when the principle of confidentiality comes into conflict with the wider legal and moral responsibilities. I certainly felt this strain at times. For example, one participant disclosed that his father had abused him and he stated that he had not told anyone else. Hence, during the interview I sensitively suggested that he told someone whom he knows well and he asked me to talk to his home manager. Again, I found it valuable to share my concerns with my supervisors and gain emotional support.

One moment sticks in my mind, whereby I was carrying out an initial meeting with a potential participant in their own home. On my arrival, the home manager said to them in a loud firm voice, ‘She’s here to talk to you about Down’s syndrome. You have Down’s syndrome, don’t you? She’s come to talk about that.’ The potential participant just stared back at her and this left me feeling uncomfortable. Roets & Van Hove (2003) argue that researchers frequently assume that disability must be central to the self-concept of people with ‘disabilities’. However, they point out that people also have a race, a class, a gender and a sexual orientation and therefore ‘disability’ is not an all-encompassing identity. This related to my experience of carrying out this project, as I would say that I was initially focused on the identity of ‘Down’s syndrome.’ However, this changed over time and I realised how this was only one small aspect of the participants’ lives as they had rich lived experiences.

Throughout this study, I questioned my epistemological position. Before commencing the study, I assumed that identity was a stable concept relating to a person’s internal characteristics, such as ‘warmth’ and to their prescribed social identities, such as ‘White British.’ Hence, my understanding of the world fitted with a more positivist worldview. However, once I started interviewing I noticed a change in my thinking and I no longer saw the ‘self’ as solely a stable concept but rather a fluid and relational concept, which was shaped by cultural and social contexts. I saw the benefits of a postmodernist narrative self and how language shapes reality. Hence, I analysed my first participant’s life story in terms of thinking about how his narrative had been shaped by culture and social factors. However, after interviewing Lily, my second participant, my thinking shifted again from the social constructionist perspective to considering Lily’s ‘personality’ and the stability of her self. For example, I immediately noticed Lily’s sociability and a sense of resilience, which led me to consider attachment. At this point, I felt confused, as thinking about Lily’s ‘stable self’ did not appear to fit with my ideas of a
‘postmodernist narrative self.’ After discussions with my supervisor I realised the benefits of integrating both the social constructionist view of self and a more stable sense of self. I found it helpful to think about Self Theory and how a person’s core sense of self can be stable and coherent across time, in comparison to their subjective and languaged sense of selves which can vary across time.

The study has affected how I use language and the impact of words. I realised the importance of empowering people and listening to them so that they can express themselves in their own words. In addition, I am more aware about the importance of asking questions, which are suited to the person’s developmental level. I can see the benefit of using cognitive assessments, in terms of providing another way of understand a person’s embodied abilities. However, I can also see the benefits of assessing competence through both the use of qualitative and quantitative approaches.

The End: My Life Story

Towards the end of the study, I noticed that by entering the storied world of the participants, I was able to reflect upon my own life story. I noticed that I had chosen to highlight the only woman in my study, perhaps because I identified with Lily in some ways. With the support of my supervisor, I reflected on my past and discovered that like some of the participants, I too had been avoiding thinking about my life as a child with a sister with learning disabilities and how this had impacted upon myself and my family. I was able to reflect upon and process the experiences and then construct a richer life story. I experienced a sense of freedom and connection after weaving personal, intergenerational and cultural factors into my life story. This personal experience was powerful in terms of enabling me to understand how my past connected with my present and future sense of selves. I then realised how similar I was to my participants...
6 References


7 Appendices
MATERIAL REDACTED AT REQUEST OF UNIVERSITY
Approved documents

The documents reviewed and approved at the meeting were:

i) NHS REC Application Form, Version 5.1, dated 26 May 2006
ii) Your curriculum vitae, Version 1, dated 26 May 2006
iii) Dr Arlene Vetere’s curriculum vitae (version undated)
v) Letter from Mrs Catherine Ashbee regarding sponsorship, dated 2 May 2006
vi) Feedback Sheet for Major Research Project Proposal (version undated)
vi) Letter from Mrs SA Jubb regarding insurance, dated August 2005
vii) Interview Schedule, Version 1, dated 26 May 2006
ix) Participant Information Sheet, Version 1, dated 26 May 2006
x) Consent Form, Version 1, dated 26 May 2006

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

Yours sincerely

[Signature]

JOHN KERSLAKE
Co-ordinator

Copy to: Mrs Catherine Ashbee, University of Surrey
Dr Tom Chan, Surrey and Borders Partnership NHS Trust
12 July 2006

Ms Jennifer Alcock
Department of Psychology
School of Human Sciences

Dear Ms Alcock

An exploration of the social identities of older people who have Down's syndrome (EC/2006/68/Psych) – FAST TRACK

On behalf of the Ethics Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the submitted protocol and supporting documentation.

Date of confirmation of ethical opinion: 12 July 2006

The list of documents reviewed and approved by the Committee under its Fast Track procedure is as follows:-

<table>
<thead>
<tr>
<th>Document</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Application</td>
<td>29/06/2006</td>
</tr>
<tr>
<td>Risk Assessment</td>
<td>29/06/2006</td>
</tr>
<tr>
<td>Insurance Proforms</td>
<td>29/06/2006</td>
</tr>
<tr>
<td>Participant Information Sheet</td>
<td>26/05/2006</td>
</tr>
<tr>
<td>Invitation Letter and Reply Form</td>
<td>26/05/2006</td>
</tr>
<tr>
<td>Consent Form</td>
<td>26/05/2006</td>
</tr>
<tr>
<td>Interview Schedule</td>
<td>26/05/2006</td>
</tr>
<tr>
<td>Research Proposal</td>
<td>22/05/2006</td>
</tr>
<tr>
<td>Approval Letter from the Surrey Research Ethics Committee</td>
<td>19/06/2006</td>
</tr>
<tr>
<td>Copy of the NHS Application</td>
<td>30/05/2006</td>
</tr>
</tbody>
</table>

This opinion is given on the understanding that you will comply with the University's Ethical Guidelines for Teaching and Research.

The Committee should be notified of any amendments to the protocol, any adverse reactions suffered by research participants, and if the study is terminated earlier than expected with reasons.

You are asked to note that a further submission to the Ethics Committee will be required in the event that the study is not completed within five years of the above date.

Please inform me when the research has been completed.

Yours sincerely

Catherine Ashbee (Mrs)
Secretary, University Ethics Committee
Registry
cc: Professor T Desombre, Chairman, Ethics Committee
    Dr A Vetere, Supervisor, Department of Psychology
    Dr K Dodd, Surrey & Borders Partnership NHS Trust
SURREY & BORDERS PARTNERSHIP NHS TRUST
RESEARCH AND DEVELOPMENT OFFICE

R&D RESEARCH PROJECT AGREEMENT

Parties to this agreement:
Surrey & Borders Partnership NHS Trust, Ramsay House, West Park, Horton Lane, Epsom, Surrey, KT19 8PB

And Jennifer Alcock (Researcher/Clinician)

Project Title: An exploration of the social identities of older people who have Down's syndrome.

Project Identification Number: SBP030

1. The Researcher may only carry out this project after having gained agreement from the Trust. This is contingent on obtaining written agreement from both the Local Research Ethics Committee and the Surrey & Borders Partnership NHS Trust Research Steering Group (Part of the Clinical Governance framework).

2. The Researcher agrees to carry out the project as described in the approved application, and to meet the terms and conditions outlined below. Researchers must ensure strict adherence to the agreed research protocol especially in relation to obtaining consent from participants, and agreed funding. Participants must receive a copy of their signed consent form.

3. The Trust agrees to allow the research to be carried out by the Researcher, subject to the terms and conditions outlined below.

4. The researcher will ensure that the research is carried out in adherence to the Trust policy and procedures for R&D and all other relevant Trust policies e.g. Confidentiality, Serious Untoward Incidents.
Supervision of the work

5. The Researcher where applicable shall be responsible for ensuring the satisfactory supervision of the project.

6. The Trust expects the Researcher to have in place adequate supervision / peer-review arrangements for the specific project and to inform the Lead Research and Development Officer (LRDO) of these in writing prior to beginning the research.

Management of the project

7. The researcher will commence the project within three months of the agreed start date unless the LRDO agrees otherwise in writing.

8. The Grantholder shall obtain all insurances necessary in connection with the project and accepts full liability for the project and its operation.

9. The researcher will ensure the safety and well being of all those involved in this project and will abide by the Trust's Health and Safety Policy.

10. The researcher must ensure the highest standards of research and not be guilty of research misconduct or fraud. This includes financial probity. The LRDO may ask the researcher to provide evidence that they are adhering to all aspects of the protocol and the R&D policy at any time.

Confidentiality

11. The Researcher must comply with the Data Protection Act (1998) and Caldicott requirements, together with any specific conditions set by the ethical agreement.

12. The Researcher must safeguard the confidentiality of the research Data at all times and ensure that it is stored securely and guard against unauthorised access.

13. The Researcher must ensure that all basic factual data is anonymised as and when it is received and that the key to personal identities of persons involved in the research is kept in a separate and secure place.

14. The Researcher must ensure that no information that could lead to the identification of an individual shall be included in any publication without the prior agreement, in writing, of that individual.

Service Confidentiality

15. The Researcher must respect the confidentiality of the service/s in which the research is carried out. Any concerns about a service must be discussed with the
relevant manager/clinician (usually the manager of the service, the relevant Consultant or the researcher’s supervisor) and not discussed in other forums.

Reporting on the Project

16. For Culyer funded projects the Researcher will provide quarterly progress and monthly finance project statements to the LRDO.

17. For non-Culyer funded projects the Researcher will provide quarterly progress reports and annual financial statements concerning the project to the LRDO, unless otherwise required by an external contract.

18. The Researcher will provide a summary report and financial statement (where applicable) at the end of the project to the LRDO. The researcher will provide a full final report within three months of the end of the project. This should include details of publishable material and those which may give rise to exploitable Intellectual Property.

19. The Trust will provide to the Researcher guidelines describing its requirements on reports. (See Attached)

20. These reports will be reviewed by the R&D Steering Group and the Clinical Governance Sub-Board

Changes to / difficulties with the Project

21. The Researcher will inform the LRDO promptly in writing of any:

- change of address or telephone number
- change of relevant staff
- difficulties or delays in the recruitment of relevant staff
- events which may have implications for the viability of the project

22. The Researcher will seek the prior written agreement of the LRDO to any:

- proposed change of the Researcher
- proposed change of the Supervisor
- proposed change of employing organisation
- proposed change in the direction or aims of the project
- proposed alterations to the timetable for the project
- proposed alterations to costs/funding for the project.

23. These will also need to be notified to the Ethics Committee and may result in the need to resubmit for approval.
24. The Researcher will inform the Administrator of the Ethics Committee who approved the project of any serious untoward incident immediately the incident occurs and inform the Trust and the LRDO within 24 hours using the Trust's SUI procedure.

