

Music therapy with adults with learning difficulties and 'severe challenging behaviour'

An action research inquiry into the benefits of group music therapy within a
community home

Volume 1

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Plate 3: Father teaching cricket, photographer: Liba Taylor, The Hutchinson Library, London.

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Abstract

This thesis describes and analyses an action research inquiry where weekly group music therapy sessions were offered to five residents in their community home over the course of a year. The residents each had a history of institutional living, learning difficulties, and the label of 'severe challenging behaviour'. The inquiry is in the tradition of participatory action research, and draws from both the new paradigm approaches of Reason and Heron and critically reflexive action research.

The inquiry took the form of two parts. A co-operative inquiry involved home staff, music therapists and daycare workers who reflected critically on the impact, benefits, barriers and threats to the music therapy process. The therapy sessions became the arena for inquiry between the residents, music therapists and daycare worker. Involvement in the dual aspects of therapeutic process and research inquiry was managed by careful consideration of the therapeutic boundaries, ongoing ethical discussion within the co-operative inquiry and perspectives from independent advisers with learning difficulties.

We as co-researchers sought to inquire into the benefits of the music therapy group within the community home. The perspective of the residents, who had few language skills, became central to this process. The main focus for inquiry within the sessions was through changes that developed within the musical relationships and by resident action. The extended epistemology of new paradigm research emphasises forms of knowing that were accessible to the residents, such as experiential, practical and arts-based forms of knowledge. Analysis of the data involved collaborative reflection, often provoked by the use of

different media, rigorous thematic analysis and creative forms in the representation of the data.

I situate the context through personal, practical, theoretical, historical, political and ethical perspectives, leading to the inquiry narratives. A detailed explanation of the thematic analysis follows before the data are presented in chapters named after each resident.

The use of music as a primary means of inquiry has meant a tension when this non-verbal experience is described in words. A number of benefits of the music therapy emerged, such as changing fixed relationship patterns and the expression of a group identity. However, the primary contribution of this research is the way in which people with severe learning difficulties were able to influence the course of the inquiry themselves, and challenge staff and institutional perceptions.

PART ONE

THE CONTEXT OF THE INQUIRY

Foreword

Music therapy practices and participatory action research approaches share common ground: they are fundamentally concerned with change for the better and they both emphasise the importance of dialogue. This thesis explores how a year of music therapy formed the focus of a participatory action research inquiry.

Statement of objectives

1. To describe, analyse and discuss an inquiry in the form of participatory action research, set in a community home for people with learning difficulties and 'severe challenging behaviour'.
2. To include the residents, music therapists and care workers as co-researchers in the inquiry.
3. To identify the benefits of the music therapy over the course of the inquiry year.
4. To value and inquire into the non-verbal communications of the residents as explored within the musical relationship.
5. To identify barriers and threats to this process.
6. To facilitate all participants in their development of critical reflexivity.
7. To provide an academic, practical and personal context to this study.

The form of the thesis

The five parts of the thesis take the reader on a journey through the inquiry. Part One contains the origins of the idea, the historical and political context, the practical, theoretical and research context within music therapy, methodological perspectives and ethical decision-making processes. I situate my personal context within the main body of the text because the thesis is essentially my reflexive account of the inquiry. Although many other participant's voices are included and given preference over my own voice at times, I am aware that they would each tell the story differently.

Part Two tells the stories of the two parts of the inquiry: the music therapy inquiry itself, and the co-operative inquiry which sought to support it. There were many other aspects of the inquiry to some of which I may refer, particularly those developed in dialogue between two individuals.

Part Three explains the phase of the inquiry where most of my detailed analysis was carried out, and how the 'data' chapters following came to be constructed. Their construction was informed and directed by the collaborative analysis undertaken during the earlier stages of the inquiry, but was essentially my own work. Chapter eight explores problems of interpretation, explains some of my solutions and acknowledges their limitations.

Part Four is the heart of the thesis. Each of these six chapters is based on one of the participants in the music therapy who was a resident in the community home. The participants have pseudonyms (devised co-operatively), although I still wonder whether 'Steve' might have preferred me to use his real name.

Part Five brings together findings and conclusions, acknowledges limitations and looks forward to further possible inquiry routes.

Supplementary material

The bibliography contains listings of all the literature referred to in the text, but also the extra reading material that I had no space to include. Supplementary material from each chapter is accessible in seven Appendices. An intimate knowledge of music is not essential for reading this thesis, and I include a glossary of musical instruments in Appendix 6 to assist the reader. A wide variety of instruments from different cultures was available to participants in the inquiry. This was in keeping with what is quite standard music therapy practice: providing the widest range of creative possibilities in sound, and opportunities to explore cultural references. We took pains to provide instruments with a range of sizes, textures and means of sound production, a lack of sharp edges, and, most importantly, instruments of good quality. An intimate knowledge of music is not essential for reading this thesis.

A compact disc (CD) of audio recordings is provided at the back of the thesis in a pocket. This forms an integral part of the text of chapter nine, and it comes from the music therapy sessions. These extracts are taken from the videotapes made of the sessions. The videotapes could not be used as their use would involve a loss of anonymity, whereas audio material is unlikely to be able to reveal identity. However, it is important to say that Steve had given permission to show some video recording in public, as he was quite proud of some of the data, particularly his drumming. Each track is clearly marked in the text, and the CD can be played on standard CD equipment.

Terminology

Throughout the thesis I use the phrase 'learning difficulties', as distinct from the

term currently used: 'learning disabilities'. As the purpose of my inquiry was to learn more from the perspectives of service users, then I feel that it is respectful to adopt the label that many people so labelled have said they prefer. I discuss euphemisms and labelling in more depth in chapter two. Two other words need some explanation: 'interaction' and 'vocalisation'. 'Interaction' was a term which verbal participants, including myself, often used instead of communication. On reflection, most participants realised that their use of it was a form of jargon which tended to be applied more to the residents than to the others. Similarly, 'vocalisation' is part of a music therapy jargon, and here verbal participants agreed to use it to denote any kind of sound that an individual might produce with their vocal chords. Therefore, when either 'vocalisation' or the word 'singing' is used instead, there a value judgement is probably being made about the musical nature of the vocalisation.

Therapeutic versus home setting

Due to the risk assessments for each resident, it was not practically possible for all five men to travel together to a group therapy room. Each resident needed two carers for support outside the home, too many for their minibus, and the only option available was for the music therapist to work within the home.

Time frames

In people's lives, in yours and mine, there are linear time sequences, with and without beginnings and endings...and there are repetitions, cycles...and there are black-outs, time lags. And spurts of time. And sudden delays. There is an overwhelmingly powerful tendency, when people are gathered together, to create a common time (Peter

Høeg 1995: 233).

Part of the problem of attempting to write about the process of the inquiry is the risk of disorientating the reader. This is first because reflexive processes do not simply happen within linear time: we move frequently from the present to the past, and at times to the future. For example, I begin the thesis with vignettes from clinical work which I was involved in several years before the inquiry. Secondly because action research models tend to be cyclical in design, there are a number of points during the inquiry where we seem to stand in a similar position as before. To assist with the orientation, figure 1 on page 6 is a calendar of the main events in the inquiry: it provides a conventional linear framework for representing time.

Summary of the inquiry process

As shown in figure 1, there were two main aspects of the inquiry running in parallel. The column marked *therapy sessions* shows when the weekly music therapy sessions took place. This was the *music therapy inquiry*. The participants were the residents, music therapist and day care assistant. Discontinuities were due to holidays or training days, and represented some disruption to the continuity, making it more difficult to pick up the inquiry after the breaks. The session cancelled in August was for the funeral of one of the resident participants.

The column on the far right represents the *co-operative inquiry* events. The participants involved in this part of the research included a representative

| Dates | | Therapy sessions | Cycles | Co-operative inquiry meetings/ dialogues and other events |
|-----------|----|------------------|------------------|---|
| January | 11 | | CYCLE ONE | PRELIMINARY MEETING |
| | 18 | | | |
| February | 25 | | ↓ | FIRST MEETING CANCELLED Dialogue with Nick |
| | 1 | | | CO-OPERATIVE INQUIRY MEETING 1 |
| | 8 | Session 1 | | Dialogue with Rose, Dialogue with Dave |
| March | 15 | Session 2 | ↓ | Bill, Ralph and Pete watch video |
| | 22 | Session 3 | | |
| | 1 | Session 4 | | CO-OPERATIVE INQUIRY MEETING 2 |
| | 8 | Session 5 | | CYCLE TWO |
| April | 15 | Session 6 | ↓ | |
| | 22 | No session | | Dialogue with Anna |
| | 29 | No session | | Dialogue with Nick |
| | 5 | Session 7 | | CO-OPERATIVE INQUIRY MEETING 3 |
| | 12 | Session 8 | | CYCLE THREE |
| May | 19 | Session 9 | ↓ | |
| | 26 | Session 10 | | |
| | 3 | Session 11 | | |
| | 10 | Session 12 | | Dialogue with Nick |
| | 17 | Session 13 | | CO-OPERATIVE INQUIRY MEETING 4 |
| June | 24 | Session 14 | ↓ | Dialogue with Steve |
| | 31 | Session 15 | | |
| | 7 | Session 16 | | Dialogue with Nick |
| | 14 | Session 17 | | |
| July | 21 | Session 18 | ↓ | |
| | 28 | Session 19 | | |
| | 5 | No session | | Dialogue with Anna |
| | 12 | No session | | Dialogue with Rose |
| August | 19 | Session 20 | ↓ | |
| | 26 | Session 21 | | |
| | 2 | Session 22 | | |
| | 9 | Session 23 | | CO-OPERATIVE INQUIRY MEETING 5 |
| | 16 | Funeral | | CYCLE FIVE |
| September | 23 | Session 24 | ↓ | |
| | 30 | Session 25 | | |
| | 6 | Session 26 | | |
| | 13 | Session 27 | | Dialogue with Rose |
| October | 20 | Session 28 | ↓ | New group member |
| | 27 | Session 29 | | Cathy risk assessment |
| | 4 | Session 30 | | |
| | 11 | Session 31 | | Dialogue with Nick |
| November | 18 | No session | ↓ | Dialogue with Rose |
| | 25 | Session 32 | | |
| | 1 | No session | | |
| | 8 | No session | | |
| December | 15 | Session 33 | ↓ | CO-OPERATIVE INQUIRY MEETING 6 |
| | 22 | Session 34 | | CYCLE SIX |
| | 29 | Session 35 | | |
| | 6 | Session 36 | | Dialogue with Rose |
| | 13 | Session 37 | | Dialogue with Anna |
| | 20 | Session 38 | ↓ | Dialogue with Nick |
| | | | | Filming stops |

Figure 1 Calendar of inquiry events

cross-section of home staff and day care team, and also the music therapist and myself. Each cycle was completed through the process of meeting together to evaluate and reflect on the inquiry processes of that cycle, and with developing an action plan for the next cycle. During each cycle some of the work involved dialogues between individual participants, also shown. These dialogues then informed the collaborative meetings of the co-operative inquiry.

The meetings were not regular, usually due to lack of availability of participants due to work shift patterns. This compromised the continuity of the process. Instead, the meeting dates were driven by the cyclical process: we met when the majority of work in the previous cycle was completed.

This thesis focuses centrally on the process and findings of the music therapy part of the inquiry. The co-operative inquiry was formed to support the process of the music therapy inquiry, and participants did not have detailed access to material that was confidential for therapeutic reasons. Nick (the music therapist) facilitated the music therapy inquiry throughout and I facilitated the co-operative inquiry, but we were both involved in the two inquiries, and met regularly to reflect on how the two parts developed and influenced each other.

In the music therapy inquiry, process was conducted through non-verbal communication in the music, which enabled relationships to form and develop between all participants. Resident choice about whether or not to participate changed every session. Personal envies and insecurities surfaced early, and the music therapist continually needed to reflect on how he managed incidents such as throwing instruments, and how to make meaning at all from the various interactions between people. The inquiry participants showed most stress during cycle four, which involved the deepening severity of the illness of one participant,

leading to his death. Cycles five and six involved the most personal change for most participants, with increased attendance and larger groups collaborating together in making music. This inquiry raised fundamental questions about power, participation, bounded practice and relationships within music. Participants began to discover more positive ways of dealing with conflict, and inquired into new ways of listening to others.

The co-operative inquiry spent the first two cycles identifying how data would be collected, and wrestling with the ethical implications of these decisions, particularly in relation to the use of video. Key decisions included agreeing the use of video, protecting this with a strict ethical protocol, leaving the therapy door open, resituating the therapy room in the dining room, providing a quiet, non-intrusive environment within the house, and preventing any coercion of the residents.

A more light-hearted look at the personal impact of the project for all participants in meeting three helped alleviate some of these tensions, allowing inquiry work to become more personally reflexive, and therefore more effective. In cycle four the focus of the inquiry changed from concentrating on attendance patterns to looking at qualitative aspects of the nature of the musical participation and interaction in the music therapy inquiry.

Events surrounding the death of one of the participants took energy away from the co-operative inquiry for a while. In cycle five a core group of three worked in detail on analysing data and identifying the main findings. In cycle six the whole group reconvened to reflect on these findings, resulting in the deepest reflection and most useful work of this part of the inquiry.

CHAPTER ONE

Personal Background to the study

1.1 Introduction

Vignette 1: Andrew

Andrew came to individual music therapy with me for eighteen months. He brought two plastic shopping bags of his possessions to each session having spent two hours in the morning packing them. He took me through the contents of each bag before he allowed any music. Although Andrew could not drive he showed me photographs of Ferraris and said they were his.

It didn't seem easy for Andrew to stay with me. He would play the drum and cymbal extremely loudly for about ten seconds and then leave the room to hide in the toilet for ten minutes. The only time he sat and shared music with me was when I played the guitar towards the end of the session. The rest of the time he rarely allowed me to play or sing. If I started anything he would rush over and restrain me. He brought his own tape recorder and tapes to play. I was not allowed to have anything.

I spent hours thinking about Andrew in terms of his music, health, anxiety, the effects of his medication and the physical risks he posed to others (including me). However, what occupied me most was how he represented the deprivation which results from institutionalisation. After living in large hospitals for forty years, he now lived in a smaller unit. Labelled as exhibiting 'challenging behaviour' he seemed to long for a different identity. He told me he was married to one of his

care workers, and showed me a plastic ring.

Andrew affected others deeply. His home manager wrote poetry about him, which culminated in an inquiry about the appropriateness of this practice.

Although exonerated, the manager was moved away. I was required to give evidence in the inquiry. When I received the draft transcript of my inquiry interview, I found the transcriber had written my surname as 'Andrew' throughout rather than the surname I had at the time: Durham. Andrew seemed to get in everywhere. His distress affected matters on an organisational level and, it seemed, unconsciously affected the transcriber.

I met Andrew when I was employed by the National Health Service. Our relationship raised questions for me that eventually led to this inquiry. I needed to know more about why Andrew had such a history, and how this affected him as a person. I wanted to hear his version of his story.

Andrew experienced both material and emotional poverty. We both experienced musical poverty in the sessions. Andrew raised questions about the imbalance of our power, status and the normality of our respective identities. I was intrigued by how much Andrew was able to communicate some of these questions by stopping the music happening. He was showing me a shadow side of music therapy where creativity and reciprocal relationship could not flourish easily because of envious feelings developed as a result of deprivation.

From Andrew I began to learn that anyone undertaking research involving people in a similar situation to his needed to take into consideration the power relations between them and others involved in the research process. I also came to believe it was important to find an approach which could accommodate unusual ways of communicating opinions. The challenge was to find a way for people with

learning difficulties to inquire together even though they might find making relationships and understanding the process difficult or pointless. To do this I began by drawing on eleven years' clinical experience of using group music therapy within community homes, grounded by the research values as described in *New Paradigm Research* (Rowan and Reason 1981; Reason 1988; Reason 1994; Heron 1996; Reason and Bradbury 2001). The fundamental principle here is that research should take place *with* people, rather than *on* or *about* them.