Publicity and Media coverage

25. Culyer funding recipients must refer to the appropriate wording when ascribing funding for the project and Surrey & Borders Partnership NHS Trust must also be credited.

26. Other projects must acknowledge any relevant funding/support and Surrey & Borders Partnership NHS Trust whenever and wherever possible.

27. The Researcher will submit any press releases concerning the project to the LRDO for approval in advance of submission for publication.

28. The Researcher and the LRDO will inform each other promptly of any media enquiries or reports concerning the project.

Publication and dissemination

29. Internal research must comply with Trust Intellectual Property Policy (see attached).

30. External research must comply with funding source policy and Trust IPR policy, where appropriate and inform LRDO.

31. The Researcher is expected to write up the research for publication in a peer-reviewed journal.

32. The Researcher will inform the Trust in advance of the publication of any report, article or book relating to the project, and will ensure that any published materials or public statements acknowledge the relevant funding source and the Trust. This should apply even if the researcher does not work for the Trust or has left the Trust at the time of publication.

33. The Researcher will send a copy of any published report concerning the project to the LRDO for dissemination to relevant Clinical Governance areas.

34. Researchers agree to work with the Trust for the purposes of publicising and disseminating the work of the project.

Variations to Agreement

35. Under special circumstances the LRDO may agree, in writing, to vary the terms of the agreement.
Major Research Project

Agreement

Signed on behalf of the Trust __________ (LRDO or Chief Executive)

Name: __________ Date: __________ Position: Director of Older People Service, Clinical lead for R&D

Signed by the Researcher: __________

Name: __________ Date: __________ Position: Trainee Date: __________ Clinical Psychologist

FOR STUDENTS ONLY

Signed by the Academic Supervisor: __________

Name: __________ Position: __________ Date: __________ Academic Institution: __________

Signed by the Clinical Supervisor: __________

Name: __________ Position: __________ Date: __________ Employer: __________

KD/2005

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Appendix 2: Invitation letter

Dear Joe,

My name is X. (photo of X). I am a psychologist working for the NHS. I am writing about a research project, which is about the lives of people who are like you.

Y (photo of Y) is doing the project as part of her college course. Y is training to be a psychologist. Y wants to telephone you in the next week. She wants to talk to you about taking part in the project.

**Do you want Y to telephone you about taking part in the project?** Please ask someone who you know well to help you make this decision. Please send the REPLY FORM back to me, X.

If you have any questions, please ring me on XXXXXXXX.

Yours sincerely,

Dr. X

cc. Person's residential home manager

Person's key worker
# Appendix 3: Participant Information Sheet

A project about the lives of people who are like you.

<table>
<thead>
<tr>
<th>1. Photo of researcher</th>
<th>My name is Y</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>I am training to be a clinical psychologist. I work at the University of Surrey.</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>I am doing a project as part of my training.</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>I would like to ask you to take part in my project.</td>
</tr>
<tr>
<td>2. The lives of people who are like you</td>
<td>What is the project about?</td>
</tr>
<tr>
<td></td>
<td>The project is about people who are like you.</td>
</tr>
<tr>
<td></td>
<td>The project is about what people think about themselves.</td>
</tr>
<tr>
<td></td>
<td>I want to talk to six people for this project.</td>
</tr>
<tr>
<td>3.</td>
<td>What will you have to do?</td>
</tr>
<tr>
<td></td>
<td>I will meet with you 3 times.</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>I will talk with you at your home.</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>I will ask you questions about yourself and your life.</td>
</tr>
<tr>
<td>4. Your life</td>
<td>I will ask you about your life now.</td>
</tr>
<tr>
<td></td>
<td>I will ask you about your life when you were younger.</td>
</tr>
<tr>
<td></td>
<td>You can tell me as much or as little as you want.</td>
</tr>
</tbody>
</table>
5. I will tape record what you talk about.
   The tape recorder can be turned off at any time.
   Only myself and another researcher called Z will listen to the tape recordings.
   No one else will listen to the tape recordings – they will be kept private.
   When the study is finished, I will destroy the tape recordings.

6. I will write a report about what you talked about.
   **I will not use your name in the report.**
   I will write the report so that other people don’t know that I am writing about you.

7. Z and X work with me.
   Z and X will read the report.

8. You can say YES to doing the project.
   You can say NO.
   It is up to you.

9. If you say YES you can still change your mind if you like.
   Everytime I meet with you I will ask you if it is OK to talk to you.
<table>
<thead>
<tr>
<th></th>
<th>If you say NO it is OK.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Nothing bad will happen if you say NO.</td>
</tr>
<tr>
<td></td>
<td>Do you have any questions?</td>
</tr>
<tr>
<td>11.</td>
<td>You can choose someone to help you make the decision if you want.</td>
</tr>
<tr>
<td>12.</td>
<td>When the study is finished, I will tell you what I found out if you want.</td>
</tr>
</tbody>
</table>
# Appendix 4: Consent Form

**A project about the lives of people who are like you**

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Jennifer has talked to me about the project □ YES □ NO</td>
</tr>
<tr>
<td>2.</td>
<td>I have been able to ask Jennifer question □ YES □ NO</td>
</tr>
<tr>
<td>3.</td>
<td>I agree to Jennifer tape recording our talk □ YES □ NO</td>
</tr>
<tr>
<td></td>
<td>I know that the taping can stop if I want it to □ YES □ NO</td>
</tr>
<tr>
<td>4.</td>
<td>I know that I can change my mind and say “No” whenever I like □</td>
</tr>
<tr>
<td></td>
<td>I know it’s OK to say “No.” □ YES □ NO</td>
</tr>
<tr>
<td></td>
<td>I know that I can pull out at any time if I want and it won’t affect my care □ YES □ NO</td>
</tr>
<tr>
<td>5.</td>
<td>I know that Jennifer will write the project up as a report □ YES □ NO</td>
</tr>
<tr>
<td></td>
<td>I know that my name will never be used in a report □ YES □ NO</td>
</tr>
<tr>
<td></td>
<td>I know that Jennifer will write the report so that other people don’t know that she is writing about me □ YES □ NO</td>
</tr>
<tr>
<td>6.</td>
<td>I know that Arlene and Karen will read the report □ YES □ NO</td>
</tr>
<tr>
<td>7.</td>
<td><strong>My Decision</strong> Yes I want to take part in the project □ YES □ NO</td>
</tr>
</tbody>
</table>

Please ask someone to watch you sign this form
Appendix 5: Format of three interviews

The format of the three interviews was based on the Booth & Booth study (1994):

- The first interview involved: introductions; clarifying the purpose of the study; asking open-ended questions to find out about their life and closed questions relating to their current situation.

- During the second interview participants were encouraged to explore their life as a child (e.g. institutional life, their school days, their family); to reflect on their experience of growing up and to assess the significance of their upbringing in terms of their current situation. They were also asked questions about being 'older' and what that means and questions finding out about how they see themselves and their achievements.

- The third interview involved going through the participant's story as recounted in the previous interviews and filling in any gaps. It also involved addressing issues of representation (ensuring the story is true to the person) and ownership (ensuring the person shares the version of their life as reported).
Appendix 6: Interview schedule

1) Life stories:
Can you please tell me about your life/ yourself?

2) Example prompt questions: Start with questions about the person's current life:
What do you like? What do you dislike?
Who do you live with? What are the other people like who live here?
How are they like you? How are they different from you?
What do you do here? What did you do yesterday? What did you do at the weekend?

Work/ Daycentre
Do you work/ go to daycentre?
What are the people like who go to the daycentre/work?
How are they like you? How are they different from you?

Family/ friends/ interests
Did you have any friends? How are they like you? How are they different from you?
What did you like doing? What do you dislike doing?

3) Further example prompt questions asking about other aspects of the person's life.

Childhood/ Institutional life:
Where did you live before here? Where did you live when you were a child/ when you were small? Can you remember your first day there? What was it like living there? Why did you live there? Who else lived there? What were the other people like? How were they like you? How were they different from you?

School/ employment
What did you do there? Did you go to school? Did you have a job? Did you go to a day centre?

Leaving the institution:
Can you remember the day you left (hospitals name)? How did you feel about leaving (hospitals name)? Where did you move?

Specific questions relating to awareness of age
How old are you? What does (being 55) mean to you? How old are the other people in your house? Are you younger, older?

Questions relating to self-concept:
What do you think you have achieved in life? What are you proud of? What has been difficult in your life? What are you good at? What are you not so good at? What are your hopes in life? Is there anything that you would like to do but do not do? What are you looking forward to in the future? What are you not looking forward to? Has anything happened that has changed you as a person?
Appendix 7: Table 2. A comparative analysis of the main features of each person’s account.

<table>
<thead>
<tr>
<th>Person/age</th>
<th>Main features (Commonalities in capitals)</th>
</tr>
</thead>
</table>
| Elliot (50)| - Tragic narrative – e.g. wanted to marry his girlfriend but could not. Sense of sadness– unfulfilled wishes, thwarted opportunities, learned helplessness.  
  - Romantic narrative - describing his dream about his girlfriend walking towards him without her wheelchair.  
  - Fantasy narrative – “saved his life” (his key worker) and “going to get a job as a builder.” Sadness over an unmet wish.  
  - Happy when he remembers the past, happy childhood memories. Close to his mother and father. Sense of warmth and comfort when he described being cared for as a baby by his mother. His father taught him to swim: “Yeah, I can swim on my own now. (He smiles).” Close relationship to his girlfriend “I love Francesca so much” and his key worker now, “I like how it feels with Simon.” SIGNIFICANT OTHERS  
  - Sad when his mother died. “It was very very sad.” Sad when his dog died. LOSS  
  - Talked about life in the hospital. He worked as a gardener and found this to be “very dull.”  
  - Talked about being wound up in hospital and then smashing his arm through a window. “Scar. I broke a window. Wind me, teased me. Trying to wind me up.” ABUSE  
  - Lived in different wards in the hospital. Prefers current home “I like it here best.” Although he liked hospital surroundings, “They had some lovely fields over there.” TRANSITION  
  - Focus on his health. He talked about how he ‘looks after himself.’ Sense of pride. Also repeatedly mentioned his forthcoming toenail operation. Anxiety over procedure perhaps. Also talked about medication. HEALTH  
  - Good at “building.” “Yeah I ride a horse sometimes, I fell it once and hurt my thigh there.” Found horse riding difficult. IDENTITY.  
  - “I am a normal man”; and talked about wanting to be a “builder” IDENTITY – GENDER and SOCIAL ROLE  
  - Gave some evaluative comments e.g. “it’s alright” REFLEXIVE CAPACITY  
  - Used actions as well as words in the interview. |
| Lily (50) | - Strong lady, heroic narrative. Her mother had a “breakdown” and that “nobody had told her.” She said that she “did not mind” leaving the family home. Sense of humour, courage... RESILIENCE  
- The reunion with her long lost childhood friend, Paul could be interpreted as a ‘happily ever after’ narrative  
- ‘Fantasy’ narrative – her mother died and lives in a different world in the TV.  
- Lived in different places in the hospital. Prefers the “freedom” of living in the community. TRANSITION  
- Talked about how her mother had moved on from heaven to a “different world.” RESILIENCE.  
- Close relationship to her mother. “My mum always tucked me into bed.” Also closely attached to her advocacy manager meetings and old friend.  
SIGNIFICANT OTHERS  
- Performer – singing, dancing, playing guitar, fantasy narrative of wanting to be a “film star.” IDENTITY. She seems outgoing and sociable.  
- “I like doing a lot of things for myself.” (E.g. cleaning, hoovering, answering the phone); Independence. Also likes “freedom” IDENTITY  
- Likes being listened too. Enjoyed being interviewed. “I like doing this.”  
- “I am a beautiful lady...a young girl...”, “Little”, “Great Aunty” IDENTITY, GENDER, SOCIAL ROLE  
- Able to evaluate an event e.g. said she felt “angry” when her housemates told on her. REFLEXIVE CAPACITY |
| John (55) | - Regressive narrative – repeatedly talked about “bad” events in hospital, how he was “sick”, “lost weight” and “died.” ABUSE(?) Shocking and confusing. COHERENCE.  
- Limited content of narrative.  
- Close relationship to his mate “Mark.”’’ SIGNIFICANT OTHER  
- Enjoys going on holidays with Mark, does rock climbing and canoeing. Sense of fun. More of a progressive narrative. RESILIENCE.  
- Good at bowling, swimming and parties. Enjoys cooking and going to work at the garden centre. IDENTITY  
- “I’ve got two” (referring to having two teeth). IDENTITY  
- Gave mainly short responses to questions. Gave some evaluative comments e.g. “it’s alright” and it’s “bad” (referring to the hospital). REFLEXIVE CAPACITY |
| David (54) | - Regressive narrative (lots of reported abuse, violence, injuries in his account...) (being “whacked” in the hospital by “Big Mick”, being hit by a hockey stick, being bitten by a boxer dog and his housemate pushing his father over). Shocking and sad. ABUSE. |
- Became more of a **progressive** narrative when described time since leaving hospital, as he said he enjoys holidays, dressing up as King George, he loves food and going to the pub and church …**RESILIENCE**
- Close relationship to the staff. **SIGNIFICANT OTHERS**
- Focus on his injuries on his body – showing me his scars. **HEALTH**
- Good at “hockey, badminton, darts and cricket.” Finds reading difficult. **IDENTITY**
- Had difficulties giving evaluate responses. **REFLEXIVE CAPACITY**

<table>
<thead>
<tr>
<th>Christopher (55)</th>
</tr>
</thead>
<tbody>
<tr>
<td>- <strong>Heroic</strong> narrative – spoke about losses but also there was a sense of fun when he spoke about positive events in his life, such as going on holiday with his brother and his dancing. Close relationship to his brother. <strong>SIGNIFICANT OTHER</strong></td>
</tr>
<tr>
<td>- Discrepancies in narrative and difficulties talking about certain things, such as his previous job as a cleaner at the hospital and his accident whereby he was hit by a car. Loss of role as a cleaner. Identity linked to being a cleaner. <strong>LOSS and TRANSITION</strong></td>
</tr>
<tr>
<td>- Responsibility. Talked about running the meetings. <strong>IDENTITY</strong></td>
</tr>
<tr>
<td>- Identity linked to his social role, cleaner. “I am the best cleaner.” <strong>IDENTITY – SOCIAL ROLE</strong></td>
</tr>
<tr>
<td>- Talked about having his own cleaners in the hospital, being a manager of meetings – authority and responsibility. A way of maintaining his dignity maybe. <strong>SOCIAL ROLE</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>George (53)</th>
</tr>
</thead>
<tbody>
<tr>
<td>- <strong>Regressive</strong> narrative as he spoke about many difficult life events, such as being physical abused and having a heart problem.</td>
</tr>
<tr>
<td>- “Heart problem” upsets him. Emotionally distressing for George. <strong>HEALTH</strong></td>
</tr>
<tr>
<td>- Father hit him. <strong>ABUSE</strong></td>
</tr>
<tr>
<td>- Close relationship to his girlfriend and the manager of his home. <strong>SIGNIFICANT OTHER</strong></td>
</tr>
<tr>
<td>- Enjoys colouring with his girlfriend. Finds certain household chores difficult because of his heart problems. <strong>IDENTITY</strong></td>
</tr>
<tr>
<td>- Said he used to be a “baby girl” but now “I am a grown man.” <strong>IDENTITY – GENDER.</strong> He also said he was “happy” but then he became visibly upset when spoke about his heart. Discrepancies in narrative. <strong>COHERENCE.</strong></td>
</tr>
<tr>
<td>- Able to evaluate an event and say how he felt, e.g. “frightened” when he was beaten by his father. <strong>REFLEXIVE CAPACITY</strong></td>
</tr>
<tr>
<td>- Said that he finds something things difficult to talk about because of the “emotion.” <strong>COHERENCE, REFLEXIVE CAPACITY</strong></td>
</tr>
</tbody>
</table>
Appendix 8: Lily’s story

This section will initially present a short summary of Lily’s story. Then the salient features of an example of a narrative analysis\(^1\) of her account\(^2\) will be highlighted.

Lily’s story

Lily is a fifty-year-old lady and she has a diagnosis of Down’s syndrome. During the interviews she wore casual clothes. She lives in a residential home with four other ladies and she is supported 24 hours a day by a team of staff. Lily likes being independent: she goes to the shops on her own and does her own cleaning. She works in a workshop and in a kitchen. She also enjoys going to advocacy meetings twice a week and has been going to these meetings for twenty years. In her spare time, Lily likes listening to music, playing the guitar, swimming, holidays, working on her ‘book about her life’ and looking at her photo boards. She also enjoys going to church every Sunday. Her parents are dead but she has three siblings who are still alive. Lily lived with her family until she was six years old, at which time her mother had a breakdown and then Lily went to live in a long stay hospital. Lily lived in many different places in the hospital. She also had various jobs in the hospital including a shop assistant and a kitchen assistant. When the hospital closed she moved into her present home.

BEGINNING...

Childhood

Lily lived with her parents until she was six years old and then she moved into the Kings Estate hospital. She said, ‘My mum and dad put me in the Kings Estate. My mum had a breakdown...No one, nobody ever told me.’ She later stated that she ‘did not mind’ leaving the family home.

Lily recounted happy childhood memories with her father, such as when they went strawberry picking together and a time when they were both playing in the River Thames. She said, ‘Dad got me out sometimes...He went off to do strawberry picking. Strawberries...Made jam out them. Jam, jam on bread...Put it on bread... Then when very little, I, my dad put a ring around me and threw me in the river Thames... Another thing with my family...I’m young. With my dad and my mother went fishing, had a rod. Do you know what I a caught? A fish...Make me (...) excited.’ There was a sense of fun and playfulness when she recalled these times. Lily also talked about

\(^{1}\) The narrative accounts are structured in the form of three-part narratives, with a beginning, middle and end, as suggested by Murray (2003).

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early family holidays. She described a time when she danced on the beach, whilst her family watched her. She said, ‘Dancing on the beach... I danced on my own...My mum and dad watching...And my three brothers...They said, ‘well done.’ (She smiles)... My mum very happy...They gave me a big clap.’ The way Lily talked about this event gave a sense of pride.

Lily’s parents

Lily’s parents married when they were ‘young’ and she agreed they were ‘very happy’ together. At one point during the interview, she showed me a photo of her parents cuddling each other on a sofa and she said,

P: ...And that’s my dad.

I: Ah...What does your dad think about you?

P: He pleased to see me. (She laughs).

I: He’s pleased to see you, is he?

P: (Inaudible). My dad same age as my mum.

I: Your dad’s the...

P: I’m my dad’s daughter.

I: You’re your dad’s daughter. Yeah.

P: Yeah. And my mum’s daughter.

I got the sense that Lily’s mother also meant a lot to her. She said, ‘My mum always tucked me into bed... I give my mum a kiss goodnight...She sings to me in my bedroom.’ The way she talked about this routine gave an impression of comfort and security.

Hospital life

Lily described how she lived in many wards in the hospital. She initially spoke about living on G ward and she seemed excited when she recalled how she ran around the bedroom with another girl. However, she also talked about some difficult times. For example, she described an incident whereby she had her hair pulled. She explained that this was because the other girl was in a ‘bad mood.’ She said that she told, ‘somebody in the office’ and hence the situation was resolved.

2 Short summaries for the remaining five participants are shown in Appendix 12.
Lily also talked about how her parents helped her when someone stole her clothes in the hospital. She stated, ‘*My mum went mad, my dad went mad...*’ She described how her parents went to see Richard, the boss of the hospital manager and how ‘*He [hospital manager] went to the ward to tell them off.*’ She added, ‘I’m glad my mum stuck up for me, and my dad.’

Lily’s favourite place at the hospital was Princes House, where she was more independent. She said, ‘*I did my own cooking, my own washing up... I do my things, done the hoovering.*’ She also talked about looking after a younger boy who lived there. She said, ‘*I helped people out. One boy lived there with me...I help (Inaudible)... He get ready for school.*’

Lily worked in a kitchen and a shop in the hospital. She stated that she enjoyed working as a shop assistant, as she found the people were ‘very friendly.’ Lily’s conversation about Kings Estate ended with her description of how she asked ‘the clinic lady’ if she could move to her current place of residence, Glebe Cottage. She said, ‘Yeah, I went to see her. I said, ‘*I want to move to Glebe Cottage.*’

**Family**

Family is a significant part of Lily’s story. She spoke fondly about her family. Whilst looking at a genogram of her family, Lily commented on how she had a ‘big family’ and what this meant to her. She said, ‘That’s a big family. (She looks at family tree and laughs)... It make me shy...It makes me happy with it.’

Furthermore, Lily talked about her siblings and their children, where they lived and where they worked. For example, she spoke about her brother’s two children and stated, ‘*That is Robert, my favourite one...He come up to me and give me a cuddle.*’ She also recalled being a bridesmaid for her siblings’ weddings. She seemed very happy recalling these times. She also talked about her ‘favourite’ uncle and how he teases her. She said, ‘*He makes me laugh...He asks me ‘have you got a boyfriend?’ (...) He always teases me.*'
Lily also identified with being a Great Aunty and she again seemed particularly proud and happy of this. She said,

P: I'm an Aunty. Now I'm a Great Aunty.
I: Now you are a Great Aunty. Oh...How does that make you feel?
P: Very happy. (She laughs)

The death of her mother
A significant event in Lily's life was the death of her mother, who died last year. She talked about how she believed that her mother has moved on from heaven and is now living in another world, perhaps indicating a way of coping.