1.2 Some initial assumptions

By involving people with learning difficulties as co-researchers in an inquiry, I make several assumptions. One is that the participants can be accountable to themselves and to others for their actions, at least to some extent. This involves arguing that people with severe learning difficulties do have *capacity* in some form. I will discuss the notion of capacity further in chapter five. A second assumption is that participants will be able to develop a degree of commitment to participation in an inquiry. A third is that they will be able to show some reflexive thought. The assumptions I have outlined may seem obvious, but often people with severe learning difficulties are excluded from having any influence on the direction of research because they are not considered to have sufficient autonomy or accountability. These assumptions are based on my beliefs I have developed during personal and therapeutic experience with many people with learning difficulties.

1.3 Introduction to the research inquiry

Andrew's questions led to this thesis which is based on a critically reflexive action

research inquiry which took place during 2001 in a community home for five people with severe learning difficulties. The focus of the inquiry was a series of weekly music therapy sessions, open to all the home residents. Six residents, including a new resident, a day care worker, two music therapists and seven nursing staff at the home joined the inquiry as participants.

1.4 The context of the community home

The community home opened six months before the inquiry began and adjoined another home that had been established in the community for ten years. Both homes were owned by a residential trust in the west of England, which employed the care staff and the day care workers. The two buildings were situated at the edge of a village in a rural setting. There was some tension between the residential trust and the owners of the properties overlooking the community home garden. A number of staff members believed that some members of the local community viewed the residents as being undesirable.

The same staff worked in both houses. Both homes were specifically for people who had 'severe challenging behaviour'. The residents of the new home had lived together for fourteen years on a hospital ward. All the staff members were previously unknown to the residents and most of them were under thirty whereas the youngest resident was forty. One man, Bill, was terminally ill with lung cancer.

1.5 The research inquiry and therapeutic issues

It is the tradition in music therapy for the therapist to concentrate on the relationship between themselves and the person or people entering into the

therapeutic relationship. However, therapists are increasingly challenged to consider the wider context, such as family influences, organisational factors and broader cultural influences. This pressure comes from developments in areas like community music therapy, ecological research, systems theory, family therapy, and psychodynamic thinking within organisational cultures. In my practice as a supervisor, I have found that supervisees need and want to spend time thinking about how institutional dynamics have an impact on their work. This makes the whole process of therapy more multi-layered and complex. Within institutional and organisational systems, there are multiple interests to be served, and therefore multiple agendas. Without doubt these will have an impact on both therapeutic and research-based initiatives taking place within the system.

My desire to ensure that political and ethical aspects were incorporated in my music therapy research pointed towards the adoption of a participatory research methodology. Having encountered this *Human Inquiry* (Rowan and Reason 1981), I found that the values were framed within a psychological and humanistic viewpoint which I found familiar and appropriate. Organisational and cultural issues were stressed and incorporated within the research designs of that approach. I wondered whether the skills that music therapists develop, such as reflective thinking, group facilitation, engaging with conflict, evaluative skills and above all, listening to and recognising non-verbal communications might lend themselves well to participatory research methods. The *extended epistemology* of Heron and Reason (1981) opened up the possibility of including types of knowledge that might be more accessible to people with severe learning difficulties, such as *experiential* knowing (knowledge gained from direct experience), *presentational* knowing (communication of knowledge through

different presentational forms, such as music, movement, drama or images) and *practical knowing* (knowledge gained from taking action).

1.6 Powerful agendas

Despite the values of inclusion which were articulated by new paradigm research, I wondered if the concepts and practices of the approach were robust enough to withstand influences within an inquiry that might bring powerful competing agendas. For example, the authors of a research study which involved deaf children and their teachers (Moore, Beazley and Maelzer 1998) describe vividly how their own research findings were suppressed externally by the commissioning body, and blocked internally by some participants whose professional agendas were in conflict with the disabled participants' interests. The following vignette describes another experience which has made me alert to the dangers of competing interests where vulnerable people are concerned.

1.7 Losing one's voice and the ethics of consent

Vignette 2: Christa

Christa, a businesswoman, decided to make an advance directive – a 'living will'. In it she stated that she did not wish to remain alive if she should be unfortunate enough to experience severe brain damage. Then, in a routine operation she reacted badly to the anaesthetic and her heart stopped. Eventually resuscitated, her anoxic brain damage resulted in no purposeful speech and almost no purposeful movement. She could not walk or communicate verbally. Yet the law prevented her original wishes from being carried out as euthanasia is not legal in Britain. Christa's husband, outraged by this, decided to publicise her situation

through the national press.

In the meantime, Christa attended rehabilitation sessions, including individual music therapy with me. A television company contacted the hospital, wanting to make a documentary about living wills, with Christa as the main focus. They wished to feature music therapy, as Christa was making progress at the time. She was using song to help organise her walking, and had regained a few words of meaningful speech.

At first I did not agree. Christa's therapy sessions were private. She could not give consent to a process that would expose her to the gaze of several million people. When the team came to film, Christa had influenza. Normally Christa would have been considered too ill to attend any rehabilitation.

The various agendas became more starkly differentiated. The film team had a time limit, and the producer wanted a powerful programme. He pushed me hard to give Christa the 'walking' session with the film crew present, and I refused.

The following day Christa was in better health, although not fully recovered. I did not think she was ready for a walking session. This time the producer felt I taking a 'precious' therapeutic stance, and ignoring the benefits for Christa. With little support from the hospital establishment, which would also benefit from high-profile coverage, I felt unable to refuse. The cameramen filmed sensitively, but it felt as though the powerful forces of the television channel and the hospital administration prevailed.

On reflection, I can see there were many conflicting interests. Christa's husband was grieving for her past voice. The producer was concerned that the case should be heard for euthanasia and at the same time he needed a successful programme. I and other colleagues wondered what Christa's present voice would

be. Hers was the most vulnerable voice. I also had to consider whether there was some truth in the producer's accusation that I was being precious. This was painful, I realised, because I also had a competing agenda: the wish for my profession to have a higher media profile.

The political issues were different from those raised by Andrew. Christa's right to privacy and anonymity were in question. Those of us who were linked to them were faced with the difficulty of interpreting the meanings of their communications and actions, and dealing with complex ethical issues. Christa's story tells me that ethical considerations need to be central in healthcare research involving the voice of the service user.

Other people also suffered because of Andrew and Christa. It seemed important to find a way of exploring issues faced by inarticulate adults, also involving the system of people surrounding them, as part of the inquiry.

1.8 Representing the 'client' voice

Is it possible to ascertain the opinion of someone who has no verbal language? Examples in the music therapy literature are rare, but recently the book *Inside Music Therapy: Client Experiences* (ed. Hibben 1999) devoted a section to 'the experiences of clients who do not have meaningful language or whose words are unavailable'. Contributors use multiple approaches to attempt to construct the experience of music therapy clients; these include behavioural observations, client music, commentaries by those who know the person and imaginative soliloquies. In the chapter entitled 'Kelly' (Nowikas 1999) the writer and Kelly's mother are at pains to stress the limitations of their interpretations.

There were some topics that she [the mother] addressed with a

great deal of assuredness and certainty but other areas in which she did not even attempt to venture an answer or explanation.

This...reinforced the idea to me that Kelly could be mysterious and in some ways 'unknowable' even to those closest to her.

[Nowikas 1999: 224]

Although little was claimed about the child's thoughts and feelings, as a result what emerged had more authenticity and weight.

The book explores the difficulties and dangers of trying to represent experience through the words of others. Without some thought about the politics of interpretation and the agenda of each party, the vulnerable voice can easily become submerged, or, worse, misrepresented.

1.9 Experience and voice

The contributors to Hibben's book were attempting to explore the *experience* of others. However, the notion of *voice* represents a step beyond experience into communication. Phenomenological research aims to understand experience, but New Paradigm research, although it sometimes draws from phenomenology (Hawkins 1988) aims to enable all participants to exercise their power to shape the process. If a person is able to say, 'I don't like this. I want something changed,' this is different from another participant realising that 'she didn't like the experience. Perhaps I should think about changing it.' The notion of the client's 'voice' standing alone implies a notion of empowerment. 'Voice' may be articulated through music, and by taking action rather than solely in verbal language.

In this inquiry, one difficulty was how to know whether some participants

were intentionally taking a stance in order to change a situation, or whether their actions were primarily reactive and expressive. For example, in the course of the community home inquiry, one participant, Ralph, hit the video camera many times over the course of the year. When the camera was not there, Ralph stayed in the room for longer than usual. As a result the therapist and day care worker agreed to stop using the camera at the end of the year. Furthermore, the therapist reflected on his general use of video in his work, did not subject the original participant to any more video and reduced his reliance on video in his normal working practice. As participants we were not certain whether Ralph was intentionally objecting to the camera, or whether he just liked thumping the object. We had to acknowledge that although we could not always know, our interpretation of the intentionality was as important a factor as the action itself, and these interpretations must be part of our critical reflection. Anna, a day care worker, decided on reflection that Ralph was intentionally objecting to the camera. She said:

He understands much more than I realised.

[Cycle 6: dialogue with Anna]

By making the decision that Ralph was expressing his opinion, that it mattered and could alter the way she thought, Anna was able to communicate back to Ralph that she had heard and understood his communication. This in turn allowed Ralph to experience a greater sense of autonomy, and perhaps reinforced his motivation for intentional communication. In the inquiry we began to acknowledge that a critical inquiry into our capacity to listen was as important as any critical inquiry into our capacity to communicate.

1.10 Challenges to the therapist's power

In the setting of a therapeutic intervention will the therapist always have the power advantage over the client? *Every Day Gets a Little Closer: a Twice-Told Therapy* (Yalom and Elkin 1974) is a dual account of a psychotherapeutic relationship between Elkin (client) and Yalom (psychotherapist). Every six months they exchange accounts, read them and continue the therapy in that shared knowledge. They find that differences between them in circumstance, history, age, gender, vulnerability and status all play their part in the diversity of their accounts. Yalom writes:

I imply to Ginny that we strive for egalitarianism, yet the notes expose our essential apartheid. I write in the third person 'Ginny', she writes to a second person 'you'. I do not, even in the safer recesses of the notes, reveal to Ginny what I expect her to reveal to me. (Yalom and Elkin 1974: 223)

Ginny is all too aware of this:

I feel there will always be an unreconciled area, a gap in therapy – that our aims were different. (Yalom and Elkin 1974: 241)

Despite these reservations, both parties agreed that the therapy had helped Ginny to make significant changes in her life. This deeply reflective account of 'successful' therapy reveals significant power differences despite the lack of interference with Ginny's articulate voice. Her words were printed unchanged throughout. How much greater could the differences be between therapists and less articulate clients, where their meanings are constructed without adequate critical reflection?

1.11 Professional barriers and participation

Braye (2000), writing generally about social care professionals using participatory inquiry methods identifies two barriers which arise from the politics of professionalism: assumptions about the capacity of vulnerable participants; and the need to balance the empowerment of individual participants against the risk factors involved. If this is so, then adults with the labels of 'learning difficulties' and 'challenging behaviour' are doubly vulnerable to a reduction in autonomy from professionals. 'Challenging behaviour' implies risk and with it the possibility that professionals might use risk assessments as a method of disempowerment, although of course they have a responsibility to safeguard clients and those meeting them. Biggs suggests that there need to be major changes to the identities and relationship between professionals and users (Biggs 1997), reconstituting the boundaries between them, and that this is likely to meet with considerable resistance from the professional. These were considerations that warned of some of the competing agendas that might lie ahead in the inquiry. They also represented a personal challenge to my identities as music therapist and researcher.

1.12 Developing the research question

In order to begin the study, there was a need to submit a proposal for funding, and gain ethical clearance from Local Research Ethics Committees before having any access to potential participants. Both procedures required a proposal identifying research questions. However, in participatory research methods the participants themselves define the research questions, so I was faced with what seemed to be a dilemma of the *Catch 22* variety (Heller 1961). To avoid this I

aimed to produce a research question that defined the general area of inquiry, and was context specific but was also malleable enough to be redefined by the participants, and acknowledged this within the protocol.

Personally I was interested in finding out about the experience of music therapy from the perspective of people who had learning difficulties and a history of institutional living. My original idea was that music therapy could be offered as a group intervention to a community of people who lived together, so we could inquire into the communal impact of music therapy if we wished. At this point I rather assumed that participants would be able to speak, as I thought this would make the collaboration more straightforward. I soon needed to question this assumption.

The original research question began like this:

What are the benefits of group music therapy for people with learning disabilities living within a community home?

From one perspective the question implied evaluation creating the potential for the research to promote music therapy. It also allowed for the possibility of using qualitative or quantitative research methods. Within the proposal I emphasised the need for this project to be delivered through a participatory action research model.

With this question it was possible to secure funding and ethical clearance. This process is described in more detail in chapter five. Once the participants were recruited the verbal participants had the opportunity to reshape the original question or devise ones more appropriate to their own inquiry, as described in chapter seven. The non-verbal participants generated their own inquiry questions quite naturally through their involvement in the music therapy, and this became an

inquiry within an inquiry. These inquiry processes are explored as a whole in chapter six and also in relation to individual participants in chapters nine to fourteen.

1.13 Construing acceptability in participation

I met several music therapists before finding my inquiry partner, Nick, who was a practising music therapist in a specialist trust for people with learning difficulties, and also in training as a Gestalt therapist. He said that in order to work therapeutically he would prefer only four members in the music therapy group with a maximum of five in order to fully focus on their needs. It transpired that in the collaborating trust the only community homes with five or fewer residents were homes where the residents had severe challenging behaviour and severe learning difficulties. We realised that this meant involving participants who might struggle immensely to communicate and make relationships. However, Nick and I agreed that on principle we wanted to open up the inquiry to anyone who would normally be a candidate for music therapy. We began to question our original motives for preferring participants who were verbal. However, at the time we felt as though we risked embarking on an unsustainable project, severely testing our personal agendas which required the project to be a 'success'.

1.14 Critical Reflexivity

In an inquiry of this nature, critical reflexivity forms the fundamental cornerstone to the approach. Brynjulf Stige argues that professionals engaging in a process involving communal reflection must develop individual reflexivity to avoid the research becoming 'a refined version of expert dominance' (Stige 2002: 296). He

emphasises the need for the music therapist's 'context-sensitivity' when engaging in participatory action research. I believe that this extends to my awareness of my own cultural setting. I need, therefore, to situate myself in the thesis from the outset, acknowledging personal agendas and cultural influences

1.15 Different selves

I have found it helpful to disentangle a number of selves which are apparent from my reflective diary, field notes and analytic memos written throughout the project. Engagement with reflexive ethnography and feminist thinking has been the primary influence in this process. For example, Reinhartz argues for a fuller realization of the author's voice, and identifies a multiplicity of her own selves as constructed by other participants in her ethnographic research (Reinhartz 1997). After Reinhartz, I have identified a multiplicity of 'research-created selves', arising as a consequence of being engaged in the inquiry. I have been seen, or have experienced myself as a visitor, a university researcher, an instrument carrier, a novice, an expert, a collaborator, a group member, a teacher, a nuisance, a transcriber, a participant observer, a peer supervisor, an organiser, a communicator, a facilitator, an interviewer, a recording technician and a mourner.