P: Now my mum in a different part now.
I: She's in a different...?
P: Died away in London.
I: Yeah.
P: Then moved on, went to heaven. Not in heaven now.(...) I: She's not in heaven now?
P: No, in her real life, she's in a different country.(...) P: I saw my mum on the telly the other day.
I: You saw her on the telly?
P: Yeah. (She laughs). (....)
P: On the telly. On the, in the morning programme.
I: Oh in the morning, is it one of the breakfast programmes?
P: Yeah. Eamon show.
I: Eamon Eamon Holmes?
P: Yeah my mum on that.
I: Your mum's on that?
P: Yeah. She said on the telly, ‘I’ve got a daughter.’ (...)

P: I watched the telly on Eamon’s programme.

I: So you feel that your mum died and she went to heaven and then now she’s...

P: In different world.

Interests and social life

Lily described how she enjoys going to her advocacy meetings, which she has been attending for the past twenty years. She talked about the importance of having ‘people listen to me.’ She also spoke about Jonathan, the manager of the meetings and how he helps her when she needs it. For example, she explained, ‘I had a problem... And someone, one of the staff, go into my room.’ She added, ‘And Jonathan he had a word with me on my own....Then Jonathan sort it out...Before he come and see me at home...He listens to me.’

Lily showed me various certificates, including a swimming certificate. She seemed particularly proud that her brother had taught her to swim. She stated that she was a ‘good swimmer.’ She also showed me a large photo board, which was made up of many photos of herself. Lily explained that she had put the board of photos together because ‘My memory in my brain a long time ago... My brain yeah. I wanted to do it for myself.’ I got the impression that it helped her to remember. Again, she seemed proud talking about her photo board:

I: It’s a really good idea.

P: Yeah.

I: Do you know anyone else who has done one of these?

P: No only me.

I: Only you. How does that make you feel?

P: Smile. (She smiles).

Lily pointed out that her favourite photo was of herself holding a guitar. When Lily spoke about the guitar, she seemed pleased with her accomplishment. She said, ‘I feel thrilled to bits with it.’
She stated that someone taught her how to play, when she lived in the Kings Estate hospital. Later on, she also described feeling like she was 'famous' when she played the guitar.

I: What does it feel like playing the guitar?

P: Famous. (She smiles).

I: Famous. Who... Famous like who?

P: Cliff Richard.

I: And what does it feel like to be famous?

P: Happy with it.

Work

Lily talked about working for an organization called Working Forward, where she does 'badges and envelopes' and 'kitchen work.' She described how she enjoyed the parties at work.

Significant others

'An old friend'

A significant person in Lily's story was 'Paul.' She said, 'I know someone who know me, my old old friend ...who I never seen a long time. His name is Paul.' Lily talked about how she has known Paul for many years and how he 'knows her.' Lily explained that Paul used to visit the family when she was a younger and she said, 'He came to my mum's house. Had a cup of tea with me and my family.' She also said that Paul visited her at hospital years ago and that 'He take me to pub and have a drink together.' Lily explained how she had not seen Paul for many years. However, she stated that Jonathan, the manager of her advocacy meetings contacted Paul and arranged a surprise reunion for them to meet. She said, 'That's what happened to me. Jonathan said I got a surprise for me...He said to me, 'you've got a surprise coming for you Lily. You've had it.' (She laughs)... I didn't believe it.' She seemed very excited by the fact that Jonathan had gotten in contact with her old friend. In the third interview Lily talked about how her meeting with Paul went. She described how he attended her advocacy meeting. She said that she felt 'nervous' about seeing him. She said, 'My hands a bit shaky. And I could not believe it I saw him.'
Lily's fellow residents

Lily talked about her fellow residents including, Tracy, Eve and Katherine, whom she met at Kings Estate. She talked about having ups and downs with her friends. For example, at one point she said, 'I go somewhere to my friend's place and some people get jealous.' She added, 'it's hard' and that it makes her feel 'angry.' Lily stated that she gets annoyed with her fellow residents when they complain to staff that she is not doing the housework. She said, 'They tell staff about me... They make me upset... They say I'm not doing the hoovering...(...) They make me cry.' She added that sometimes her fellow residents Eve and Katherine get in a 'bad mood...sometimes they get funny ways.' When this happens, she said, 'Me walk away and go into my room.' Lily talked about how she spoke to Jonathan (advocacy), 'He had a word with me on my own...Then he sort it out and Jonathan to ring Claire and then Claire come see me again.'

END...

Hopes and wishes

Lily seemed to find it hard to talk about her wishes and hopes. After several prompt questions, she said, 'Wishes I go... I be film star.' Lily said that she hoped to have her 'own place' one day as she found her fellow housemates as 'bossy' sometimes. She said, 'I want to have my own place...And do things for myself... And meet different people.'

Identity

Lily spoke positively about herself in the first interview:

I: (...) And can you tell me a little bit about yourself?

P: I'm very beautiful lady.

I: Very...?

P: Beautiful.

I: Beautiful, yeah.

P: Then I me (...) I am little girl, I am young.
Lily also identified herself with her parents ('I am my dad's daughter') and she spoke about how her physical appearance is like that of her parents. She said, 'Yeah. Grey hair. My mum got grey hair and my dad got grey hair...My nose a bit like my dad's. See that nose?...Bit like my dad's nose. (She laughs).' Furthermore, the way Lily talked about her life showed how she wanted to present herself as an independent woman. In the first interview, she said, 'I like doing a lot of things for myself...I've done the shop on my own....I do my own cleaning.' Similarly, when Lily was asked about her personal strengths she said, 'I do hoovering...And the table...I'm good help answering the phone...Another thing good at bath...Sitting in my room, watch my own telly, watch my own DVD player.' When asked whether she found anything difficult, Lily did not identify any limitations. Instead she continued to talk about her achievements, 'I got my own tablets. I do it myself now...Yeah. I always save my money up...Good at time.' As well as independence, Lily talked about 'freedom.' She spoke about why having freedom is important to her, such as being able to stay in her room if she chooses and having her own possessions.

I: And why is freedom important to you?

P: I do things myself.

I: You do things for yourself. So it is like being independent?

P: Yeah.

I: And that is important to you. And and what is freedom to you?

P: Them bits on there, they're all mine. (She points to her ornaments on her shelf).
Appendix 9: Gergen & Gergen’s (1984) narrative forms

Gergen & Gergen (1984) identified three basic narrative forms:

- A **stable** narrative is one in which the person’s evaluations of situations and events remains the same over the course of time
- A **regressive** narrative is one in which evaluations get worse with time
- A **progressive** narrative is one in which evaluations improve over time

The authors explained that these three narratives were the basis for more complex narrative forms such as:

A **tragic** narrative is a **progressive** narrative followed by a rapid regressive narrative.

A **happy ending or comedy** is the reverse of a **tragic** narrative and involves a regressive narrative followed by a progressive narrative.

A **happily ever after** narrative is a progressive narrative followed by a stability narrative.

A **romantic saga** is a series of progressive-regressive phases, for example the individual sees his life as a continuous array of battles against the powers of darkness.
Appendix 10: Labov & Fanshel structural types of narrative clauses (1977)

An abstract is an initial clause in a narrative that reports the entire sequence of events of the narrative.

An orientation clause gives information on the time, place of the events of a narrative, the identities of the participants and their initial behavior.

A clause of complicating action is a sequential clause that reports a next event in response to a potential question, "And what happened [then]?"

A resolution is the conclusion, which cannot be defined until the concept of 'most reportable event' is introduced.

An implication: All sequential clauses are clauses of complicating action and all clauses of complicating action are sequential clauses.

A coda is a final clause which returns the narrative to the time of speaking, precluding a potential question, "And what happened then?"

An evaluative clause provides evaluation of a narrative event.

Retrieved 24th June 2007, from the World Wide Web:
http://www.ling.upenn.edu/~wlabov/sfs.html
Appendix 11: Providing credibility checks: summary of Narrative Analysis group

In the Narrative Analysis (NA) group, I met with two other trainees who were also using NA. During one session, I swapped my transcript with Sarah\(^3\), another trainee and she read Lily’s first interview and she made the following comments:

Family is significant in Lily’s account and she noted how Lily positioned herself alongside her relatives.

Lily’s account was seemed quite positive at times and Lily seemed like a funny lady.

Much of the events in Lily’s account are located in the present tense, rather than in the past or future. We reflected on how this may be due to the people around the person being more focused on the current situation of clients as opposed to their past or their future. That is, perhaps care staff are more occupied with the person’s everyday life and supporting them with their current needs as opposed to thinking about their future and their history.

It was interesting when Sarah and I compared each others transcripts as we noticed that they looked very different. Sarah’s transcripts consisted of very few questions on her part and instead large paragraphs of text where the participants had spoken at length. In contrast, my transcripts comprised of many questions and the participants often gave short responses or one-word answers. However, we then reflected that despite this difference in how the transcripts looked we still had come up with similar narrative forms. For example, Sarah had also interpreted her accounts as ‘heroic’ as she had found that the person would describe various obstacles but then talk about how she overcame them. This is similar to Lily’s story, as she spoke about difficult times (e.g. leaving the family home, having her clothes stolen at the long stay hospital) but then she talked about how she overcame them (e.g. having her parents support her, talking to her advocate). Sarah had also interpreted that her accounts had different narrative forms, such as ‘heroic’, ‘tragic’ and ‘happily ever after.’ This observation fits with Gergen & Gergen (1984) ideas that narrative forms in a given culture are limited in number due to social utility, aesthetic desirability and cognitive capacity.

\(^3\) The trainee’s name has been changed for reasons of confidentiality.
Appendix 12: Short summaries of participants’ life stories

Elliot’s story
Elliot is a fifty-year-old man and he has a diagnosis of Down’s syndrome. During the interviews, he wore casual clothes. He lives in a residential home with six other people and he is supported 24 hours a day by a team of staff. Elliot has a key worker who is called Simon, who supports him with various daily activities, such as cooking and shopping. Elliot works in a workshop, where he puts nuts and bolts together. In his spare time, he enjoys watching television, listening to music and going to the pub. Elliot spent the first few years of his life in Malaysia with his mother, father and younger brother. His parents are dead but he has four siblings who are still alive. Prior to his current home, Elliot lived in an old long stay hospital. He had some difficult times in this hospital and he states that he prefers to live in his current home.

John’s story
John is a fifty-five year old man and he has a diagnosis of Down’s syndrome. During the interviews he wore casual clothes. He lives in a residential home with seven other people and he is supported 24 hours a day by a team of staff. John enjoys going on holidays. He has been to North Wales, where he has done various activities, such as canoeing and rock climbing. He also likes listening to music, such as ABBA. In addition, John likes his advocate, whom he goes out with in the car. During the day John does gardening at a day centre. John’s parents are dead. He spent the majority of his life living in Kings Estate hospital. When the hospital closed he moved into his current home.