Reinhartz also identifies 'imported selves'. These relate to our history and culture, and some selves are imported unconsciously. Part of the process of developing critical reflexivity is to become conscious of these, encouraging other participants to do likewise. Through processes such as personal therapy, working as a therapist and peer discussions there are four selves that I identify as most relevant: being a sister, a musician, a music therapist and a parent.

Being a family member

As a child in an extended multi-ethnic family where several children were adopted, I was introduced to rather complex issues of 'difference' from an early age. Family beliefs and values ranged from entrenched colonial attitudes to radical socialism, and I have been trying to make sense of it all ever since. I believe that this is where the origins of my interest in inclusion and exclusion lie. Family life has developed my belief that shared experience is as important a link as shared genetic inheritance but it has also given rise to my sensitivity to attachment and rejection issues. This means that I needed to hold in mind that other participants in the inquiry were likely to have different experiences of attachment and separation, and to try not to bring my own unexamined projections to the inquiry.

Being a musician

As a classically trained 'cellist and pianist who has also experimented with orchestral conducting, I import many values and assumptions from the traditions of Western classical music. In the last ten years my focus has been on developing as an improvising musician, so I have needed to relinquish traditional notions like playing the correct notes, having a sense of control over the direction in which the music is heading and having certain aesthetic expectations. I bring a belief that how we listen and hear is fundamental to our musical creativity and expressive potential. This belief stems from both my classical and improvisatory paths.

Being a music therapist

This identity seats me in a more 'useful' position in society than being a musician. Musicians, despite their extensive skills, are rarely accorded much status in

Britain. Therapists can be powerful, and music therapists have a tool that allows immediate access to people's feelings.

My eclectic music therapy training was at the Guildhall School of Music and Drama. In music therapy supervision and practice I have experienced client-centred, psychodynamic (psychotherapeutic, Gestalt and group-analytic models), music-based and behavioural models. I also realise that I have some investment in certain types of therapeutic practice that may not be shared by other participants, particularly psychodynamic models.

Being a mother

Having become a mother during the course of this inquiry, I have been alongside my son as he has explored a bewildering array of experiences. From the many hours spent receiving my son's sounds and gestures and responding to him, I have had opportunities to reflect on non-verbal communication on many levels. Some experiences have enriched my inquiry by questioning notions of what constitutes 'normal' behaviour, just as dialogue with the residents in the inquiry has raised my awareness of how frustrated, powerless, but also how powerful a non-speaker can feel and be.

1.16 Writing and words

One developing self is that of the writer. The paradox of using words within this thesis to convey meanings that live in non-verbal forms has been a constant source of frustration and yet has intrigued me. Although I enjoy writing, my creative flow has often halted when I have tried to convey meaning in a way that satisfies the many contradictory levels of the inquiry. It is difficult to feel that my writing can do justice to the richness and subtlety of the inquiry. Likewise, some of

the literate inquiry participants at the community home have found that reading transcripts of their own words has made them painfully self-conscious, because of their perceived colloquialisms, contradictions and lack of certainty. Although this is an academic thesis, written in a particular style, I believe it is important to value all the different types of language, music, communications, actions and feelings that have formed and been formed by the inquiry.

Even if an individual has only a few words in her vocabulary, these may well produce strong emotional impact. John Barton expresses an interesting thought about Shakespeare's use of English vocabulary:

It's the monosyllables that are the bedrock and life of the language. And I believe that is so with Shakespeare. The high words, the high phrases he sets up to then bring down to the simple ones, which explain them. Like 'making the multitudinous seas incarnadine, making the green ones red'. First there is the high language, then the specific clear definition.... Deep feeling comes from monosyllables. (Bragg 2003: 150)

I believe that if we wish to develop our general understanding, theory or practice of music therapy, we need the simple voices woven in or contrasting with more complex voices to give the bedrock and life to music therapy.

CHAPTER TWO

Theoretical Influences in Music Therapy Research and Practice

2.1 Introduction

Engagement with the music therapy literature – an outline

Beginning with the idea of using action research with people with severe learning difficulties, my search began to find any similar or related research studies in the music therapy research literature. Discovering that there was no action research in music therapy at doctorate level, and few other examples, I began instead to set the context of this particular project. To do this, I looked at how thinking about the researcher-subject relationship had been treated through an exploration of music therapy research with people with learning difficulties.

Finding that this literature was largely traditional in the sense that the researcher-subject divide was maintained, I moved to explore the clinical writing about music therapy work with people with learning difficulties and a history of institutionalisation. I aimed to explore whether the research reflected practice, or whether there were more innovative approaches in clinical writing.

I found that much of the detailed and reflexive writing in Britain for work of this kind was based on psychodynamic models of music therapy. I was puzzled that there were many discrepancies in thinking between research and practice models with people with learning difficulties. I decided that in order to make sense of this, a more detailed exploration of the historical, theoretical and social context of music therapy was necessary.

Setting the context meant the identification of a number of important influences which guided me towards the way I was able to approach the research. First, I identified the presence of a strong interest in research and practice based on early interaction theories, and this linked music therapy from a variety of origins. Early interaction was important in terms of thinking about non-verbal interaction and some studies addressed how this might be applied to adult interaction as well. Second, I became aware of the important agendas within the music therapy profession, and this was important when considering the research design and setting. Third, the influence of the new musicology within music therapy brought fresh perspectives on aspects of musical participation. Then the developing theory and practice of community music therapy introduced a considerably more critically reflexive look at conventional approaches of music therapy by introducing the importance of the social context, offering new practice solutions and questioning the meaning of the work of the music therapist. I undertook a more detailed engagement with research which had been influenced by new paradigm thinking, in order to gain insights into research design, and particular challenges faced when using this thinking within music therapy research. As participatory inquiry was going to move the project towards collective music-making and meaning-making, I explored the literature about group music therapy, only to find that very little research or practice existed except in the last two years.

Finally, I needed to explore theoretical influences that were going to be more useful for making sense of music therapy from the point of view of all collaborators, be they 'clients', care workers or music therapists. This involved carrying out an exploration of the influence of group analytic thinking in music

therapy, and then some more radical theory in this area, as I found that group analysis embraces difference in groups and community as a central notion.

Initial literature searches

The search began with the question 'How has music therapy research with people with learning difficulties prepared the ground for this particular project?'

The searches involved the following databases: the *British Institute of Learning Disabilities Current Awareness Service*, the *British Humanities Index*, the *Cochrane Library*, the *Applied Social Sciences Index and Abstracts* and the multiple databases available through the *OVID Biomedical Collection* and the *Web of Science Citation Indexes*, as well as music therapy databases from Witten-Herdecke University, using the following keywords (with their variations): music, music therapy, group therapy, institutionalisation, community care, and the numerous euphemisms which denote learning difficulty (see Appendix 2 for a discussion on euphemisms). The number of references was significant enough to warrant confining the range to studies in the English language. Most of the research I reviewed at first was from Britain, the United States, or Australia, and therefore relatively restricted in a cultural sense.

2.2 Positivism in music therapy research in mental retardation 1964-1991

Published reviews of the literature have helped me gain an overall picture of the dominant influence of behavioural and experimental studies. Decuir's analysis of articles in the US based *Journal of Music Therapy* from 1964-1986 showed that 24% of the articles on research were in the area of developmental disability, higher than in other clinical areas such as child and adult psychiatry, the elderly

and general medicine (Decuir 1987), but that these were primarily behavioural or outcome studies. Wheeler used the same method as Decuir to review literature from a range of American music therapy journals from 1964 to 1987 (Wheeler 1988). Wigram brought in a British perspective by collating the previous studies' findings and extending them to 1991 (Wigram 1993). He included the *Journal of Music Therapy*, *Music Therapy*, *Music Therapy Perspectives*, *The Arts in Psychotherapy* and *The Journal of British Music Therapy* (Wigram 1993) and found that until 1987 research in these journals was primarily experimental, and statistically based. From 1987 to 1991, the proportion of articles dedicated to work in the learning difficulties field had diminished to 15%. Across the client groups there were nearly twice as many articles on behavioural work or outcome research as on any qualitative research.

An American review of Master level theses in music therapy to 1987 shows a similar trend (Bruscia and Maranto 1988). Of 73 theses, 22 (29%) focus on 'mental retardation' or 'profound handicap' but only one explores philosophical issues relating to deinstitutionalisation. Again, the majority have a behavioural focus.

The electronic database searches revealed articles by psychologists and educationalists using behavioural studies to investigate the effects of music on people with severe disabilities. A recent example is a study in which 'musical manipulations' were used to determine whether music with fast or slow beats affected the number of times a person displayed a challenging behaviour (Durand and Mapstone 1998). Another study (Kennedy and Souza 1995) showed that a youth, who continually self-injured by poking his eye, poked his eye less when watching a video game than when listening to music.

Reflection

The high proportion of experimental studies reflects the dominance of a positivistic research paradigm, especially in North America, using research on subjects rather than with participants. Furthermore, the emphasis on a behavioural clinical approach is indicative of a therapist-client relationship where the emphasis is on modifying what the subject does, rather than exploring and addressing any emotional basis of the behaviour. The music-based studies negate the significance of any creative role for the music therapist, investigating the effects of music which could just as well be recorded. Dialogue between two or more people in music does not seem to have a value in these studies.

One recent music therapy handbook summarises the benefits of using a behavioural approach (Wigram *et al* 2002): first, behaviour can be measured and secondly the problem for the patient is solved quickly and effectively without recourse to a detailed examination of the patient's history.

Reflection

Proving that changes in behaviour can occur through music therapy may be an effective way of convincing the medical establishment that it is worth incorporating it within a health service. However, the rationale for these arguments is based on the benefit of the service: behaviourism saves money and is more likely to impress those in authority. Although in the short-term it may be advantageous to help someone reduce their self-injury, in the long-term surely it is important that the underlying causes are addressed.

2.3 Music therapy research with people with learning difficulties in Britain – relationships between researcher and researched

In the United Kingdom there is little research on, about, or with people with learning difficulties in a music therapy context. Some of the most important work (Bunt 1985: Oldfield and Adams 1983) is founded on an ethological descriptive analysis of data captured on videotape. This approach involves the identification and independent measuring of behaviour which is considered important. The focus is on communication and the relationship with the therapist. Leslie Bunt's doctoral research on work with children measured the levels of the children's engagement, such as eye contact, gesture and looking at an instrument. Bunt's clinical approach is underpinned by humanistic theory, and it would be a mistake to assume that the use of an ethological approach implies a behaviouristic clinical model.

Oldfield and Adams studied music therapy with a group of profoundly disabled adults and used a comparison with play therapy rather than with a more ethically contentious control group. The researchers noted that the presence of the video camera resulted in staff showing increased engagement with the subjects, and Oldfield as the therapist reflected that her practice was altered by the greater accountability she felt when her work was being evaluated. The research model she had chosen however, did not take this information into account; in fact, these data were presented as 'confounding factors' rather than as an integral part of the phenomena being investigated.

Toolan and Coleman (1994) also used independent observations of changes among five children and adults with learning difficulties during music therapy. The authors developed a method of measuring levels of engagement

using a rating scale which had a range from 'avoidance' to 'clear engagement' and the study demonstrated significant improvements in the levels of engagement of the subjects.

Woodcock and Lawes (1995) used a randomised controlled trial with adults with severe learning difficulties who self-injured. The hypothesis was that with music therapy their self-injury would diminish. Unlike Bunt's findings this study reports no change of statistical significance although the authors comment upon several other factors within the therapeutic relationships, which again could not be recognised or incorporated into the research design. A more recent paper has argued that music therapy research which aims to achieve statistical significance may risk failure; and suggests that researchers should concentrate on measuring effect size within a randomised controlled design (Gold *et al* 2001).

Reflection

Some of this research has been useful in demonstrating to funding bodies the communicative and social value of music therapy. An important feature of these studies is a focus on the behaviour of the clients in the therapy, rather than of all the people in the interaction. There is less emphasis on the essence or quality of the experience. However, in each study the researchers included sections reflecting on the limitations of the research, and every study indicated that they needed to think more about the relationships between participants. Clearly these researchers, all of whom were music therapists researching their own clinical work, were sensitive to issues of relationship and power.

Why is it that music therapy research on people with learning difficulties has tended towards a positivistic paradigm? It is not solely related to the time when

the research took place. The examples above range from 1983 to 1995, by which time music therapy research with other client groups was tending towards process models.

One reason may be the influence of the *context*. Most of this research took place before the move to community care. Within a hospital culture the medical model was dominant. A second reason may be that of *survival*. The earlier research is certainly due in part to the need for a minority profession like music therapy to gain some sort of credence with the considerably more powerful medical establishment. A third reason may lie with *social perceptions* of people with learning difficulties. Although process research has been attractive to music therapy practitioners in some fields, this does not seem to have been applied to more severely disabled clients. Just as Sinason has challenged Freud's contention that only intelligent people could benefit from psychoanalysis, it seems possible that a prevailing assumption has been that people with learning difficulties could not easily be involved in process research. Research methodologies which primarily value written texts immediately produce restrictions on the involvement of non-verbal people. Much of the most sensitive qualitative research in music therapy has depended upon clients who have been able to talk in detail about their musical experiences. Two examples of doctoral research where this is the case are Amir's work on moments of significance in music therapy (Amir 1992) and Lee's inquiry with people living with HIV (Lee 1992). In both studies musical texts are important, and these are very rich in detail.

Clients who can demonstrate reflexivity in their thinking through their own words can indicate all sorts of radical and subtle change: it is tempting to assume that someone with a learning difficulty may not articulate reflexive thinking in such

conventional or detailed ways, if at all. Similar assumptions may apply in relation to musical texts. It is easier to count the number of times someone repeats a positive behaviour than it is to demonstrate changes in attitudes and behaviour of which the meaning is difficult to discern.

2.4 An alternative approach to engagement with the literature

The literature surveyed so far did not indicate to me an obvious research direction, but further reinforced my desire to seek new ways of involving people who receive music therapy in research. I was interested and encouraged to read that in critically reflexive action research, certain forms of literature review may be experienced as a hindrance to inquiry. In the following quotation from an inquiry concerning the high level of coronary heart disease in South Asian men in Britain, the identities of Bhandari and Shah were considered more valuable to the context-specific inquiry than findings from the medical literature:

Traditional academic research defines problems in terms of prior research: the 'building blocks' upon which knowledge is added...Further in-depth searching...could lead us to unwittingly devaluing the depth of our practice-based knowledge and experiential understandings as rooted in our identities as South-Asian women and health care professionals.

(Weil, Bhandari and Shah 2002: 119)

My experience of the literature search led in the opposite direction: to value increasingly my practice-based knowledge, and that of others around me. I was aware that the research literature did not always connect with what I knew to be highly developed and thoughtful clinical practice in Britain with people with

learning difficulties. It became clear that the value of engagement with the literature was in helping illuminate some of this knowledge, and in allowing me to challenge and reframe the theoretical assumptions practitioners adopt. Instead of concentrating on reviewing the literature before the inquiry, I found that reading as the process developed, and afterwards in reflection, was a more useful practice. I realise that many researchers continue to read and engage with the literature as they move through their studies, but it is rarely recommended in preference to a traditional literature review.

Two texts that I have found influential were published after 2001, the inquiry year. These are *Culture-centred Music Therapy* (Stige 2002) and *Complexity and Group Processes* (Stacey 2003). They offered a richer cultural context to some of the theoretical influences I had already identified and an opportunity to challenge my own thinking in these areas. *Culture-centred Music Therapy* also contains the only published account of a participatory action research project within music therapy.

In the spirit of a culture-centred approach as advocated by Ruud and Stige (Ruud 1998; Stige 2002) and also in the historical tradition of Bunt (Bunt 1994), I decided that the next step should be an attempt to link together the major influences in British music therapy (historical, theoretical, philosophical and political). Figure 2 below summarises these connections. The grey boxes contain examples of predominant practitioners and researchers, but this is not an exhaustive list. The blue ellipses indicate how I see the main theoretical influences on writing within the profession.

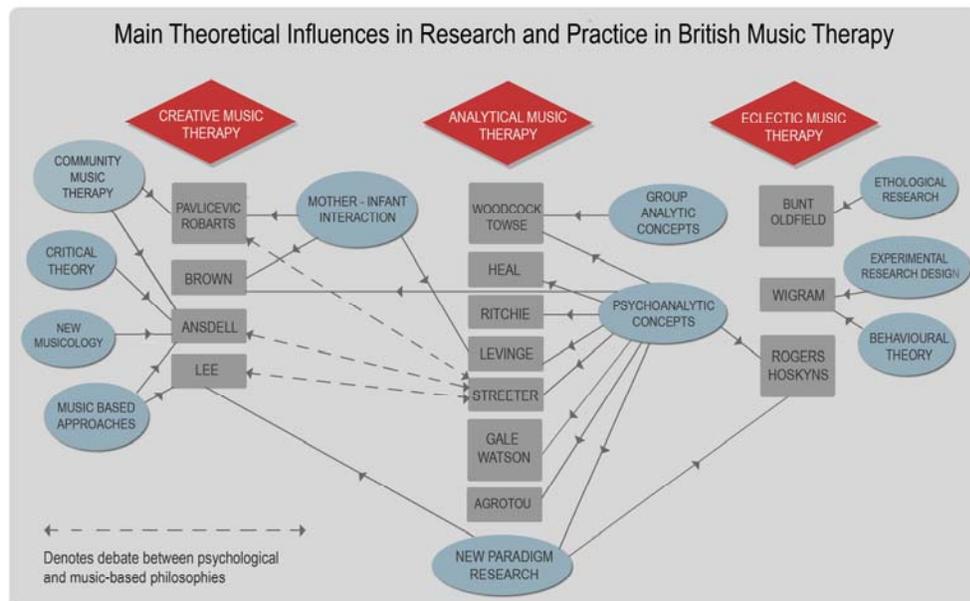


Figure 2

2.5 The origins of British music therapy

In Britain, the three pioneering influences from the early 1960s were Paul Nordoff and Clive Robbins with Creative Music Therapy or CMT (Nordoff and Robbins 1971; 1976), Mary Priestley with Analytic Music Therapy or AMT (Priestley 1975; 1984; 1994; Eschen 2002) and Juliette Alvin (Alvin 1975) with a more eclectic model which emphasised the role of the music therapist within a multi-disciplinary team. Alvin, and Nordoff and Robbins established two training courses in London in 1968 and 1974 respectively, with Sybil Beresford-Pierce continuing to run the Nordoff-Robbins course. Elaine Streeter, a graduate of the first Nordoff-Robbins course, established a third training course at the Roehampton Institute in 1981, predominantly influenced by psychoanalytic thinking (see figure 3, p 38).

Graduates from these training courses developed a new wave of training courses in each tradition outside London, led by Leslie Bunt (Bristol 1992), Helen Odell Miller (Anglia 1994), Alison Levinge (Wales 1997) and James Robertson (Scotland 2002). Tony Wigram and Gary Ansdell now head PhD programmes in music therapy at Aarlborg University in Denmark and at the London Nordoff-Robbins Centre.

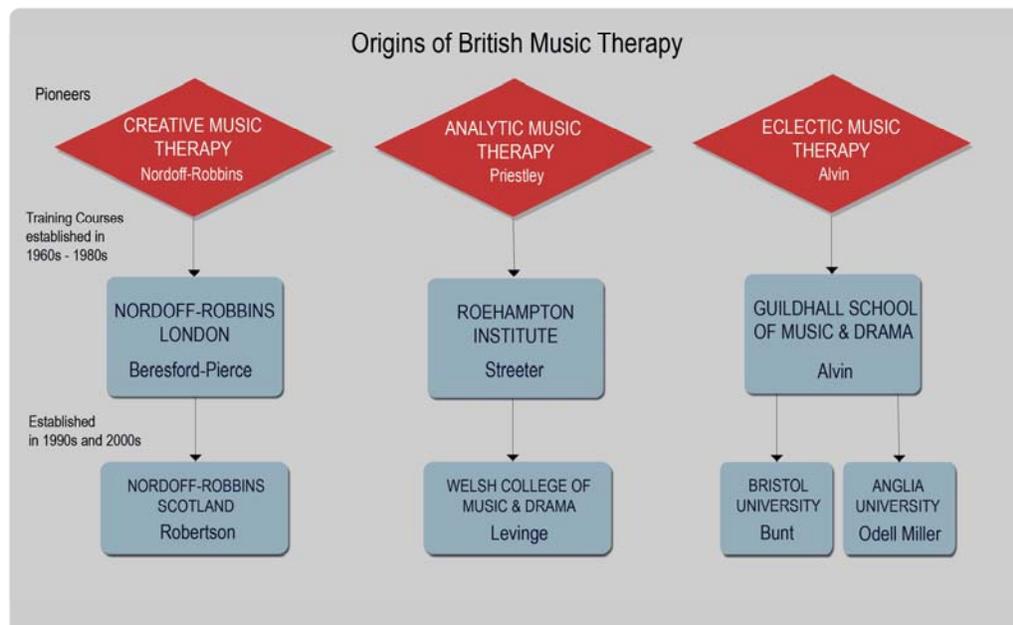


Figure 3

Creative Music Therapy

CMT has its origins in humanistic psychology and the anthroposophic movement of Rudolph Steiner. Nordoff and Robbins started by working with children with special needs, although today CMT practitioners often work with adults across a

wide variety of client groups. It is perhaps because of the emphasis on diversity that surprisingly little written material is available in the field of learning difficulties with either children or adults. The central focus of the work is how therapy happens *within* the music (usually improvised music), and is often described as a 'music-centred approach' (Aigen 1999). Practitioners usually involve a co-therapist even with individual work. One therapist often uses a piano or other instrument capable of providing strong musical containment. CMT is practised widely across the world.

Analytical Music Therapy and psychodynamically-informed music therapy

Analytic Music Therapy is another major branch of music therapy practice, well-established in Europe and the USA. Mary Priestley was a graduate of the Guildhall course and developed her approach while engaged in Kleinian analysis.

She says

AMT was born out of psychoanalysis but it is very different from psychoanalysis (Eschen 2002).

The concepts she applied and developed through music include free association, transference and three types of counter-transference: classical, complementary and emotional. Although Priestley did not establish a training course, she, together with colleagues Marjorie Wardle and Peter Wright, became the first pioneers of a strand of thought that has a strong hold on music therapy practice. Many practitioners in Britain study and apply analytic concepts from various branches of psychoanalysis and psychotherapy although few rely directly on Priestley's model.

Eclectic models

International 'cellist, teacher and music therapist Juliette Alvin established the first training course in Britain. Her practice model was based in humanistic psychology and her emphasis was on developing a professional role for the music therapist. In a variety of ways graduates of the course have continued this direction: notably Leslie Bunt, Tony Wigram and Helen Odell Miller. The eclectic training offers a range of approaches for students to develop according to their interests, although the models are primarily humanistic and psychoanalytically-informed.

From these three distinct strands of thinking in music therapy, the cross-fertilisation and debate between them has developed in recent years, as demonstrated by the arrows in figure 2. From figure 2, much of the clinical research with children and adults with learning difficulties has sprung from the tradition of Alvin, yet when we look at writing on clinical practice, the key influence is from the psychoanalytic influences.

2.6 Clinical practice in music therapy with people with learning difficulties

In Britain today, 47% of the users of music therapy have learning difficulties, communication disorders or acquired brain-injury, severely restricting their verbal communicative capacity (Stewart 2000). Although there are notable exceptions, such as Gary Ansdell (CMT) writing about 'Emanuella' in *Music for Life* (Ansdell 1995), much of the published literature on music therapy casework in this client group seems to have been informed by psychodynamic theory.

Margaret Heal (1989a; 1989b) was the first music therapist in Britain to publish work about music therapy with people with learning difficulties from a

psychodynamic perspective. She adopted the psychoanalytic concepts of *secondary handicap* (Sinason 1986) which is explained in chapter three, and *potential space*¹ (Winnicott 1971).

Fiona Ritchie, working in a large institution in Scotland, published powerful case studies of her work with people with profound learning difficulties (Ritchie 1992, 1993). She described how she used music to support people who were in a high degree of confusion and distress. As Ritchie felt the clients were unable to believe that anyone wanted to communicate with them, therapy took place over an extended period: in some cases several years.

More recent accounts of work in this vein, such as Chris Gale (1998) and Tessa Watson (Watson 2002; Watson and Vickers 2002) also refer to Winnicottian notions of play, and theories of secondary handicap. From Heal to Gale there is careful thought about the impact of institutionalisation and notably from a psychological rather than political perspective.

Although European work has often focused on similar models there seems to be wider a range of approaches in the published material regarding clinical practice. For example Schalkwijk (1987) used questionnaires to review the practice of most of the music therapists in the Netherlands who worked with people with 'developmental disabilities'. From the data he identified three types of practice: musical activities, remedial music-making and music therapy. He recognised that many people with developmental disabilities experience

¹ Winnicott refers to the 'overlap of two areas of playing, that of the patient and that of the therapist'. For some patients, this space is 'potential' as they have not yet developed a state of being able to play. The therapist works towards bringing the patient into this state of play (Winnicott 1971: 45).

emotional distress, and this was best alleviated by 'music psychotherapy' rather than activities or remedial music-making. In contrast to the generally non-directive music psychotherapy practices within the UK, Schalkwijk found that most therapists practised group work in line with his category of remedial music making, in that it was highly structured with a directive approach.

A separate influence on clinical practice within the UK from psychoanalytic literature, rooted within biology, social psychology and developmental psychology have been developed and integrated by Pavlicevic and Robarts within the creative music therapy tradition. This provides the first real evidence of overlap or integration of thinking between the traditions of Alvin, Priestley and Nordoff and Robbins, and includes mother-infant interaction theories and affect attunement. Most importantly for this thesis, the focus here is on non-verbal communication.

2.7 Non-verbal communication and mother-infant interaction theories²

It is not good enough to call the communication 'non-verbal' as if it were a kind of darkness lacking the light of language. It deserves a better name (Colwyn Trevarthen from the introduction to *Music, Meaning and Context* Pavlicevic 1997: x).

Throughout my review of the literature on learning disability research, I have found that the views of non-verbal people have been, in many cases, avoided and nearly always seen as problematic. Are the non-verbal forms of communication second-rate media for exchanging meaning? Does someone's ability to use

² Although the term 'mother-infant' is generally used, theorists acknowledge that this can apply to father interactions too.

language mean that we can know for sure what he or she really wants or thinks? There are several challenges to this way of thinking: from mother-child interaction studies (Stern 1985, 1995), from philosophy regarding the 'linguistic turn' (Wittgenstein 1953), and from the work of music therapists themselves (Pavlicevic 1997, 1999). There is also the perspective from psychoanalytic psychotherapy (Sinason 1992) that the communications of people with profound learning disabilities are often very clear, but the content of the communication is too painful for others to hear; thus professionals themselves are rendered 'stupid'.

2.8 Mother-infant interaction and dynamic form

The work of the mother-infant interaction theorists shows how communication derives from the exchange of gesture between infant and caregiver from birth. John Bowlby examined patterns of interaction between infant and parent (1969), and Daniel Stern (1985) undertook research into the way a mother attunes her reactions to the spontaneous gestures and sounds of the infant; *affect attunement*. They both concluded that the motivation to communicate is innate. Daniel Stern introduced the concept of *vitality affects*: where aspects of infant gestures such as an arm movement, a gurgle or a changed facial expression relate to the infant's internal feeling state. Vitality affects relate to the form of that emotional state (in other words, the feeling) and can occur in different *modalities* as in an arm wave or a gurgle. The music therapist and researcher Mercedes Pavlicevic has used the concept of vitality affects to construct a theory of 'dynamic form' in music therapy (Pavlicevic 1997). She argues that music itself is able to reproduce the form of a vitality affect through the shape of the sound. As a client and therapist improvise music interactively, the therapist can sense, through the

shapes of the client's music, the predominant emotional state. These states are fluid, and can range between the expressive forms of, for example, rigidity to fragmentation or stability to contrast.

2.9 The application of dynamic form: from infant to adult

This theory provides some explanation of how the musical elements such as rhythm and pitch may correspond to emotional states, and also relate to early and therefore fundamental forms of communication. In music therapy, the early infant and mother interactions are often the focus for work with children. For example Jackie Robarts uses the theories of Trevarthan and Alvarez to understand how autistic children work with music in therapy (Robarts 1996). Levinge applies three concepts from the work of Winnicott to her clinical music therapy work with non-verbal children who had disorders on the autistic spectrum (Levinge 1999). The influence of mother-infant interaction theories is certainly not confined to British music therapy: for example Valgerour Jonsdottir in Iceland explores the relationship between carers and young children with special needs in detail using Stern's concepts (Jonsdottir 2002).

When a child has not yet learned to speak, she or he has a different sense of identity (Phillips 1998). Phillips believes there is a quality to the nature of communication that is somehow lost when language develops.

From the point of view of the infant and young child, language is not missing. What is to be mourned is the pre-linguistic self.

(Phillips 1998: 47)

If this is the case, then we all lose as well as gain by learning to speak.

Other developmental stages may also move people away from the

importance of non-verbal communication. For example, when a child develops reading and writing skills, a whole world of propositional knowledge is presented to the child, with a strong claim to represent reality (Stacey 2003). However there are many other influences throughout our lives which form and change the way in which we choose to communicate.

Pavlicevic shows how music may help people access the nature of feelings which they experienced when they were very young. Perhaps there is a question here about the applicability of the theory of dynamic form to feeling states experienced by everyone. Do adults who have not developed language communicate using vitality affects as an infant does? When music therapists communicate through music with adults, are they doing reparative work by returning to an early form of interaction, or is all interaction based on this early pattern?

Niels Hannibal, a Danish music therapist, has used Stern's theories to describe relational themes in both the musical and verbal context in his research into music therapy with adult clients (Hannibal 2002: 87). He argues that the relational patterns expressed in musical interaction contain *non-verbal knowledge* about relationships. In this way, musical interaction, by relating to early non-verbal communication, has relevance for all people at all stages of communicative development. If this is the case, what is the nature of this non-verbal knowledge changed for people who have received neglectful parenting? What about others who have organic brain damage and sensory impairment, making their original mother-infant interactions more problematic? Is this discernible in their musical interaction, and more importantly, can this undergo a process of transformation within music therapy? Stern uses his theories to address how things can go

wrong in early interaction. There is, however, another theoretical influence preceding Stern, attachment theory, which is often used by music therapists to explain why long institutionalisation of adults with learning difficulties might have had such a devastating effect (see attachment theory, Appendix 1). One prime example is the doctoral research of Agrotou.

2.10 Music therapy research with institutionalised adults

Music therapist Anthi Agrotou facilitated and studied a group of three women with profound learning disabilities and four carers over a period of four years (Agrotou 1998; video 1999). This longitudinal case study was set in a long-stay institution, where the residents and carers are working towards a move to community care. Trained at Roehampton, Agrotou's clinical style is informed by psychodynamic theories, including those of Stern and Bowlby. (For an exploration of Bowlby's attachment theories, see Appendix 1, p418). The untrained carers involved in the therapy show signs of having internalised aspects of these conceptual frameworks through what Agrotou calls 'unconscious observational learning'. Agrotou met the carers monthly in 'free discussion meetings'. Findings from these inform the analysis. Agrotou emphasises that the carers had a fundamentally different role from those accorded to them by other music therapy models (e.g. Oldfield 1985) where carers were fundamentally passive. In Agrotou's group, they became 'facilitators on the route to becoming auxiliary therapists' (p68). The clinical work took place in Cyprus, and there are differences in the cultural context. Strong on reflexivity, this is a powerful and skilful piece of work and the video recording seems respectful of all participants.