David’s story
David is a fifty-five year old man and he has a diagnosis of Down’s syndrome. During the interviews he wore casual clothes. He lives in a residential home with one other person and he is supported 24 hours a day. David has lived in his current home for five years now. Prior to this, he lived at Dukes Hall and Lampeter Estate long stay hospitals. David lived through difficult times at the hospitals. During the day, he attends classes where he enjoys doing art and cooking. David likes eating and his favourite food is fish and chips. At the weekends, he also enjoys going to the pub and drinking beer and he goes to church on Sundays. He also likes going on holidays. David once went on holiday to Devon and dressed up as King George. David’s parents are dead, however he has a sister who is alive who visits him occasionally with her own family. He also
has a good friend called Ruth whom he met at Dukes Hall hospital.

Christopher's story

Christopher is a fifty-five year old man and he has a diagnosis of Down's syndrome. During the interviews he wore jeans and a T-shirt. He has lived in his current home for twelve years and he lives with six other people. He attends 'Trust' meetings. Christopher also attends evening classes once a month, where he does art and crafts and pottery. He likes watching television in his own room in the evenings. He also enjoys music, dancing and going on holidays. In 2006, Christopher was in an accident, whereby a car hit him and his leg was hurt. Since then, he is no longer able to walk to the shops on his own. Before his current home, Christopher lived in Duke's Hall hospital. In the hospital, he worked as a cleaner for twenty years. His mother and father are dead but his brother is still alive and they go on holiday together.

George's story

George is a fifty three year old and he has a diagnosis of Down's syndrome. During the interviews, he wore smart trousers and a shirt. He lives in a residential home with eight other people and he is supported 24 hours a day by a team of staff. George has a heart problem and hence he has to take care not to rush about. This can get him down sometimes. He spends his days at college, where he does cookery and arts and crafts. He also attends a day centre where he makes rugs. In his spare time, he enjoys watching television, films and doing colouring in his room. He also likes going to see Pantomimes. George has a girlfriend whom also lives with him. Prior to his current home, George lived with his parents. He talked about how this was difficult, as his father used to hit him. George became upset during the interviews when he spoke about this and he stated that he has difficulties with his 'emotion.' He also described how he used to be a 'baby girl' but now he is a 'grown man.' George also stated that he used to live in a long stay hospital. However, he stated that he could not remember anything about it or when he lived there. His manager stated that George had met his girlfriend in the old hospital.
Appendix 13: Topics covered for the three interviews for Elliot

**Interview 1**

Look after himself  
Listens to music  
Watching TV, DVDs, watch TV in own room.  
Playing games  
Going to club  
Acting  
Having operation on toenail.  
Had tonsils out when younger  
Mother and father passed away  
Brothers and sisters  
Kings Estate  
Did weeding at Kings Estate – dull work  
Learned reading and writing  
Francesca met at Kings Estate  
Holidays  
Poorly – take tablets  
Horley workshop

**Interview 2**

Family  
Musical interest in family  
Friends in Malaysia  
Father in Army  
Dreams about Francesca  
Teasing in Kings Estate – hit window  
Being a builder  
Francesca  
Horse riding with Francesca

**Interview 3**

Life in Malaysia and Chloe  
Mother looking after him  
Growing up – feeling like a normal man.  
Deaths of mother and father  
Dog died  
Mother used to be a dancer  
Francesca and wishing to marry her.
Appendix 14: Example transcript

LILY (Participant 2). Interview 2. 28.11.06

I: Right, so if I carry on from last time…

P: Yeah.

I: And asking you some more questions about your life?

P: Yeah.

I: Yeah and so last time I came…

P: Yeah.

I: I found a lot about your life.

P: Yeah.

I: Yeah. You told me um that you were born in London.

P: Yeah.

I: Yeah and that you lived with your mother and father and three brothers.

P: Yeah.

I: Yeah and there was Dennis. Let me get the family tree here. There was Dennis the oldest, then Richard and Paul the baby, you said.

P: Yeah.

I: And you said you quite liked having a big family.

P: Yeah.

I: Um and now all of your brothers are married with children.

P: Yeah.

I: Yeah. And your, that makes you an Aunt.

P: Long time

I: Long time, yeah.

P: I’m an Aunty. Now I’m a Great Aunty.

I: Now you are a Great Aunty. Oh…How does that make you feel?
P: Very happy. *(She laughs)*

I: Does it?

P: Yeah.

I: Oh that’s good.

P: Shall I tell you why? My Aunty Grace…

I: Your Aunty Grace…

P: Her daughter Emma had a baby boy.

I: Ah I see.

P: Now, I’m a Great Aunty.

I: Ah so your Aunty Grace was that your mother’s sister?

P: Yeah

I: Yeah. So that’s your mother’s sister. Wow. So yeah that makes you a Great Aunty.

P: Yeah.

I: And that makes you feel really good.

P: Yeah.

I: Yeah. Oh…So we talked about your big family.

P: Yeah.

I: And how you liked that. And you said that you you and Paul and um your dad come and see you here and um Paul drives his car, he’s got a car.

P: Yeah.

I: He comes and sees you with your dad.

P: Yeah.

I: And um unfortunately you said that your mother had passed away last year.

P: Yeah

I: And you found that really difficult.

P: Yeah.

I: Um because you…
P: Now my mum in a different part now.
I: She's in a different?
P: Died away in Croydon.
I: Yeah.
P: Then moved on, went to heaven. Not in heaven now.
I: She's in heaven now?
P: My mum?
I: Yeah.
P: Not in heaven now.
I: No? She's not in heaven now?
P: No, in her real life, she's in a different country.
I: She's in different country.
P: Yeah. *(She smiles).*
I: Oh...And how do you know this?
P: I saw my mum on the telly the other day.
I: You saw her on the telly?
P: Yeah. *(She laughs).*
I: Did you?
P: *(She nods).*
I: Oh...
P: Before her name was Pat.
I: Yeah.
I: Her name was Pat, yeah.
P: On the telly. On the, in the morning programme.
I: Oh in the morning, is it one of the breakfast programmes?
P: Yeah. Eamon show.
I: Eamon Eamon Holmes?

P: Yeah my mum on that.

I: Your mum’s on that?

P: Yeah. She said on the telly, ‘I’ve got a daughter.’

I: You’re...?

P: I’m my mum’s daughter.

I: You’re your mum’s...

P: Daughter.

I: Daughter. Yeah, you are.

P: I watched the telly on Eamon’s programme.

I: So you feel that your mum died and she went to heaven and then now she’s...

P: In different world.

I: In a different world. Ah...She’s living in a different world now, that’s what you think.

P: Yeah.

I: Yeah, ah...How does that make you feel to know that that she lives in a different world?

P: In the real life.

I: In real life.

P: Yeah

P: My mum is a good singer.

I: Your mum is a good singer? Singing as in songs?

P: Yeah

I: Was she?

P: My mum sing to me in bed.

I: Oh did she? When was this?

P: At Christmas time, with my mum. I’m a little girl.

I: Yeah.
P: Then I’m a little girl. My mum every night I’m grown up.

I: Yeah.

P: My mum always tucked me into bed.

I: So when you were growing up your mum tucked you into bed?

P: Yeah.

I: Ah...

P: My mum, I give my mum a kiss goodnight.

I: You gave your mum a kiss good night?

P: She sings to me in my bedroom.

I: And she sings to you in your bedroom?

P: Yeah.

I: Ah that sounds lovely

P: Yeah

I: Yeah. She looked after you.

P: Yeah

I: She cared for you

P: Retired a long time now

I: Yeah

P: My dad is retired now.

I: Your dad is retired?

P: Yeah

I: Oh is he?

P: He don’t work now.

I: Where did he work before?

P: He’s a, he’s a decorator and painter.

I: Oh, he was a painter.
P: Sometimes he do my room out for me.
I: Did he?
P: Yeah.
I: Oh...Did he paint this room?
P: Yeah.
I: Did he? It's lovely.
P: My dad, my dad is a good painter.
I: Good painter.
P: My brother Paul...
I: Yes.
P: ...works for telecoms.
I: Oh does he, telecoms.
I: Ah...
P: Dennis, my brother Dennis works for garden centre in Cornwall.
I: Oh does he?
P: Richard works for television firm
I: Richard works for the television firm, does he?
P: Yeah.
I: So they all do different things?
P: My sister in law Emma work on a garden centre.
I: Does she? So Emma does the same job as Dennis in the garden centre.
P: No, Dennis he works, Dennis on garden centre but in Cornwall.
I: Oh, I see right so different garden centres.
P: Yeah.
I: Yeah.
P: My sister in law Emma...
I: Yeah.

P: ...is a typist.

I: Oh she's a typist. So they all have different jobs?

P: Yeah.

I: What do you think about that, them all having different jobs?

P: Yeah. Have you got Betty on there?

I: Betty?

P: Yeah.

I: Um...

P: My sister in law Betty.

I: I don't think we've got Betty on there. Let's have a look.

P: What's that say there?

I: Your sister in law. Now there was Richard who was married to...

P: Betty.

I: Right, so there's Betty. Then you said that Richard has been married before?

P: Yeah.

I: To another lady there.

P: Yeah, Gail.

I: Gail, right we'll put Gail on there. And then they got divorced and he so he remarried Betty.

P: All three of my brothers are married now.

I: All three of them are married. Yes I remember you said, yeah.

P: I remember. I was a bridesmaid (she laughs).

I: You were a bridesmaid, were you?

P: Yeah.

I: And...

P: I went to Dennis's
I: You went to Dennis's wedding, yeah.

P: And he got married in a pub.

I: Did he? Yeah. Were you a bridesmaid for that?

P: Yes.

I: What was that like?

P: Wearing pink.

I: You were in pink. And what was it like?

P: Very nice. (She laughs).

I: Was it?

P: Yeah.

I: Yeah. Why was it nice?

P: I had my hair different.

I: You had your hair different? What was it like?

P: Perm.

I: Perm. Sort of curly?

P: Yeah.

I: Curly, yeah.

P: Then I went to Richard. Then I went to Dennis. Went to Richard 's.

I: You went to Richard 's wedding as well?

P: I was in peach.

I: Oh peach this time, was it bridesmaid again?

P: Yeah.

I: Did you have a nice dress?

P: Yeah.

I: Yeah.

P: Lemon. (She smiles).
I: Lemon, oh...

P: And then to Paul's one, I'm a guest.

I: Oh, you were a guest for that one? Ah... So you went to three weddings?

P: Yeah.

I: Yeah.

P: Then the baby got christened.

I: And the baby got christened.