Agrotou draws detailed attention to what the meaning of the actions of the

women with learning difficulties in the group might communicate, concluding:

Whatever the person's degree of disability and deprivation, every minute signal carries a meaning; and that person's desire to be reached and share his/her world transcends their cognitive, physical and environmental difficulties.

One of the key findings is that the level of the isolation of the residents was transformed through the musical relationships developed between each other and the carers in the group. Agrotou emphasises the peer relationships and gives ample description and analysis of how one person's gesture has resonance with the gesture of another, however minimal. Although the group and context has many similarities to my own inquiry, Agrotou's research used case study design rather than a participatory methodology and was both enriched and limited by the clear theoretical position she takes.

This raises the question which has occupied the profession for a considerable time: should a theoretical position always drive the ways in which music therapists research and practice? If so, which is the theoretical position best to take? If not, how am I contributing to theoretical understanding in a contemporary context in music therapy? By introducing participatory methodology into music therapy research I necessarily incorporate a social and political theoretical perspective. The following localised debate illustrates how theoretical positions can sometimes become polarised recently in music therapy, and how important the place of ethical thinking becomes in this arena.

2.11 A debate between psychoanalytically-informed music therapy and CMT

In 1999 Elaine Streeter wrote an article in the *British Journal of Music Therapy* which provoked a detailed response from CMT practitioners in the following issue.

Her main argument was that:

Musical experience alone cannot provide the music therapist with the means to ensure safe, effective practice (Streeter 1999).

By incorporating psychological thinking into the music therapist's practice, Streeter argued that the music therapist develops safe practice. Streeter chose to illustrate lack of safety with examples of clinical work from the literature, notably from Lee's book *Music at the Edge*, a case study of a musician with AIDS (Lee 1996), and Ansdell's account of 'Emanuella' from *Music for Life* (Ansdell 1995). Although this was a cogently argued article, the practice of openly critiquing individual therapists' practice provoked a backlash in the next edition, where four CMT therapists responded. Ansdell was concerned that Streeter's article had 'lurking philosophical projects' or agendas, and that she demonstrated neither reflexivity nor critical thinking. He also accused her of aligning her theoretical position with an ethical position by suggesting that only a psychologically-based approach is acceptable for a client (Ansdell 1999: 74-5).

Reflection

What is interesting for me in this debate is not primarily the content of the arguments but that Streeter's article provoked such a powerful editorial response that three of the four articles published in the next edition were extremely critical. After an attack of this magnitude in print, there was no

continuation of the debate in the journal and no published defence by Streeter, or on her behalf. This may partly be due to Streeter's stance and agendas, so clearly identified by Ansdell, but he, as editor, also had agendas of his own.

Another theme in this debate is the toleration of difference: if one practice is so directly attacked, the psychological motivation behind this perhaps ought to be examined. This debate raises many questions for the music therapist. How often am I aware of my own political agenda as a music therapist? Do I seek to take the ethical high ground? I am influenced and impressed by the skilled practitioners who are able to integrate psychological thinking into their music therapy practice, but I also believe that musical experience opens up for the client and therapist important dimensions of feeling that psychotherapy cannot. I believe that psychological thinking is helpful for understanding some of the unconscious agendas we may bring to the workplace, or the public forum.

In Agrotou's study, a psychoanalytically informed model of practice was effective in changing carers' attitudes in a way that allowed much warmer relationships with the residents in the music therapy, and beyond. However, the question remains what might have happened if the carer was unable or unwilling to assimilate this model?

In the context of the Streeter debate, Sandra Brown asks whether it is ever the case that a theoretical model should generate rules for the particular. She emphasises the need for sensitivity to the context and the individual needs of the client (Brown 1999: 64). She also identifies, as I do, the fact that the clinical issues generating most controversy in the debate surrounded therapy with a dying

man. Streeter questions Lee's move from 'therapist' to 'friend' of a client with AIDS. Brown reminds us that our therapeutic frameworks are culture-specific. In addition I feel that there are other frameworks in our culture (for example, spiritual frames) that may be more powerful or relevant to people who are approaching death. I mention this point, because, as I will explain later in the thesis (in chapters six, seven and thirteen) the death of a participant in the inquiry led to a major reframing of ethical thinking for at least one participant, and also caused some disturbance in power relations between different cultural groups (therapist and care staff). It is as though when experiences of mortality or the significant life events qualitative researchers call 'epiphanies' (Denzin 1994: 510), it is necessary to broaden theoretical and belief systems. With Lee's work, the imminent death of a client opened up a debate in a way that seemed to make it difficult to retain balance.

In summary, the importance of both social and political thinking have been present but largely unacknowledged in clinical and research writing about music therapy, and in particular in relation to work with people with learning difficulties. However, I will now introduce some ideas which have begun to address this within the literature recently: New Paradigm research, ideas about participation from New Musicology and the concept of Community Music Therapy.

2.12 The influence of New Paradigm thinking

An additional perspective is that Lee was influenced by his explorations of New Paradigm thinking in his doctoral research. The client with HIV mentioned in Streeter's article was a participant in Lee's inquiry. The inquiry focused on the analysis of improvisatory music rather than focusing on bringing about social

change for the participants in the research, but it did involve a strong emphasis on the perspective of the participants.

Earlier than Lee, Sarah Hoskyns had advocated the use of New Paradigm research, again using *Human Inquiry* as the starting point (Reason and Rowan 1981). In this inquiry, the participants were offenders. They were involved in some aspects of the design, data collection and evaluation, although they did not generate the research questions. For example, participants were involved in the creation of their own rating scales for self-evaluation in music therapy. Drawing on personal construct theory (Kelly 1955) she designed a music therapy grid in order to examine the clients' own perspectives on how they changed during group improvisations (Hoskyns 1988;1995).

Penny Rogers, using a cyclical model of action research initiated two co-operative inquiry groups. One group included music therapists who worked with survivors of sexual abuse. This acted as a consultative body to the research process. The other comprised ex-clients who had been sexually abused and some of the clients she was seeing during the research. Rogers's careful attention to boundaries meant that she was able to involve people retrospectively and she was able to retain her theoretical underpinning (psychoanalytically-informed music therapy) within this paradigm. Clients who did not want to be involved in the co-operative inquiry group while they were having therapy contributed to the process by writing diaries. These were analysed retrospectively thereby enabling clients to participate in a different way.

Rogers wrote:

One issue for people with a history of sexual abuse is 'the power of the secret' which sexually abused participants found strongly

inhibited their wish to be involved in the group aspects of the inquiry (Rogers 1992).

Rogers does not claim that the clients' therapy was unaffected by writing the diary, but the threat to the therapist/client relationship was reduced.

By facilitating a degree of ownership of the research with the clients, it is hoped that such experiences are not avoided and ignored but consciously acknowledged by all involved in the research at all stages (Rogers 1992).

Unfortunately neither Rogers nor Hoskyns completed their doctoral dissertations and neither inquiry has been published in detail. Their methods and findings have therefore not made much impact on the music therapy profession, despite the potential to do so. Neither of their methodologies brought about a reframing of therapeutic practice. As yet there is only one example of a participatory action research project in music therapy where this has been achieved (Kleive and Stige 1988) and this will be explored in detail in chapter four.

Lee, Hoskyns and Rogers all researched with people who used language as their primary means of expression, and who were able to improvise music to a fair level of sophistication. Their research does not aim to develop insights into how a participatory research model might work with participants who have little or no verbal language. It might not be possible to construct a rating scale or embark on a detailed mutual analysis of improvised music with someone who has a severe learning difficulty. This raises the question of how one might conceive of ways in which someone with a learning difficulty could participate in research. I begin trying to answer this by examining the concept of participation in music.

This involves discussion of another important influence in music therapy thinking: New Musicology.

2.13 Ideas about participation from *the New Musicology*

Traditional musicology tended to focus on the structure of musical forms, rather than regarding music as a process. Ansdell first brought recent insights from New Musicology to inform theoretical thinking about music in music therapy (Ansdell 1997; 1999). He introduces the critical theory of Adorno (Padham 1996) and other writers who focused on the cultural context of music such as Blacking (Byron 1995) and Said (Said 1991). These writers emphasised the cultural context of music, its participatory and social nature and music's link to meaning and feeling. This thinking was developed further by Christopher Small through his concept of 'musicking': where the act of engaging in music may take many forms:

Listening, setting up the stage, composing, creating the sounds or dancing (Small 1998).

The value of this way of thinking is that it expands the idea of music to include many other aspects of participation around the music. In music therapy sessions I have encountered people (clients) who do not wish to play or sing, or who have unconventional ways of taking part in the musical experience. Many people import values which limit the ways in which they can recognise the experience as valid. It is important to find ways of valuing their participation in terms of the discourse about the music. Traditional classical music practices can set up a social process of exclusion, and in, I believe that the emphasis in music therapy should be on inclusion. In the analysis of the inquiry presented in this thesis, I name one analytic category 'what is music?' This question was asked in

various forms by participants, for example ‘what sound do I consider to be noise rather than music?’ and ‘is this music?’ when someone was playing with beaters on a trolley.

Ansdell introduces a different model for making sense of musical interpretations: semiology, the study of signs. The basic principle of musical semiology, according to the theories of Nattiez, is that the person receiving (or hearing) the music may not necessarily understand any of the intended meaning that the producer of the music intended. Therefore the communication system within music is essentially *ambiguous*. (Ansdell 1997: 42; Nattiez 1990) This differs from AMT, where it is suggested that in musical transference, the therapist is able literally to receive the feelings of the client. Although it is not within the scope of the thesis to explore in detail how this theory of musical communication sits with theories of AMT and mother-infant interaction, semiology does seem a very different way of thinking about the musical communication of feelings. When considering how meaning is made from the music discussed and described in the data chapters, it is clear that interpretation of the meaning of music is going to be problematic if any of these theoretical frames are used.

2.14 Community Music Therapy

Although a relatively new body of literature, writing concerning community music therapy is fast gaining a practice foothold in Britain. The concept was originally developed by Stige (2002), building on the work of Ruud (1987/1990), who emphasised the idea of music therapist as social being, and also urged that the cultural musical language of the client must be taken as the starting point in any musical engagement.

Community music therapy is the use of music therapy to work with social systems, rather than confining practice to individual clients and small groups. Effective working carries various implications: a cultural awareness of the context, a commitment to social change and flexibility in practice regarding boundaries. Ansdell (2002) examines the context in Britain where the roles of music therapist and community musician are made distinct. He identifies a 'consensus' model of music therapy, for the sake of argument, which borrows heavily on psychological theory. The community music therapist focuses on music for the central theoretical basis to his work, may be critical of professional roles and holds moral obligations to the client (which may be an institution) higher than professional obligations. Proctor (2004) develops this further by arguing that a therapist is also a political being, and that this cannot be separated from his practice.

Both Stige and Ansdell stress the role of ethics as a guiding principle. However, there are some difficulties if morality is at the centre of any theoretical view. The success of the work is reliant on the therapist's view of what is moral, there is both the strength and danger of quite discrepant practice. Psychological models may have their limitations, but at least they have been developed over a number of years and in settings where their accountability has been under scrutiny. Although I agree that it is imperative that current conventional practices are subjected to critical scrutiny, the challenge is on for the community music therapists to find sound theoretical bases for their approaches, and establish critically reflexive practices of their own.

Some psychological theory relates directly to the study of large community groups, institutional dynamics and society as a whole. These are models that have influenced music therapy very little, but may in fact offer something to the

community music therapist. In a different vein, Maratos (2004) uses Kleinian theories such as 'splitting' to understand some of the emotional processes occurring during her work in a psychiatric hospital. Criticised by colleagues for straying beyond conventional boundaries, she nevertheless remained true to her psychoanalytic theoretical orientation, using it to some advantage.

The contribution of thinking about community music therapy to this inquiry is clear. It offers a much wider range of radical practice than I was prepared to attempt within this project. However, it lends support to the various ideas of critiquing professional music therapy practice, of working with the institution rather than just the client, of focusing on social change and of placing ethics in a central position.

2.15 Group music therapy

Group music therapy in practice

There is so little research on group work in the music therapy literature that I have included a review of some of the research in other arts therapies that proved useful for developing my research method (Appendix 1). The work of Katrina Skewes is a welcome exception (Skewes 2002). In a revealing review of practice in group music therapy improvisations, she observed that the music therapy literature 'barely addresses the musical material created in group improvisations'. She did, however, discover, through interviews with music therapists in America and Britain, that there was plenty of expertise available (Skewes and Wigram 2002: 52). She identified the difference in philosophical stance I have already discussed between practitioners of CMT, and those who favoured an interpretative or analytic stance. However, she found that in terms of the nature of

the improvisations themselves, the basic qualities of facilitation and the group outcomes, there was very little difference between the approaches. What did differ significantly was the leadership style of the facilitator and the amount of musical structure the music therapists offered the group (in CMT more musical structure was offered).

As Skewes states, with few exceptions (Woodcock 1987; Bryan 1989), clinical writing about group work in Britain is relatively recent. Only eleven years ago Towse and Flower wrote:

Our only experience [in training] of being in a group was the classes in movement and improvisation. Yet group work seemed so obvious for music therapy. Music, unless produced in extraordinary conditions, such as a soundproofed room or a desert island, always affects another person or other people. The degree to which we are aware of those others will depend both on our characters and on external reality (Towse and Flower 1993:73-74).

In the clinical setting of psychiatric in-patient units in Britain, group work is very much part of the culture and music therapists working in this area have tended to take the lead in thinking about group work practice. The main theoretical models in this area are from psychoanalysis and group analysis. So how has this influence been absorbed into music therapy?

Bion's seminal text on group dynamics, *Experiences in Groups* (1961) has influenced music therapists such as David Stewart (Stewart 1996). On the other hand, group analysis (GA) is a particularly British therapeutic practice developed by Foulkes (1984, 1990) and has a greater influence on music therapy practice. GA is informed by psychoanalytic thinking, but also the process sociology of

Norbert Elias ([1939] 2000, [1969] 1983, 1991). Foulkes emphasises that belonging, socialization and support are central to feeling human.

The first and foremost aspect...is that of belonging, of participation...the need for psychotherapy arises when this participation and sharing are disturbed. (Foulkes 1966, reprinted in 1990: 155-156)

Dalal (1998) is concerned that the two theoretical origins of group analysis, Freudian psychoanalytic theory and process sociology of Elias are contradictory. Despite this apparent problem a number of music therapists have adapted group analytic thinking to inform their practice (Woodcock 1987; Plach [USA] 1996; Towse and Flower 1993; Towse 1997; Towse and Roberts 2002; Davies and Greenland 2002; Tyler 2002 and Durham 2002).

Foulkes introduces an image of the group facilitator as *conductor*. The musical metaphor of the group as a collection of musicians resonates quite powerfully with some practitioners. Towse even develops this to think of musical improvisation in a music therapy group in terms of *fugal* form (Towse 1987). However, to me this is not the primary contribution of group analytic practice and theory. Aspects such as dealing with differences or conflict, and understanding the relationship between individual and collective identities seem to be central. Another important notion is that each group member acts as therapist to other members of the group, and to me this implies greater autonomy for the client.

New thinking in group analysis – adopting complexity theory

However, some new thinking in group analytic theory which shifts the focus onto relational behaviour seems to offer possibilities of talking about non-verbal interaction, which I have found helpful. Instead of dealing with Foulkes'

paradoxical strands of thought, Ralph Stacey advocates a process perspective: a theory of human interaction, which he calls a complex responsive process of relating (Stacey 2003).

Rejecting psychoanalytic metaphors such as the 'internal' and 'external' worlds of individuals, Stacey draws analogies instead from three types of *complexity* theory: chaos theory, dissipative structures and complex adaptive systems. These scientific and mathematical theories consist of rules of interaction between individual entities within a system, rather than any rules of the system as a whole. In these theories, the systems take on a 'life of their own'. For example, in studies of systems as diverse as the brain, weather systems and bacterial colonies, processes of spontaneous self-organisation emerge from disorder *without the need for a blueprint*. Stacey finds that analogies can be directly drawn between these patterns and human patterns of interaction, fitting well with the theories of Elias.

Stacey argues that it is much more important in groups to focus on changing patterns of interaction which have been set, rather than thinking about the 'group-as-a-whole'. Thinking of the group-as-a-whole is the tradition now developed in group analysis and systemic practice. A process perspective does not involve full-scale rejection of psychodynamic notions however, because the idea of early childhood patterns, which influence the psyche so much, can also fit into the idea of emergent patterns of interaction.

Although Stacey's analogies are very new, and there has been little time for them to be exposed to critique or put into practice, I am drawn to this way of thinking. I have found that the process of making sense of the actions of the participants in the inquiry lends itself to thinking about patterns of interaction.

Within a type of participatory inquiry where participants are involved at all stages of the research, I think that a process perspective may offer an accessible theoretical base.

A process perspective may also help to keep in the frame important aspects from both behaviourism and psychodynamic thinking. Stacey's process perspective includes looking at patterns of behavioural change, on the understanding that the behaviour is *interactive*. It further allows for understanding the way in which recent events affect how people relate to each other, rather than focusing on early infant interaction patterns.

Afterthought: the large group and beyond

Group analytic thinking has turned to look at the practice of larger groups, such as the *median* group (Dalal 1998), which typically involves about thirty people. Unlike group analysis, the larger group has been neglected in music therapy practice in Britain although this group size is more likely to be embraced by community musicians. As Stige and Ansdell are in the process of developing the concept of the community music therapy (Stige 2002, Ansdell 2002) it may be that the music therapist begins to turn to the idea of larger groups in practice. Certainly orchestral musicians are used to working in teams of over eighty musicians at a time.

2.15 Summary

What began as a research review developed into a review and discussion of theory, practice and research in music therapy. One notable feature has been the reliance I have needed to place on writing about music therapy practice, and much of this has had more relevance than some research examples. This is

consistent with current thinking in critically reflexive action research, where engagement with the literature is seen as an unfolding process, rather than a predetermined process which may prejudice the research direction before it is begun.

I have found that much of the focus needed to be on situating this particular piece of research within a context of music therapy research, practice and the profession. This is because there is almost no precedent in the music therapy research literature of the use of action research. However, the work of music therapists using new paradigm thinking, and the positive outcomes of the action research project in Norway have given me greater confidence to embark on this current project.

I have also found that some new influences accommodated within music therapy, such as community music therapy, new paradigm thinking and the new musicology have offered support for my move towards participatory research. My concern about the way that people with learning difficulties are viewed, and sometimes treated, in behavioural and outcome research have further strengthened my resolve to try a different and more respectful way of involving them.

If I were to repeat my journey through the literature, I would not choose to start with the combination of music therapy and learning difficulties. Rather, I would begin by exploring music therapy approaches from the point of view of their social context. I would not have chosen to explore some of the theories in so much detail, but rather focus on those parts of the literature that were the most useful. However, I could not have avoided the need to place the research within a detailed contextual picture.

The review has shown that there is a largely unresolved debate about 'how music means' (Ansdell 1997). This has convinced me not to pursue a route which involves detailed musical analysis of data, but rather to explore the musical behaviour and thinking of all participants. However, there will still be room in this inquiry to tackle some of the concerns about the meaning and interpretation of communications with non-verbal people in music therapy.

Although this chapter has concentrated on early interaction theories, I have chosen not to explore the developmental psychology of music, or research relating to physiological response to music. As the focus of the work will be on how meaning is constructed in music therapy, there is less need for structured biological or psychological theory. I am not so interested in determining whether music therapy helps participants move to a different developmental level, but rather what sense they make of it, and how other participants also learn from this.

CHAPTER THREE

The context of community care for people with learning difficulties

In this chapter I explain the national and local context of social change for the institutionalised person with a learning difficulty, and then explore a range of attitudes towards disability, empowerment and difference which I have found helpful to consider during the course of the inquiry. This leads to an investigation of the relatively new phenomenon of participatory and emancipatory research involving people with learning difficulties. The chapter ends with an exploration of the impact of community integration, challenges for carers, and perspectives on user involvement and challenging behaviour. During the course of the chapter reflective paragraphs are interspersed with this material, in italic font.

3.1 Historical context

Prelude

The five participants with learning difficulties in the music therapy inquiry had only lived in a community home for five months when the inquiry began. They shared a history of institutional living in long-stay hospitals, and four of them had lived there since childhood. Their move into the community represented an enormous adjustment in lifestyle.

Origins of the move to community care

In the 1970s public attention increasingly focused on the situation of adults living in large institutions for the mentally handicapped. This was influenced by the

publication of a number of critical accounts of life within the institutions. For example, in 1980 Ryan and Thomas wrote *The Politics of Mental Handicap*. The book criticised the attitudes of carers within long-stay institutions and included extracts of a diary written by Thomas when he was employed within one such institution. He revealed shocking attitudes as well as low staff morale:

Kath [staff member] looks aghast that I have made the staff tea in one of the teapots used by the patients. She was nearly sick at the thought that tea would pass her lips that had even a remote connection with the patients (Ryan and Thomas 1980: 62).

Ryan identified a number of dehumanising factors such as barriers towards access to the outside world, a distorted sense of what is 'normal' and a deficit-led view of people with mental handicap. She argued for the right of mentally handicapped people to live differently and to question consensus definitions of normality.

Legislation

Adverse media coverage and other critical accounts concerning the dehumanising effects of institutionalised living led to government reform through the Community Care Act (1981). In 1980 hospital residents began to be moved out into the community. By 2002 most of the long-stay hospitals had closed.

In 1990 the NHS and Community Care Act ³ was passed. This was aimed at various vulnerable adult populations, including those with learning difficulties,

³ This Act brought together several pieces of legislation, including the Mental Health Act (1983) and the Disabled Person's Act (1986). It was influenced by the Children's Act (1989) where the concept of 'children in need' was adapted and applied to cover other vulnerable groups including people with learning difficulties.

mental health needs and those who were elderly. Local authorities were given the responsibility for community care but were enabled to purchase care from the private sector. The Act insisted on a comprehensive assessment of needs for vulnerable adults and made a distinction between multiple needs and complex special needs⁴. One theme of the Act was 'service user involvement'. This allowed people with learning difficulties to be involved in determining the services they should receive, although no involvement in the *assessment* of their needs.

The launch of the government White Paper *Valuing People* (2001) was the first White Paper in thirty years to focus specifically on the needs of people with learning difficulties. The four main principles guiding the document were civil rights, independence, choice and inclusion. *Valuing People* proposed that people with learning difficulties should have access to a range of housing and support opportunities, including home-ownership. It aimed to provide high standards of care by developing person-centred planning. This emphasised a shift towards co-operation between professionals and people with learning difficulties at every level of service delivery, including involving service users in training and development activities for staff. Learning Disability Partnership Boards were set up in each region to enable the implementation of these recommendations, for example by writing local housing strategies. A Learning Disability Development Fund allocated funds to help move any residents still remaining in long-stay hospitals.

⁴ Complex needs are those which have an impact on other needs, and are not necessarily dealt with by involving a large number of professionals. This is relevant to the resident participants in the inquiry as they each had identified mental health needs which had an effect on their learning difficulties.

The White Paper gave little detail about how people with profound or complex needs might be involved in communicating their experiences, but emphasised their right to a range of services with 'adequate and appropriate facilitation'. *Deciding Together* provided advice for organisations on how to involve people with learning difficulties in aspects of their care and living situations (IAHSP 2001). It contained examples of good practice using different communication approaches such as the use of pictures and signing. It emphasised the importance of involving committed staff leaders in these approaches and the need for further staff training.

Local context

In 1993 a specialist National Health Service Trust for people with learning difficulties was established for the counties of Bristol, North Somerset and South Gloucestershire (part of the county of Avon at the time). The Phoenix NHS Trust was given a lifespan of seven years and its main function was to support people with learning difficulties and their carers to move towards full hospital closure by 2000. The Phoenix Trust covered an area which included five hospitals, housing people who had come from all over south-west England. The trust offered a wide range of healthcare, employing music, art and drama therapists to help work towards community integration. I worked in the music therapy department and was involved in running groups to support people before and after they moved.

The Phoenix Trust set up a number of community care trusts with responsibility for both residential and daycare services. One of these was the Brandon Trust, which hosted the music therapy inquiry and employed all the residential and daycare staff who took part. The community home residents who took part in the inquiry happened to have been the final residents to be

resettled from the last hospital to close, which implies that they may have been the most difficult people to place in a community setting. They would have experienced the departure of many other residents, and they had themselves been moved from one hospital to another during the closure years. It seemed that because of funding issues small group homes in the community were relatively rare. When I approached the Brandon Trust as a potential collaborative partner for this inquiry, they identified only one group home which had five because of the high staffing levels needed for each resident⁵. These residents were the group which participated in the inquiry.

The music therapy inquiry took place in the same year as *Valuing People*. Managers of the Brandon Trust were aware of the opportunities and demands of the White Paper and recognised that the inquiry might help inform the organisation by investigating the opinions of residents with challenging behaviour.

3.2 An overview of changing attitudes towards people with learning difficulties

In this part of the chapter I explore a number of concepts which have been explored in relation to people with learning difficulties: normalisation, disability, empowerment and difference or 'othering'.

Normalization

The guiding principles which led to the move into the community were the concepts of *normalisation* and later *social role valorisation* (Wolfensberger 1972; 1980; 1993). Although the concepts originated in Denmark, Wolfensberger adapted them for use in America, subsequently influencing thinking in Britain.

⁵ Each resident needed two staff members to support him on every encounter 'in the community'.

Wolfensberger thought that a person becomes devalued through negatively valued differences which are culturally defined, and that it is partly through improving the image of people with learning difficulties that normalization can take place. Candappa and Burgess (1989) found that staff members in hospitals for people with learning difficulties did not always take up the principles of normalization. They report similar attitudes to sharing food and cutlery as Kath (p67), for example. Ryan found that unrealisable goals of normalization and behaviour modification created:

vacillation between hope and resignation, at both a social and personal level amongst nurses (1987: 2nd edition).

Although Ryan was reporting attitudes within hospitals, we discovered during the community home inquiry that some of the language used by staff participants implied a similar oscillation between hope and resignation. This is significant because many of the staff had not worked in a hospital and were new to working with people with learning difficulties, so it seems unlikely that these were attitudes learned from hospital culture.

Disability

Challenge to the principle of normalization comes from proponents of the social model of disability who hold that the concept of disability is socially constructed. Michael Oliver, a pioneer of the model, writes:

All disabled people experience disability as social restriction (Oliver 1990: xiv).

Drawing parallels with Foucault's analysis in *Madness and Civilisation* of how madness became a uniform category of pathology (Foucault 1965), Oliver argues

that disabled people have become excluded from society by being isolated within a medical domain, which fosters dependence. Furthermore, Oliver highlights an attitude he terms 'the personal tragedy theory' of disability. In British society, Oliver says, disabled people are seen as victims and this in turn reinforces a dependent relationship with professionals. Developing this line of argument, Ken Davis directly attacks the notion of the caring professions:

Those of us who are familiar with some of the history of the disabled people's movement will recognise that today's 'disability professionals' are on a career path, which has been carefully and painstakingly carved out by generations of their predecessors. (Ken Davis 1996:198)

Oliver cited Manion and Bersani (1987) who examined the concept of 'Mental Retardation' as a cultural construction; he also refers to Brechin and Swain who wrote that the professional is 'enshrined' in a 'world of exclusive and privileged knowledge', encouraging the client/therapist relationship to become one of interdependence (Brechin and Swain 1988: 218). In more contemporary writing, Anne Chappell believed that the social model of disability was more relevant to people with learning difficulties than the medical model of disability as it focused on notions of *access* and *barriers* rather than *impairment*. She criticised the prime motivating ideas of normalization for ignoring the social construction of both *normality* and *disability*. She also detected a tendency in Oliver's writing to stray towards notions of impairment in the context of mental disability, suggesting that within the disability movement there may be a divide between people with physical disabilities and mental disabilities (Chappell 2000; Chappell and Lawthron 2001).

A psychological dimension of disability (although they prefer the term *handicap*) is introduced by the work of Valerie Sinason and Jon Stokes (Sinason 1992; Stokes and Sinason 1992: 46-59) who developed the notion of *secondary handicap* for the person with a disability. Whereas *primary handicap* is the result of organic brain damage, *secondary handicap* is not only a social construction but was emotionally based. Secondary handicap exists when disabled people are impaired by the reactions of others and their own reactions to their perceived handicap. Even if she does not understand the meaning of the words uttered to her, the person with a learning difficulty understands the non-verbal and therefore emotive aspects of the words.

Sinason's powerful case studies showed how she addressed the secondary handicap by using words with people who cannot speak. For some people the level of 'mental handicap' lifted when they addressed the traumatic origin of their 'stupidity' and in some cases she discovered that a person had developed a learning difficulty purely on the basis of childhood trauma. Sinason argued that notions of grief, disgust and self-disgust were central to a negative construction of an individual's disability. She also acknowledged that music therapists had been addressing secondary handicap in their work for a number of years.

Reflection

The social model of disability has had little influence within the music therapy profession in Britain. However, in Norway, Even Ruud has emphasised a critical social perspective:

Music is communication and interaction, music therapists claim. In so doing, they provide a concept of music that argues in favour of a

certain therapeutic use of music (Ruud 1998: 81).

I have always believed that forming relationships with people in music has enabled them to find a way of developing their potential to relate to others and themselves. Therefore the notion that I might have become a 'disability professional' for my own employment ends, and as a means of disempowering others is somewhat shocking. Perhaps this is an important critique to apply. There have been times when it has been important to get a job and my intentions have been less than altruistic. As we explored in chapter two, the justification for certain types of research which might seem counter-intuitive to music therapy process has rested on how they will help the profession survive, rather than whether it is really needed by the people they serve. I would, however, argue that there are many people who need access to an alternative and dynamic form of communication and will benefit as the music therapy profession grows and develops. As there is little research centred on user views of music therapy, music therapist perspectives are likely to be prominent.

One reason for the lack of attention to the social model might be that much of music therapy work takes place within medical and educational settings; here, too, the frame of thinking is not predominantly social.

Sinason shows me that the way in which we construct notions of ourselves, through a process involving others, is an important focus for inquiry. I am reminded of Christy Brown, born with cerebral palsy, who wrote that although he knew he could not do all the things his brothers and sisters could, he did not experience himself as being 'different' until he saw pity in the eyes of a girl he loved. He wrote 'I almost hated her for

that' (Brown 1954:73). It is the way that this self-construction happens that seems to be the basis for disagreements. Music therapists do try to work with the notion of secondary handicap, rather than with an emphasis on cure. The social model implies that I have a greater responsibility than this: I need to be continually critically reflexive in my attitudes to and conceptions of disability, and bring this into my dialogues with others.