P: Me got christened.

I: And you got christened?

P: When I was a little girl.

I: When you were a little girl?

P: Yeah.

I: Do you remember it?

P: Yeah.

I: Do you? Is that with your family?

P: Yeah.

I: Yeah. Sounds like you're quite a close family. Quite um... You know each other well?

P: Yeah.

I: Yeah.

P: One meeting, I know someone who know me, my old old friend...

I: Yeah.

P: ...who I never seen a long time. His name is Paul.

I: Oh yes, I remember you told me Paul. Yeah this was...

P: And this Friday I'm going to see him. (She smiles)

I: So this Friday you are going to see him again.

P: At the meeting.
I: At your meeting.

P: With Jonathan and April.

I: Yes, I remember you told me about your meetings. The meetings are very important to you aren’t they?

P: Yeah, Paul is.

I: Paul is.

P: Yeah.

I: Paul’s important to you.

P: He knows me.

I: He knows you.

P: He…Long long long time ago.

I: Many years.

P: Long time ago.

I: Lots of years. Yeah, a long time ago.

P: He knows me, I know him.

I: You know him. What would what would Paul say about you?

P: I’ve got a lot about me. (She laughs).

I: If Paul was here…. 

P: If I see Paul, gonna write it down.

I: You what?

P: I’m going to ask Paul to write it all down. He know all about me.

I: He knows all about you. What would he say about you?

P: He’d say ‘hello’, I’d say. ‘hello Paul.’

I: What does Paul think about you?

P: Sometimes sometimes I met him once, I’m a bit shy.

I: You were a bit shy were you?

P: Now, now, now he’s my old old friend.
I: So he's an old friend.

P: I've seen him a long time.

I: Yeah. He knows you very well?

P: Yeah.

I: Yeah. And that's important to you.

P: Yeah. And I find out um Jonathan was in the meeting. Hannah went with him. Except me. I don't know about it.

I: You didn't know about, about what?

P: About Paul.

I: About Paul coming to the meetings?

P: (Inaudible) in the meeting. I went down. Jonathan asked me about Paul. I asked Jonathan what his name is. Jonathan told me his name is Paul.

I: Ah... and and you knew Paul from when you were younger, didn't you?

P: Yeah, in London.

I: In London. So a long time ago.

P: Yeah.

I: Was Paul like you?

P: Yeah.

I: Yeah. How is Paul like you?

P: He's got his eye on me.

I: He's got his eye on you?

P: Yeah. (She smiles).

I: Has he? How, how do you know that?

P: Before, I walking about somewhere in London. He walking by, he smiling at me.

I: Oh he was smiling at you? Yeah and and so you knew Paul when you were in London before and...

P: I was with my mum.
I: You miss your mum?

P: No, I was with my mum.

I: Oh, you were with your mum. You were with your mum and...

P: And then I met Paul.

I: And your mum met Paul.

P: Yeah, my mum know Paul.

I: Does she?

P: And my dad know him.

I: Oh how do they know him?

P: He met, he met my parents.

I: Did he?

P: Yeah.

P: He came to my mum’s house. Had a cup of tea with me and my family.

I: Yeah. What does Paul do?

P: I don’t know where he works. I don’t know.

I: You don’t know.

P: (Inaudible).

I: Pardon?

P: I don’t know.

I: Not sure, no. Does um... who does he live with, Paul?

P: Hey?

I: Who does Paul live with?

P: I don’t know.

I: Does he live on his own?

P: Yes.

I: Does he?
P: He he lives in Croydon way.
I: Croydon, near your...
P: My dad lives in a different part of Croydon.
I: Right, ah...
I: Jonathan and April?
P: Not April. Hannah .
I: Hannah .
P: And Jonathan.
I: And Jonathan.
P: They went up there (inaudible) Croydon way.
I: They went up there for a card?
P: They going to see my old friend.
I: Oh, they are going to take you to see your old friend?
P: No, they is coming down for the meeting.
I: Oh he is coming down for the meeting?
P: Yeah.
I: So Jonathan has contacted Paul to come to the meeting?
P: Yeah. I will see him then.
I: Ah...
P: That’s what happened to me. Jonathan said I got a surprise for me.
I: A surprise? Has he told you about Paul?
P: He said to me, ‘you’ve got a surprise coming for you Janet. You’ve had it.’ (She laughs).
I: Pardon?
P: I didn’t believe it.
I: You didn’t believe it, that Paul was coming?
P: Yeah.
I: It's exciting?
P: Hey?
I: It's exciting?
P: Yeah.
I: Yeah. So and that's Friday.
P: Yeah.
I: So you'll find out what Paul's doing?
P: Yeah.
I: Yeah. And you knew Paul when you were younger?
P: Yeah.
I: Does, did um your brothers know Paul?
P: Yeah.
I: Did they?
P: My brother and my other brother went out with Paul.
I: They...?
P: Went out with a drink like that.
I: Oh they used to go for a drink with him?
P: Yeah.
I: Did they? And um…
P: My brother Dennis had a car.
I: And Dennis had a car.
P: Yeah. And Paul gives my brother car went to my mum's house.
I: Did he?
P: Yeah.
I: Oh, and did Paul…
P: He said to my mum and dad, ‘Lily come down, you’ve got an old friend here.’

I: He said what?

P: My mum called me down. I was in my bedroom.

I: Yeah.

P: Me was in my bedroom.

I: You were in your bedroom.

P: My mum said, ‘Lily come down, you’ve got an old friend here.’ (She smiles).

I: Oh and Paul was there. Oh... And what did you do?

P: I come down and have a cup of tea with him.

I: Did you?

P: Yeah.

I: Ah... Paul sounds friendly, a friendly man.

P: Yeah.

I: Yeah. Is he um, is he older than you?

P: I don’t know. He knows me.

I: He knows you. So an old friend.

P: Yeah.

I: Yeah. That’s important to have people who...


I: For you? Was that for you?

P: (She nods and smiles).

I: So Jonathan got in touch with Paul for you.

P: Yeah. (She smiles).

I: Is that to help you?

P: Yeah. Jonathan. I sit there in the meeting this Friday and listen to what he says about me.

I: Ah I see. (…)
P: Jonathan told me, 'the only who me know is Paul.'

I: Jonathan said?

P: Jonathan said, 'the only one know me. His name is Paul.'

I: Ah...

P: He's got a lot, a lot about me.

I: He's got a lot...

P: A lot about me.

I: He knows a lot about you. Yeah.

P: (She laughs).

I: So you are looking forward to that.

P: Yes.

I: You're very excited about seeing Paul?

P: I'm going to sit next to him.

I: You are going to sit next to him. (...) Brilliant.

P: I give my old friend my address and my telephone number.

I: You gave your telephone number to...

P: My address.

I: And your address.

P: I give him my address and my telephone number. I gonna get him to phone me.

I: Oh you are going to give it to Paul and get him to phone you.

P: Yeah.

I: That'll be good.

P: Yeah. Give him me his address and his telephone number.

I: Then you can meet up with him?

P: Yeah.

I: Yeah. So you can see each other more?
P: Yeah.

I: Yeah. When when was the last time you saw Paul?

P: Only in London.

I: Yeah. So years ago.

P: Yeah.

I: Did you know him in the Kings Estate as well or...?

P: No, he don't live in the Kings Estate.

I: Oh didn't he? No.

P: No. (...)

I: You, so you knew him from before the Kings Estate?

P: Yeah.

I: And then you went to the Kings Estate and Paul...?

P: And Paul see me in the Kings Estate.

I: Did he come and see you in the Kings Estate?

P: Yeah. He's got his own car.

I: Ah right. I see.

P: He take me out in his car.

I: Did he? Ah...

P: He take me to pub and have a drink together.

I: Did you?

P: Yeah.

I: And what was that like?

P: Great. (She laughs).

I: Okay...and um so we have talked about Paul and...I'm just thinking about um your um the meetings again you know that you go to, these meetings. And um last time I saw you...

P: Yeah.

I: You said that you um you felt that it was important because um you felt listened to in these
meetings.

P: Yeah.

I: You like, you like people listening to you.

P: Yeah.

I: It's important isn't it?

P: Yeah.

I: Yeah. Um and, and you said um that Jonathan listens to you.

P: Yeah.

I: Yeah.

I: And I was wondering um (...) have people um (...) have have you always felt listened to?

P: Yeah.

I: Yeah, yeah. Have there, have there ever been any times when somebody didn't listen to you?

P: Long time now.

I: Long time ago?

P: Yeah.

I: When when...

P: I met him in London.

I: Ah right. Paul?

P: Yeah.

I: Ah...So so you are looking forward to seeing Paul?

P: Yeah.

I: Good, good. (Pause for 15 seconds). Do um do other people listen to you?

P: Here?

I: Yeah.

P: Yes, Tracy.

I: Yeah. Does she listen to you?
P: Yes.
I: Yeah.

P: Hannah.
I: Hannah listens to you.

P: That woman there. *(She points to photo on wall).*
I: Does she? She listens to you.

P: Then Eve and Katherine.
I: Eve listens to you and Katherine. Do they listen to you?

P: Sometimes they get funny ways.
I: They get funny ways, do they? In what way?
P: Bad mood.
I: Oh, they get in a bad mood. Ah...

P: Me walk away and go into my room.
I: So you walk away?
P: Yeah.
I: And that helps you does it? Yeah.

P: Yeah. *(Pause for 12 seconds)*
I: Are you okay?

P: Yeah.
I: Good. Um...How can, how can people listen better?

P: Hey?
I: Um...you know um in your meetings, with Jonathan.

P: Yeah.
I: Yeah. Jonathan listens to you.

P: Yeah.
I: You like that and...
P: And April.
I: And they stand up for you.
P: Yeah.
I: Yeah, yeah.
P: Before I had problem with one of the staff.
I: Ah yes I remember you said.
P: I went back to tell Jonathan, Jonathan sort it out for me. He ring Claire.
I: Claire …
P: Claire come see me in my room.
I: Ah I see…
P: And told him all about it. He wrote it all down.
I: Ah…And so the meetings sort out problems.
P: Yeah.
I: If you have a problem, you can talk about it in these meetings.
P: Yeah.
I: And people listen to your problems.
P: Yeah.
I: Yeah. Have have people always listened to your problems?
P: Only one, only one staff.
I: Just one staff.
P: Not all of them lot. Only one.
I: No, no. And um yeah so it’s important for people to stand up for you.
P: Yeah.
I: Yeah. Like your, your parents stood up for you in the Kings Estate?
P: Yeah.
I: I remember you told me about how um somebody stole your clothes, was it?
P: Yeah.
I: And um your mum and dad went mad.
P: Yeah.
I: And they um went to see the boss.
P: Yeah.
I: Was it Graham? The boss of the Kings Estate um and yeah your parents stood up for you.
P: Yeah.
I: Yeah. At the Kings Estate.
P: Yeah. *(Pause for 15 seconds).*
I: It's important for um people to stand up for you.
P: Yeah.
I: Does anyone else stand up for you?
P: Yes, Hannah.
I: Hannah. Who's Hannah?
P: Hannah Hannah listens to me. I known Hannah along time.
I: Have you?
P: I've known Hannah in the Kings Estate.
I: Oh. Is Hannah um a staff, a member of staff here?
P: Yeah.
I: And and so she stands up for you.
P: Yes.
I: And listens to you.
P: Yeah.
I: Yeah. *(Pause for 4 seconds).* What does it feel like to have somebody stand up for you?
P: I get more freedom.
I: More freedom.
P: Yeah.

I: And and what does that mean?

P: People like me.

I: And people like you. (...) So more freedom (...) to do what you want?

P: Yeah.

I: Yeah. And that’s important to you?

P: Yeah.

I: Yeah. Shall we just have a break?

P: Yeah.

(Break for a few minutes. She brings some photos along to the interview, after I invited her to do so).

I: Okay so...

P: This is my mum.

I: ....you’ve got some photos here.

P: That one’s Rory.

I: Rory. And Rory was Paul’s son.

P: Yeah.

I: Yeah.

P: I’m, I’m looking for my dad. (She sorts through photos).

I: And you’re looking for your dad.

P: I did put it in.

I: Yeah. Is that, is that him?

P: This one my dad.

I: Is that one?

P: Yeah.

I: Yeah.

P: His name is Harry.
I: Ah that’s your dad. His name is Harry.

P: Yeah.

I: Yes. So it’s Harry and Pat.

P: Yeah. Then, that’s Jonathan.

I: And that’s Jonathan? And who?

P: Yeah. April.

I: Ah, so it’s Jonathan and April who run the meetings?

P: Yeah.

I: Let’s have a look. Can I have a look? Ah...And and do they did they set up the meetings?

P: Yeah.

I: Did they?

P: Yeah.

I: Is that their job?

P: Yeah.

I: To run the meetings.

P: Yeah.

I: And is it Working Forward?

P: No, (Inaudible).

I: What’s it called?

P: (Inaudible).

I: All...What’s it called again? Yeah, show me. (She gets out a folder with details about the meetings).

P: Them the dates.

I: Ah these are the dates.

P: Have to get a new one when I go back.

I: Ah so I see so it’s advocacy?

P: Yeah.
I: Ah I see.

P: Yeah

I: ‘Advocacy Rocks.’ (I read from her folder of advocacy leaflet).

P: Yeah.


I: And Jonathan’s the person who runs the meetings and these are other people who...

P: Yeah. Derek, Patti, Hannah, Betty, don’t know that word.

I: Yeah. Simpson? Sandra Simpson and...

P: And me.

I: Yeah. And it says that you…this is … So did all these people live in the Kings Estate?

P: No, he does.

I: Yeah.

P: And this one.

I: So those three?

P: And myself.

I: And yourself. Ah.

P: I’ve got a picture of Tracy in there. Do you want to see it?

I: Go on then.

(Pause for 10 seconds whilst she finds photo).

I: Oh yeah there she is. So she’s joined as well now.

P: Yeah.

I: And she lives here. Ah that’s good isn’t it?

P: Yeah.

I: Okay, well thanks or showing me that. So the next meeting is...

P: The first.

I: On the first.
P: Room three.

I: Room three. Ah that's good isn't it.

P: Yeah. *(She smiles).*

I: Yeah. Right, and are your brothers um on these photos as well?

P: Hold on, I've got two up there. *(She looks in a cupboard).*

I: Yeah. Can I have a look?

P: That's my brother.

I: That's your brother

P: There's my other brother.

I: Ah, he's lying down in the garden.

P: Yeah.

I: Yeah, getting some sun. And... which...is that...?

P: That's Paul.

I: Paul.

P: Graham.

I: And that's Graham.

P: I haven't got a picture of Dennis.

I: No. Haven't you?

P: No. My my sister-in-law got that.

I: Ah right.

P: I've one big picture of my mum.

I: Have you?

P: I get it out.

I: Yeah, that would be good.

P: My mum and dad together. *(She shows me another photo).*

I: You've got a picture of them together. (...) Ah that's a lovely photo isn't it?
P: Wedding anniversary.
I: That was their wedding anniversary was it?
P: Yeah.
I: Ah they look happy.
P: Yeah.
I: Don’t they?
P: They been to a dance.
I: They been to a dance, yeah.
P: I went to a wedding anniversary party.
I: And then you went to their wedding anniversary party.
P: Yeah. Grey hair. My mum got grey hair and my dad got grey hair.
I: Yeah.
P: Then I got grey hair. *(We both laugh).*
I: Oh yeah. *(…) Do you like that photo?*
P: Yeah.
I: Yeah. What do you like about it?
P: It’s my family.
I: Yeah, yeah. *(…) It’s lovely.*
P: Someone told me, I bit like my mum.
I: Yeah, you do look like your mum. Yeah you do.
P: My nose a bit like my dad’s. See that nose?
I: Yeah.
P: Bit like my dad’s nose. *(She laughs).*
I: It’s a bit like your dad’s nose.
P: Yeah.
I: Yeah. So you’ve got a bit of both. A bit of both in you. Yeah.
P: Yeah. I've got more up there. *(She gets some more photos down).*

I: Have you?

P: Yeah. (...) My dad's got a tortoise. *(She shows me another photo).*

I: Has he?

P: Call it Beady.

I: Beady. Have you seen the tortoise?

P: I like him. *(She shows me a magazine cut out).*

I: Oh, Bergerac.

P: Yeah I like him.

I: Do you? What do you like about him?

P: He's a good actor.

I: He is a good actor, yeah.

P: See this one. This is my room. *(She shows me a photo of her bedroom).*

I: Ah here. Can I have a look?

P: Yeah.

I: Thank you. (...) Is this your room here?

P: *(Inaudible).* This one is Working Forward. *(She shows me another photo).*

I: Can I have a look?

P: Yeah.

I: Thank you. That would be good. (...)  

P: *(Inaudible).*

I: Who are these people Lily?

P: Ah, here's the family. . . *(She shows me another photo).*

I: Who are these people?

P: They're people I work with.

I: Oh are they?
P: Yeah.
I: Where, where's this?
P: Working Forward in London.
I: Working Forward. And you um you do different things there don’t you? You do badges and envelopes.
P: Yeah.
I: Yeah. Do you like your work there?
P: That family one. (She finds another photo).
I: Okay, that would be lovely. I think we’ve got enough to look at now. You’ve got lots of photos haven’t you?
P: Yeah. (She smiles). (…) What have I got in there? (She gets up to look in another box of photos). Parties.
I: Lily, do you um do you like Working Forward?
P: Yeah.
I: Do you? What’s good about it?
P: We’ve got things, we got parties at work.
I: Parties.
P: If someone’s birthday.
I: If it’s somebody’s birthday, then you celebrate do you?
P: Yeah.
I: Yeah.
P: And Christmas.
I: And Christmas.
P: Have a disco.
I: You have discos and things. So there is lots of social things to do with other people.
P: Yeah. And and music.
I: And…?
P: Music. What's that say there?

I: Oh music, yeah, yeah. (...) Do you want to sit down?

P: I'll sit on my bed.

I: And these are all people at work then.

P: Yeah.

I: Your Working Forward.

P: Yeah.

I: It sounds to me that you work hard?

P: Yeah.

I: Yeah. You've always work hard?

P: Yeah.

I: Have you...?

P: Yeah.

I: Yeah. Is working important to you?

P: Yeah.

I: Yeah. (...) 

P: That is Sandra. Sandra is the boss. (She shows me a photo).

I: Sandra is the boss.

P: Sandra.

I: Sandra. (...) 

P: Yeah. (She shows me another photo).

I: And that's...?

P: Sue's car. (She shows me another photo).

I: Somebody's fifty there.

P: That's Trevor.

I: Trevor.
P: And that’s Sandra again.
I: Ah... That looks a happy, happy photo.
P: Yeah, I done them ones.
I: You did?
P: That’s last Christmas.
I: Did you?
P: Yeah. (...) That’s Mick. (She points to a photo).
I: And that’s Mick. Who’s Mick?
P: Hey?
I: Who’s Mick?
P: One at Working Forward.
I: Ah, yeah. (...) Did these people go to the Kings Estate as well?
P: Them two do.
I: Did they?
P: Yeah.
I: Did you know them in the Kings Estate?
P: Yeah.
I: Did you see them in the Kings Estate?
P: Yeah.
I: Did you live with them or?
P: No.
I: No.
P: This one I know him. Russell.
I: You knew him at the Kings Estate.
P: Yeah.
I: Did you live with him?
P: Yeah.

I: In the same place?

P: Yeah.

I: Yeah. Did you like him?

P: Yeah. I know him and Jennifer in the Kings Estate.

I: Oh do you?

P: Yeah.

I: Yeah. Are these, are these people like you?

P: Yeah.

I: Yeah. Ah.

P: (She coughs). I have a drink.

I: You are going to have a drink. Are you okay?

P: Yeah.

I: Good. Well it's interesting to see your work place.

P: (Inaudible). Jules is staff.

I: Yeah...

P: That Ken Ellis.

I: Ellis?

P: Yeah.

P: That's my new boyfriend, Ben Smith.

I: Oh it's your new boyfriend?

P: Yeah (she smiles).

I: What's his name? Ben...

P: Ben Smith.

I: Ben Smith. And how long have you two been together?

P: I met him at Working Forward.
I: Did you?

P: Yeah. No no I mean Nescot College.

I: Nescot College?

P: Yeah.

I: Is that before um Working Forward?

P: Yeah. (...) Here’s George.

I: Ah…and who’s George?

P: Yeah.

I: Who is he…? Does he work there?

P: Yeah.

I: Ah...

P: There are three staff work there.

I: Three staff. So there’s Sandra, George and Mick.

P: George.

I: And how long have you been with your boyfriend?

P: Six years now.

I: Six years. And what’s it like to be with your boyfriend.

P: He make me happy.

I: Does he?

P: Yeah.

I: How does he make you happy?

P: I danced with him once.

I: Did you?

P: At a Christmas party.

I: What was that like?

P: (She smiles).
I: What was that like?

P: Very good. *(She smiles).*

I: Was it?

P: Yeah. (...) Them my friends.

I: These are all your friends.

P: Right, that’s Tracy. That’s Hannah.

I: Ah...so these...So you live with these people?

P: Yes.

I: And they used to live in the Kings Estate or?

P: Yes.

I: Yes.

P: And Eve in the Kings Estate.

I: And Eve.

P: Not Katherine.

I: Not Katherine.

P: I met Katherine in Princes House.

I: Oh in Princes House...

P: Yeah.