Empowerment

Just as notions of disability are subject to cultural construction, notions of empowerment might equally well be socially constructed. For example, in a project working with disabled people in Afghanistan, Peter Coleridge wrote:

the word 'empowerment' was rejected by all the participants on the grounds that power in Afghanistan means power over somebody else. It is not regarded as win-win, only win-lose (Coleridge 1999: 162).

Servian explored a number of different meanings of empowerment. His examples included challenging the traditional roles of health professionals in order to change the value bases within organisations (Servian 1996: 5-6). Servian's working definition was that empowerment occurred when an individual had enough power to meet his or her needs. In contrast, Gustavsonn found that people with learning difficulties living in Sweden recognised professional support as their *right* rather than their need. This perception was important for their positive sense of self-image (Gustavsonn 1998).

Reflection

I find this a significant distinction. The concept of need seems more likely

to be linked with a view of disabled people characterised by Oliver's personal tragedy theory of disability and dependency.

Difference

Can thinking about difference in other contexts provide any helpful insights? From a feminist perspective, Wendell thought that just as *gender* is socially constructed, as opposed to *sex*, so *disability* is socially constructed as opposed to *impairment*. She asked what it would mean for people who attempt to *cure* disabilities if we try to value difference (Wendell 1996).

Farhad Dalal, who wrote about racism, said that to name a difference was to create an identity. He argued that some groups have the power to name other less powerful groups and racism is any use of the notion of race as an organising principle. He saw the process in psychoanalytic terms: hatred in a person becomes projected into another. As the word 'black' or 'white' moves from being an adjective to a noun, so the whole psyche becomes racialized (Dalal 1997a, 1997b).

Another thinker who uses psychoanalytic concepts is Paul Hoggett. He wrote about Freud's notion of 'the narcissism of minor difference'; that is, those who are closest to each other have the most difficulties. (Hoggett 2001).

In a different vein, Redworth and Redworth discussed notions of integration within the community, and argued that the concept of *pluralism* might be more helpful to disabled people than the notions of assimilation or integration. When difference is tolerated, disabled people retain their identities. Differences can then be valued through an ethos of equal opportunities (Redworth and Redworth 1997).

Reflection

The fundamental learning for me here is that instead of trying to change the people who are different, differences are to be accepted and other people's perceptions changed. Donna Williams, a woman with autism, argues that 'repetitive behaviours' and other mannerisms associated with autism are often essential to allow the person with autism to manage being in the world. She argues against the desire to change these behaviours just because they are perceived as being not normal. Other people need to see that being autistic is simply a different way of being (Williams 1996). Notions of difference are very relevant to our inquiry, and in particular to the way in which different resident participants tolerated or competed against each other (which brings to mind the narcissism of minor difference). The notion of difference between the men became an extremely important area of inquiry.

3.3 Emancipatory Research

Chappell, rightly in my view, identified the limitations in the way in which Oliver and other disabled academics perceived people with learning difficulties.

However, they did make a major change to the research process for people with learning difficulties. In a special edition of *Disability, Handicap and Society*, three advocates of the social model of disability produced a collective definition of emancipatory research. The five main points were:

1. Research should be used as a tool to improve disabled people's lives
2. Disabled people should have more opportunities to become researchers

3. Researchers must adopt a more reflexive stance
4. Democratic organisers of disabled people should fund and commission more research
5. Researchers should be accountable to the democratic organisation of disabled people (Morris *et al* 1992).

This is a clear argument for research to be used for political change. One of the most radical changes proposed above is the idea that disabled people themselves fund and control the production of research. In the world of people with learning difficulties, there is only one democratic organisation, which is run by people with learning difficulties: People First.

The work of the Norah Fry Research Centre in Bristol has been significant in the development of emancipatory models of research with people with learning difficulties, often in collaboration with People First (see Appendix 2, p420). From my review of examples of this type of research, it seems that participants have been primarily people with moderate or mild disabilities. The most recent inquiries have developed increasingly successful methods of inclusion for almost all parts of the research. For example, researchers were able to conduct a literature review in a participatory manner with people with learning difficulties by circulating relevant articles in advance, then meeting with people and their supporters to discuss their attitudes to the literature (Burke *et al* 2003).

Differences between emancipatory and participatory research

In a fully emancipatory design, all the criteria that Morris, Oliver and Zarb identified must be fulfilled. There are many more examples of participatory research designs which partially involve people with learning difficulties. Chappell (2000) questions Zarb's suggestion that participatory research is a

methodological 'staging post' on the way to emancipatory research (Zarb 1992:125), arguing instead that there are irreconcilable differences between the two. Participatory models incorporate:

a more diffuse objective of alliances or partnerships between researchers and people with learning difficulties (Chappell 2000: 40).

The powerful competing agendas of other participants are likely to influence the direction of the research, and participatory projects are more likely to be attractive to funding bodies because of this.

Critiques of emancipatory and participatory paradigms

Participatory and emancipatory paradigms are not without their critics within the learning disability world. Kiernan (1999) was concerned that carers and parents might need to be involved in participatory research because of communication issues amongst the more severely disabled people. If the views of these groups of people were in conflict, whose would be heard as the most valid? Kiernan does not think that people with a milder disability will necessarily represent the view of a severely disabled person better than a non-disabled person, as shown in the research of Downer and Walmsley (1996). His final concern is that researchers playing support roles will bring their own agendas, and that indeed this might be as problematic in new paradigm research as in any more traditional form.

Reflection

One response to this would be to ensure that in inquiring together, we allow differences in views to surface. Clearly different agendas are likely to exist, but this is the whole point of participatory research: by identifying agendas and subjecting them to critically reflexive processes, new solutions might become evident.

I would contest Kiernan's argument that the communication of a person with learning difficulties may need to be interpreted through some form of mediation. The solution is, surely, to change the medium in which the communication takes place, which is exactly what is offered in the extended epistemology of Heron and Reason. If people with learning difficulties cannot put their own views across in ways that are traditionally valued in research, then perhaps it is the limits of the traditional forms of knowledge that need to be changed.

In order to deal with competing agendas from participants and researchers, a refined discipline of critical reflexivity on the part of the initiating researcher, and a development of this within the culture of the inquiry, is essential.

There seem to be no participatory or emancipatory inquiries which explore the experience of having moved from hospital into a community home, or involve people in making changes within their community homes. However, as our inquiry began to identify some of the main issues relating to the inclusion and exclusion of both residents and staff, I found that some of the more traditional research literature was helpful in further understanding the context.

In the following section, I explore some of the literature I have found relevant, and reflect on how this explained issues within the specific context of our community home inquiry.

3.4 Community integration

How well has community integration been achieved?

In a detailed review of research into the community integration of people

with learning difficulties in Britain, most studies were found to show that whilst 'being physically within' a community, many people with learning difficulties were not seen, or did not see themselves, as being a social part of that community. Significantly, people with the most severe disabilities had the fewest opportunities (Myers *et al* 1998).

In a study in which residents in community homes were interviewed, the findings revealed that factors such as dislike for other residents or for a member of staff were significant reasons for people wanting to leave their community homes. More than 50% of the people in this small study wanted to leave (Holland and Meddis 1997).

Reflection

Within the music therapy inquiry some residents expressed strong dislike for other residents. I aim to show that both the music therapy and the inquiry did help participants to negotiate some of the conflicts, and that relationships did improve. However, a more fundamental question is whether people who strongly dislike each other should be expected to live together for years.

A further study found that the attachment-related experiences of adults living in community homes were related to measures of self-esteem and independence, but bore no relation to intelligence (as determined by IQ testing) or, interestingly, independence outside the home (Smith and McCarthy 1996).

Reflection

In our findings during the inquiry, the two people (Steve and Pete) who developed the strongest attachments to the therapist were the two with

highest and lowest IQ respectively. They were also the two people who still had contact with their parents, implying that their parental attachments may have been stronger than for the others. However, they were also younger than the other men, which might be another factor.

3.5 Attitudes from the wider community

The organisational consultants Foster and Roberts remind us that communities were not consulted as to whether they wanted community care before the NHS and Community Care Act of 1990 was passed (Foster and Roberts 1998). At the time, the prime minister, Margaret Thatcher, had declared that 'society' did not exist and a mentality that Foster dubs 'not in my backyard' was flourishing. Using case studies of consultancy managerial supervision she gave to managers of organisations caring for people with learning disabilities, Roberts discusses how different staff groups held different types of feeling within the organisation, such as 'hope' or 'despair'. She suggests that even if some of the ideals of community care are ill-conceived, it breaks a cultural taboo to admit this.

One case study describes a situation which resembles the house in which our inquiry took place, with

five such violent and disabled residents placed under one roof to live an as-if ordinary life.

Roberts suggested that the home manager had been given an unworkable situation. She summarised by saying that workers needed to:

face the fundamental tensions between the ideals that give the work its meaning, and what is required for survival, so that neither is sacrificed. (Foster and Roberts 1998: 57).

Reflection

The design of the co-operative inquiry group ensured that different groups of professionals met together regularly so that such potential divisions could be recognised within the inquiry. We looked at roles and responsibilities, and explored how people felt about them. This allowed insights into the situations of others to be made, and this was particularly evident from the third inquiry meeting onwards.

Our inquiry was not so radical as to suggest that the community home represented an unworkable situation. People continued to work in difficult and demanding situations. One of the contributions of the inquiry was to enable people to stay there for longer because of an increased sense of personal value and changed attitudes to the capabilities of the residents.

3.6 Issues for carers

Staffing levels

Alaszewski found that on a ward for profoundly handicapped patients, eighty different nursing staff had worked on the day shifts during a six-month period. These staffing levels indicate the vast number of different relationships the profoundly handicapped person would need to negotiate (Alaszewski 1977).

Reflection

In our inquiry, I found that the number of staff with which the residents came into contact with was about the same number (eighty), although this included agency workers and people on night shifts. For the residents, who had moderate to profound learning difficulties, eighty relationships was a very large number to deal with.

Organisational culture

Consultative work and research by Clements suggested:

A multi-layered hierarchical system, with tight job demarcation, relying heavily upon set working procedures and using aversive control mechanisms with staff is incompatible with an organisational culture that emphasises participation, mutual value, respect and innovation (Clements 1993: 329).

One study researched staff satisfaction, emotions and attitudes in a unit with five men with serious challenging behaviour: a similar arrangement to the one in our inquiry. They found that staff experienced a high level of satisfaction in working with the residents, and gave a high degree of practical support to one another, although their sense of satisfaction with management was low and they felt undervalued (Bell and Espie 2000).

Reflection

Despite interest in creative solutions from some of the management figures in the residential trust, and an optimistic climate for change, our inquiry was based within a nursing culture which was strongly hierarchical. Staff members frequently mentioned whether someone was qualified or unqualified. Most were strongly reliant on the medical model from their training background, and struggled to accommodate newer ways of looking at things, despite a will to do so.

Stress

Of the various studies exploring stress amongst the workforce, two pieces of research provide illuminating findings.

The first, by Lally, studied people who were working in challenging behaviour units, and found that if they were stressed by other aspects of the job, their ability to cope with incidents of challenging behaviour was compromised, and they are more likely to move into 'fight/flight' reactions (Bion 1961: 63). Residents were either subjected to aggression or were ignored because members of staff were tired and stretched to the limit. Lally warned that staff members often risked 'burn-out', and for the person with learning difficulties, that might mean yet another loss of an important carer relationship (Lally 1993).

Holt found that work stress was related to role ambiguity and role conflict, exclusion from decision-making, poor use of skills and demands that workers could not meet (Holt 1995).

Reflection

In our inquiry there was some evidence (gained mainly from dialogues with individuals) that some workers at the community home were confused about their roles, and were expected to meet unreachable goals. The staff involved in the co-operative inquiry at least had the possibility of defining their roles within the research, making the main decisions and developing reflective and, in some cases, observational skills.

3.7 Obtaining the views of service users

The communication strategies in Myers' review of community integration studies showed that there were three main ways in which most of the studies attended to the difficulty of obtaining the views of people with learning difficulties. The first was to limit the studies to articulate people, the second was to adopt participant

observation and the third was to interview proxies rather than the person with the learning difficulty (a practice that was adopted by many studies in a surprisingly uncritical way). Myers concluded that a move towards a participatory research paradigm as reviewed by Simons *et al* (1989) would be helpful.

Redworth (1997) identified a number of barriers to involving people with learning difficulties in their own community care planning. These included the fear of being tokenistic, the desire to protect people from risk, having low expectations of people with learning difficulties and their disempowerment. He gave a number of practical strategies and principles to help the formation of planning groups, including having the meetings at a time and place convenient to the service users, even if it were outside the working hours of the professionals.

Reflection

The introduction of a participatory research paradigm and situating the inquiry within the home, so that residents could be involved if and when it suited them, does relate to some of the findings and recommendations referred to above. Although I took part in some participant observation during the inquiry, the views of the residents were directly sought and a different medium, music, was available for certain types of non-verbal communication. In the early stages there were both high and low expectations of the residents from different participants, but all those involved had higher expectations of the residents by the end of the inquiry.

3.8 Perspectives on Challenging Behaviour

What is challenging behaviour?

This term covers a range of meaning from self-injury and physical violence to continually running away. Self-injury takes up much of the literature, and I suspect that this is because it is the most distressing type of behaviour to encounter. One team of researchers found that the prevalence of self-injurious behaviour was higher for those in hospital than in the community at large (Murphy *et al* 1993). Large numbers of people were on psychotropic medicine although there was little research to support its use. Many people wore restraining devices such as arm splints, which reduced their quality of life and were often not properly applied. The researchers concluded that resources would be better spent on preventing childhood self-injury, because the outcome for older people looked so bleak. In contrast Hare and Leadbeater argued:

All investigations of self-injurious behaviour, including those in which autism is implicated, should be undertaken from a wider ecological perspective. (Hare and Leadbeater 1998: 65).

Abberley asks why it is that labels used about people with learning difficulties tend to be evaluative and imply deficiency, in contrast to other socially constructed labels such as 'black' (Abberley 1992). The description of 'people with behaviour which challenges the service' is an attempt to address this tradition, as the onus for change is shifted to the service rather than the person with the behaviour. (See Appendix 2 for information on the provision of services for people with challenging behaviour, and different ways of thinking about challenging behaviour).

Perspectives of people with challenging behaviour

There is very little literature exploring the views of those who challenge, or the possibilities of self-advocacy for such people. Is there a fear that the views expressed will be so objectionable that they are impossible to hear? Preston (1998) described a self-advocacy group for adults with challenging behaviour who had mild/moderate learning difficulties. He introduced ground rules so that participants could 'learn how to be in a group'. Once these were established the group moved on to identify and explore what members wanted to change. Preston wrote:

Initially the group members fought for attention, argued, and had little respect for each other. The behaviours ranged from physical fights to shouting, swearing, verbal threats, and unco-operative behaviours i.e. not sitting with the group (1998: 110).

However, the participants were able to move to a point where they were able to identify some changes that they could make to their living conditions.

Reflection

What does participation mean?. Sitting out of the group, an unco-operative behaviour for Preston, is acceptable in a music therapy group, although physical and emotional threats are not. One contribution made by the music therapy inquiry was the way in which residents were able to inquire into the nature of participation, by being free to come in and out of the room as they chose. This prevented some of the conflict of the nature Preston described, and contributed to a development of group identity without it being forced.

Challenging behaviour and the community home inquiry

Challenging behaviour as a concept turned out to be relatively unimportant in our inquiry. However, in chapter nine, we will see that Pete's constant throwing of instruments did threaten to hurt others, and this was often viewed as a challenging behaviour.