I: And that was your favourite place in the Kings Estate wasn’t it because...

P: Yeah.

I: ...you did your own um you did your own cooking...

P: Yeah.

I: ...and your own cleaning. And you said you were independent there.

P: Yeah.

I: Yeah. (...)

P: That’s Tracy again. Lady in red.
I: Ah...Lady in Red. Like the song.
P: Yeah.
I: Chris De Burg.
P: I've got it on a disc.
I: Chris De Burg?
P: Yeah.
I: Do you like that song?
P: Yeah.
I: It's a nice song isn't it?
P: This is my family. *(She shows me another photo).*
I: This is your family?
P: Yeah.
I: Ah...
I: Ah, that's nice isn't it?
P: Aunty Lily. Great Aunty now.
I: Ah yeah, Great Aunty.
P: Leo.
I: Leo.
P: Yeah
I: Oh...
P: That's my brother. *(Another photo).*
I: Oh yeah. And that, which one is that?
I: Paul. Your younger brother?
P: Yeah. That's my...that's Carly.
I: Carly.

P: This my mum.

I: And that’s your mum holding a baby.

P: Yeah, Russell.

I: Russell. Then there’s a wedding.

P: My my cousin.

I: Your cousin.

P: Andrew he’s married.

I: Yeah.

P: He got married in Redhill.

I: Did he? (...) There’s a baby.

P: That’s my dad. That’s my dad. And that’s my dad.

I: Ah...What does your dad think about you?

P: He pleased to see me. *(She laughs).*

I: He’s pleased to see you, is he?

P: *(Inaudible).* My dad same age as my mum.

I: Your dad’s the...

P: I’m my dad’s daughter.

I: You’re your dad’s daughter. Yeah.

P: Yeah. And my mum’s daughter.

I: Yeah.

P: Here’s Rory.

I: Rory.

P: Russell.

I: Russell.

P: Yeah. This is my mum again.
I: Who’s that?

P: That’s my mum.

I: She looks younger there?

P: Yeah and that’s my dad.

I: Oh is it? They look younger there, don’t they?

P: Yeah.

I: Let’s have a look? Ah…she’s got a funny hat on, hasn’t she?

P: Yeah. My dad’s got a hat on. (She laughs). Kylie.

I: And Kylie.

P: Rosy dog.

I: Ah, it’s a pretty photo of the dog. And that’s your dad again.

P: There’s my dad. That’s my nephew.

I: Yeah.

P: That’s my dad. Mum and dad.

I: Ah yeah. That was when they were younger wasn’t it?

P: Yeah.

I: Were they happy together?

P: Yeah, very happy.

I: Were they?

P: They got married young.

I: Did they?

P: My mum is seventeen, my dad is sixteen.

I: Oh that is young isn’t it?

P: Yeah they got married young.

I: So they they loved each other …?

P: Yeah.
I: ...very much.

P: This is my mum.

I: That's your mum.

P: That's my sister-in-law.

I: Ah right.

P: Emma.

I: Emma.

P: My mum. My my Rory.

I: Rory.

P: My cousins.

I: Another wedding.

P: Rory.

I: Yeah.

P: And that's my mum's garden.

I: In a shopping basket?

P: Leo.

I: Leo. (...) Ah right, can I just ask you a few more questions, um I was just wondering um...

P: My dad collects cars.

I: Ah your dad collects cars.

P: That's my brother Richard.

I: Ah yes.

P: That's me and my mum

I: Can I have a look? (...) Ah... (...) 

P: This is my cousin.

I: Your cousin's wedding, yeah.

P: Mum and dad. (...) This my brother, Paul.
I: That’s Paul and his two boys there?

P: Yeah.

I: Yeah. And that’s your two brothers again.

P: Yeah and my two sisters-in-law.

I: Ah yeah.

I: Lily what’s it like to have brothers?

P: Hey?

I: What’s it like to have brothers?

P: They listen to me.

I: They listen to you do they?

P: Yeah. (...) That’s in Devon ward.

I: Oh is it? Can I have a look?

P: Yeah. In the Kings Estate.

I: Is it?

P: Yeah.

I: Who are the ladies?

P: That’s my mum.

I: Oh is it? She looks younger there?

P: Yeah.

I: And who’s that one?

P: My dad dressed up. *(She laughs).*

I: Your dad dressed up? Oh I thought it was a lady. And who is that?

P: Teddy bear.

I: Who’s underneath the costume?

P: Here’s my mum.

I: So your mum and dad came to see you at the Kings Estate?
P: Yeah.

I: Was that some party?

P: Yes.

I: And your dad dressed up?

P: Yes.

I: Did you take the photo?

P: No somebody else did it. That my brother Roy when he was young.

I: Oh is it. Can I have a look? Ah these are younger photos then. That’s your mum again?

P: No it’s my sister in law’s mum and dad.

I: Oh is it?

P: That’s my brother Paul. That’s my mum. That’s my mum and dad again.

I: Another wedding.

P: Yeah.

P: That’s my favourite Uncle.

I: Favourite Uncle.

P: Yeah

Is it?

P: Frank

I: Frank. And why is he your favourite?

P: He makes me laugh

I: Does he?

P: Yeah

I: What does he do to make you laugh?

P: He asks me ‘have you got a boyfriend?’ (...) He always teases me.

I: He teases you. Does that bother you?

P: No.
I: No. You like it.

P: Yeah.

I: Yeah.

P: That's Paul and his wife.

I: Paul and his wife.

P: That day he got engaged.

I: Engaged. Did he?

P: Yeah.

I: And he's got a pirates hat on?

P: Yeah. (...) Mum and dad. And that's my cousin Jim.

I: Jim.

P: Snowy.

I: Snowy.

P: More Snowy.

I: Snowy looks a lovely dog.

P: My mum. That's mother's day.

I: Was it? When was that? Last year or...

P: A long time ago.

I: A long time ago. Ah....Well, thanks for showing me all your photos Lily.

P: Yeah.

I: Thank you. Lily just to finish off, um...

P: Yeah.

I: Have you...I was just wondering have you got any hopes?

P: Hey?

I: Have you got any dreams in life?

P: In my dreams. My dreams about different things.
I: Can you tell me one dream of yours?

P: I lay in my bed, I think about where I am. I found out I am down at the seaside.

I: You dream about the seaside.

P: Yeah.

I: And what about your wishes? (...) Do you have um any hopes?

P: My wishes.

I: Wishes?

P: Wishes I go... I be film star.

I: I can't hear you.

P: I want to be a film star.

I: You want to be a film star? Is that what you would wish for?

P: Yeah. *(She laughs).*

I: That's a nice wish. And is there anything you are looking forward too?

P: I look forward. Meeting. Clare. You see Clare?

I: Um I don't know Clare...Which one is Clare?

P: Clare Clare. That's Clare's daughter.

I: Yeah.

P: That's Becca. (...) Here's Clare.

I: Ah yes. And what about Clare?

P: Clare go out to different places.

I: She...

P: Come here and pick us up and take us out.

I: Takes you out...Ah, so she takes you to different places.

P: Yeah.

I: Ah...well thanks for talking to me today.

P: That's Pamela.
I: Yeah.

P: Emma’s mum. Where’s Martin? Martin is Emma’s Dad.

I: Ah right.

P: That’s Gheeta.

I: Gheeta.

P: Ah here’s Martin.

I: That one?

P: Yeah. That’s Gheeta, (inaudible) daughter.

I: You’ve got a lovely photo board. Who did this? Who did the photo board?

P: I did.

I: You did.

P: I done that one of myself.

I: They are lovely.

P: That one there is all of me. (She points to another photo board).

I: We could look at that one next time.

P: Yeah.

I: Yeah. Shall we look at that one next time?

P: Yeah, I’ll put this one away.

I: Alright then thanks for today Lily. Thank you for talking to me about your life.

P: Yeah.
## Research Log Checklist

<table>
<thead>
<tr>
<th></th>
<th>Description</th>
<th>Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Formulating and testing hypotheses and research questions</td>
<td>✔</td>
</tr>
<tr>
<td>2</td>
<td>Carrying out a structured literature search using information technology and literature search tools</td>
<td>✔</td>
</tr>
<tr>
<td>3</td>
<td>Critically reviewing relevant literature and evaluating research methods</td>
<td>✔</td>
</tr>
<tr>
<td>4</td>
<td>Formulating specific research questions</td>
<td>✔</td>
</tr>
<tr>
<td>5</td>
<td>Writing brief research proposals</td>
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</tr>
<tr>
<td>6</td>
<td>Writing detailed research proposals/protocols</td>
<td>✔</td>
</tr>
<tr>
<td>7</td>
<td>Considering issues related to ethical practice in research, including issues of diversity, and structuring plans accordingly</td>
<td>✔</td>
</tr>
<tr>
<td>8</td>
<td>Obtaining approval from a research ethics committee</td>
<td>✔</td>
</tr>
<tr>
<td>9</td>
<td>Obtaining appropriate supervision for research</td>
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</tr>
<tr>
<td>10</td>
<td>Obtaining appropriate collaboration for research</td>
<td>✔</td>
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<tr>
<td>11</td>
<td>Collecting data from research participants</td>
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<tr>
<td>12</td>
<td>Choosing appropriate design for research questions</td>
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<tr>
<td>13</td>
<td>Writing patient information and consent forms</td>
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<tr>
<td>14</td>
<td>Devising and administering questionnaires</td>
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<tr>
<td>15</td>
<td>Negotiating access to study participants in applied NHS settings</td>
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<tr>
<td>16</td>
<td>Setting up a data file</td>
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</tr>
<tr>
<td>17</td>
<td>Conducting statistical data analysis using SPSS</td>
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<tr>
<td>18</td>
<td>Choosing appropriate statistical analyses</td>
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<tr>
<td>19</td>
<td>Preparing quantitative data for analysis</td>
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<tr>
<td>20</td>
<td>Choosing appropriate quantitative data analysis</td>
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<tr>
<td>21</td>
<td>Summarising results in figures and tables</td>
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<tr>
<td>22</td>
<td>Conducting semi-structured interviews</td>
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<tr>
<td>23</td>
<td>Transcribing and analysing interview data using qualitative methods</td>
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<tr>
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<td>Major Research Project</td>
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<tr>
<td>24</td>
<td>Choosing appropriate qualitative analyses</td>
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<td>25</td>
<td>Interpreting results from quantitative and qualitative data analysis</td>
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<tr>
<td>26</td>
<td>Presenting research findings in a variety of contexts</td>
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<tr>
<td>27</td>
<td>Producing a written report on a research project</td>
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<tr>
<td>28</td>
<td>Defending own research decisions and analyses</td>
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<tr>
<td>29</td>
<td>Submitting research reports for publication in peer-reviewed journals or edited book</td>
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<tr>
<td>30</td>
<td>Applying research findings to clinical practice</td>
<td>✓</td>
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