3.9 Summary

There is clearly a large gap in the literature dealing with how people with severe and complex needs are able to be involved in research, and in decision-making about many other aspects of their lives. Despite the launch and development of *Valuing People*, the literature presented and discussed in this chapter indicates that there is much that still needs to change for adults with learning difficulties in Britain, and particularly for those with severe disabilities. The attitudes we all have to the people we see as different seem to be central, and it is important that inquiry should be able to help participants address and change their perceptions.

The introduction of the social model of disability to my thinking about music therapy is an important and radical step. I have also found the examples of participatory methodology with people with learning difficulties practically helpful and inspiring. It seems that there is plenty of interest in participatory approaches, but because of the methodological and practical problems involved, more care is needed with the design and implementation of such projects. The lack of studies involving people with severe disabilities or challenging behaviour highlights the radical nature of this inquiry, and its potential contribution in the field of participatory research.

Reviewing some of the more conventional research literature with regard to

the difficulties experienced within community homes as been useful as a context to understanding some of the pressure and agendas of both residents and staff participants in the inquiry. It may also add a dimension to the impact of the findings, and help to make meaning of some inquiry events. However, the focus on challenging behaviour, although a moving and interesting part of the study, may not be particularly useful in the inquiry, as there is likely to be little focus on the view that participants have challenging behaviour or not.

CHAPTER FOUR

Participatory action research traditions and the inquiry design

4.1 Introduction

In chapter one I introduced the notion of New Paradigm research, explaining that I was drawn to this approach by the recognition that I shared some of its values. New Paradigm research only acquired this title from the 1980s, having developed from the rich tradition of action research. In this chapter I will briefly review some of that tradition and identify the salient features of any inquiry which comes under the umbrella of action research. New Paradigm research (NPR) and Participatory Action Research (PAR) have been the most influential types of action research in the design of the inquiry I am presenting here, so these are explored in more detail.

After reviewing the thinking which supports the use of action research within music therapy research, I examine some of the threats to this type of inquiry from within the profession. Finally I explain the design of the community home inquiry. As in the earlier chapters, reviews and discussions are interspersed with reflection.

4.2 A brief history of action research

Action is human only when it is not merely an occupation but also a preoccupation; that is, when it is not dichotomised from reflection (Freire 1970: 35).

Origins

There are a number of detailed histories of action research, and I have relied mainly upon the detailed account of Hart and Bond (1995) because they write from the perspective of health and social care.

Kurt Lewin's contribution to the development of action research was so influential that he is generally regarded as the founder (Hart and Bond 1995:13). However, the term *action research* is attributed to Collier when he was commissioner at the Bureau of Indian Affairs in the USA (Collier 1945). Lewin first called his approach *rational social management*. The roots of this thinking came from social action integrated with experimental social science, with the primary aim of bringing about social change (Lewin 1946).

Lewin identified a series of stages within the process of rational social management as:

a spiral of steps, each of which is composed of a circle of planning, action and fact-finding about the result of that action (Lewin 1946: 205-6).

This was the birth of the action cycle, which in various forms underpins all forms of action research.

Contemporary writers have found Lewin's approach limited: he did not take into account the power relationships between participants, and sought to find generalisable laws using experimental methods (Adelman 1993). Modern approaches, in contrast, have moved on to value democratic group decision-making as a central principle, where the knowledge generated is context-specific rather than universal (Carr and Kemmis 1986). Susman and Evered argued that cyclical action research processes were more appropriate for organisational

problem-solving than those developed from a positivistic paradigm, and that action research could be viewed as a science (Susman and Evered 1978).

Action research traditions in Britain

The predominant early influence in Britain was from the Tavistock Institute of Human Relations, which aimed to develop organisational research based on the principles of psychoanalytic theory and social psychology. These areas had been developed during the second world war, particularly through the group theory of Bion and Foulkes (see chapter two), and this learning was made available to and used by organisations in ways that are now recognised as being very similar to the developments in action research in the USA at the time.

In contrast to the client-consultant model of the Tavistock, independent researchers at the London School of Economics developed a flexible approach in which they were able to take on an advocacy role on behalf of less powerful workers when feeding back findings to management groups (Town 1978). In this way, they were often able to serve the interests of a number of parties involved in the research.

Action research had a central role in the Community Development Projects set up by central government in Britain in the 1960s. These projects aimed to tackle poverty in the most deprived areas in Britain. By 1972, when, for various political reasons, central support was withdrawn from these groups, they continued to function as pressure groups. Their fundamental message was that poverty was a consequence of economic and political inequalities rather than the fault of the individuals in poverty (Hart and Bond 1995: 28). I note that this argument has obvious parallels with the view that disability is socially constructed.

In education, action research was developed in the USA from the 1940s, but was adopted in Britain in the 1970s as a result of increasing interest in curriculum development (Stenhouse 1975; Elliott 1978). For educationalists it meant the opportunity to close the theory-practice divide (Kemmis *et al* 1982) and develop a critically reflexive practice in order to produce theory and learning. Similarly, in nursing the benefit of action research was that it brought about an opportunity to bridge the gap between theory and practice by involving patient and nurse on an equal basis (Webb 1990). It is interesting that although the fields of education and nursing share some common ground with therapy, the therapy professions have not embraced the possibilities of action research in the same way.

From the educational tradition of action research, I find Jean McNiff's writing about the dynamics of change inspiring, particularly in the way she emphasises metamorphosis rather than restructuring:

In dialectics the focus is on change which will *move*, not *oust* or *supplant* another point of view, including one's own (McNiff 1988: 41).

Mc Niff also discusses the notion of generative action research (see figure 4, p 84). She uses a central spiral to indicate the main thrust of the research (which recalls Lewin's original description of a cyclical process) but other spirals are generated at different points in the research (McNiff 1988: 45, figure 39). This model allows for the possibility of parts of the inquiry changing direction, or of researchers coming on board with new questions after an inquiry has started.

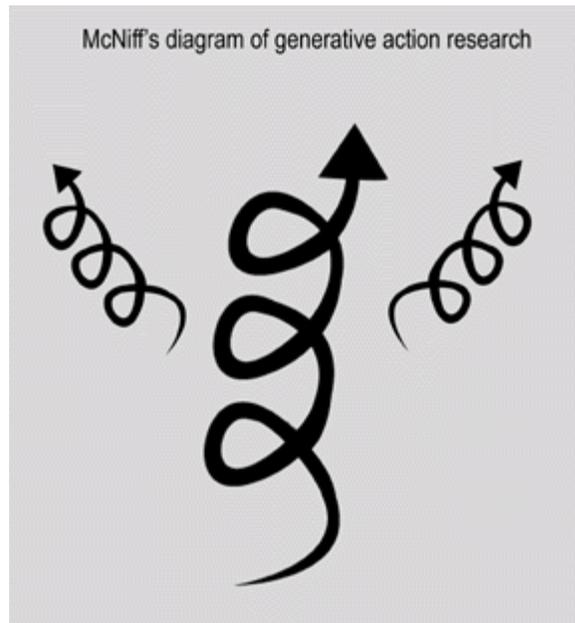


Figure 4

The strength of action research has always been its ability to adapt itself to the specific context and needs of the participants, but the most recent changes are concerned with developments in the flexibility of the methods, so that inquiries can follow the directions which emerge. In parallel with this runs an emphasis on the rigour of reflexive thinking: for example, Heron's work on validity and special inquiry skills (Heron 1988) and Marshall's exploration of personal inquiry disciplines (Marshall 2001) which I will explore later.

A number of different types of action research have evolved since Lewin's time, including emancipatory research, which I discussed in chapter three. It is beyond the scope of the thesis to review all the types here, although I recommend Dash's review of the current debates (Dash 1999). Instead, we will explore participatory action research and new paradigm developments in more detail.

4.3 Participatory Action Research

Participatory action research (PAR) involves members of an organisation in

all stages of the research and was partly influenced by work at the Tavistock Institute (Whyte 1991: 21). The roots of PAR came from a liberationist tradition where the focus was on powerless or vulnerable sections of society, particularly, although not exclusively, within the third world. One aim was to challenge the way in which established and powerful parts of society used and valued knowledge, favouring instead the knowledge and experience of more oppressed people. This was exemplified in the work of Paulo Freire (1970) who named his first chapter in *Pedagogy of the Oppressed*, 'Liberation: not a gift, not a self-achievement, but a mutual process' (Freire 1970: 5).

With the emphasis on mutuality, the initiating researchers must have an authentic commitment to honouring the values of the people with whom they work. Through dialogue the academic knowledge of formally educated people is held in tension with the knowledge of the people in the project, to form a deeper understanding of the situation. During the process knowledge that is useful to the disempowered participants is produced. At the same time the knowledge that the participants already have is directly valued. Dash points out that participatory action research serves as a critique for the forms of action research controlled by the researcher (Dash 1999).

PAR often uses creative arts forms as part of the inquiry process: for example art, photography (Brinton Lykes *et al* 2001), plays and song. PAR introduced an extended epistemology, generally presented as three broad ways of knowing: *thinking*, *feeling* and *acting* (Tandon 1989). In the case of our community home inquiry, the therapeutic knowledge of the music therapist was in dialogue with the tacit knowing of the residents of the home. The sounds made by the men in the project were in dialogue with the sounds of the therapist, and in the

way he listened and adjusted his music, he learned from their very different sound worlds, as they did from his. This process has links with Freire's notion of *conscientization*: a 'process of self-awareness through collective self-inquiry and reflection' which takes place within a more radical agenda. He is describing the process of oppressed peoples generating and sharing knowledge which they can use to increase their power.

As I mentioned in chapter one, New Paradigm approaches further extended their epistemology to include presentational, prepositional, practical and experiential forms of knowing.

An example of participatory action research in music therapy

The only music therapy research project using a PAR approach took place between 1983 and 1986 (Kleive and Stige 1998: Stige 2002: 119-127). The music therapists actively focused on the need for the research to bring about social change for a group of people with learning difficulties in Norway. One participant, Knut, was able to articulate his own research question verbally within a group music therapy session, which (perhaps significantly) took place outside their home. The question: 'May we too play in the brass band?' (Stige 2002: 119), addressed the group's exclusion from community music-making. Knut asked the question after seeing a photograph of the band which happened to be on the wall. I will explore other examples of the use of images to stimulate inquiry in chapter nine.

The results of this research project brought a high yield of practical results in terms of social change. With the emotional, musical and practical support of the music therapists, members of the group became involved in community musical performances and social events which had not been accessible to them before.

Stige contends that social change might be part of the therapist's remit:

The music therapist could try to help clients through changing the world, if only a bit. The changes may be small, and the part of the world where the therapist is working may be very small indeed, but social change could be part of the therapist's agenda (Stige 2002: 128).

Reflection

The success of the Norwegian research project depended on the therapists' ability to hear and value Knut's question, and commitment to questioning social aspects of traditional music therapy practice. It is an important example of how it really is possible to develop ways of empowering people with learning difficulties to become more fully integrated within society. The political and social climate in Norway must also have had a bearing, as the project was funded by the Norwegian government. In a British context, such work is more likely to be carried out by community musicians, a different group of workers from whom music therapists have traditionally kept their distance (Ansdell 2002). Would using participatory action research in music therapy inevitably lead to rethinking and redefining the role of the therapist?

One way forward might be for music therapists to use the new paradigm approach of co-operative inquiry, which is often used for practitioner-based inquiry (Heron 1996, Reason 2001). However there is some opposition to the idea on the grounds that the therapeutic relationship will be threatened by the reframing of the client-therapist relationship. This is discussed more fully in Appendix 3.

4.4 New Paradigm Research

This has developed as part of the participatory action research tradition. One established form of new paradigm research is co-operative inquiry (Heron 1988; Reason 1994; Heron 1996; Reason 2000; Reason 2001) and this was my starting point. All researchers are involved as co-researchers (and therefore co-subjects) and are included in all stages of the research (Reason and Rowan 1981; Reason 1988, Reason and Bradbury 2001).

The practice of co-operative inquiry is characterised by a cycle divided into four phases, and as co-researchers move through the cycle, they engage with four different types of knowing. For example, in the first phase, the co-researchers agree the focus for the inquiry, and plan how the inquiry actions will be carried out. This usually involves an emphasis on propositional knowing (concepts and ideas). The means by which the inquiry focus is reached may well involve presentational knowing (such as story-telling or creating images).

In the second phase the participants engage in the agreed plans of action. They observe and record the process, paying particular attention to subtleties and unexpected happenings, and how their expectations may be challenged. The emphasis here is on practical knowing.

The third phase is where participants become deeply immersed in the experiential aspects of the research and open themselves to reframing their perceptions and moving the action in a different direction. The primary form of knowing at this point is likely to be experiential and is the most difficult to describe, but may take many forms depending on the individual participants.

In the fourth phase, the participants meet together and consider their original questions informed by their experience. This may involve reframing

questions or moving towards a new form of action. This allows a new cycle to begin.

In the community home co-operative inquiry, we met together six times, which enabled six cycles of action and reflection. I describe this process, and the details of the cycling in the narrative of chapter seven.

As the inquiry progressed I became influenced by the work of SOLAR⁶ and in particular the development of critically reflexive action research (Weil 1998). This approach incorporates critical systems thinking and field theory as well as participatory action research traditions and emphasises a discipline of challenge of self and others by being critically creative. Weil writes:

We attend to what is insufficiently understood and possibly silenced, at the margins of our fields of practice and to how context and meaning shape each other (Weil *et al* 2002: 116).

Critically reflexive action research has had more impact on the way I have chosen to extend the inquiry through writing this thesis than it had on the inquiry cycles of 2001, although some of the creative methods we explored in the sixth cycle of the co-operative inquiry came directly from ideas of critically reflexive action research. At times during the inquiry it felt as if we were inquiring on the edge of what was knowable, and we were constantly challenged by the way different voices and parts of us were silenced.

4.5 Special inquiry skills

Heron emphasises the need for special inquiry skills: non-attachment, reframing, emotional competence and bracketing (Heron 1996).

⁶ The Centre for Social and Organisational Learning as Action Research, now based at UWE.

Non-attachment

Heron writes:

wear lightly and without fixation the purpose, strategy and form of your behaviour and motive.

I found it helpful to read that in a project which involved researching Shared Action planning with a group of people with learning difficulties, Brechin found that her own vested interest in promoting Shared Action Planning was difficult to manage, and complicated the research agenda. However, she showed how, by reflecting on her agendas, she was able to let go, and to tolerate often not knowing what was going on during the project (Brechin 1993). As I will describe in chapter five, the music therapist and I, as initiating researchers, spent some time identifying our agendas together as part of our preparation for the project.

Reframing

This is where the participants leave behind fixed theoretical frames to explore alternative constructs. If a participant is able to develop this skill, then she becomes more able to question her imported assumptions and values. This is similar to the idea of double and triple-loop learning as described in Action Science (see Appendix 3).

Heron acknowledges that some unconscious processes come into play when people are together. For example, in the community home inquiry I was concerned that the residents might respond to social pressure in the form of learned helplessness and acquiescence (saying 'yes' to every question) if they did not feel in control of the situation (Sigelman *et al* 1981).

Emotional competence

Heron identifies the need to keep out 'distorted reactions to current events driven by the unprocessed distress of earlier years'. The reference to psychoanalytically-informed theory is obvious and the skill referred to is clearly an ideal, because, even after years of therapy, no-one could claim to be totally free of reactive patterns. I am concerned about the implication that people who have not had an opportunity to explore the impact of their emotional history would not be able to undertake co-operative inquiry. If this were the case, it would exclude rather a large number of people. However, Heron's skills are required of the initiating researchers, and an inquiry of this sort should be able to provide opportunities to challenge other participants who might be in danger of projecting their own fantasies on others.

Reflection

Within the community home inquiry I discovered there were examples of potential staff participants being asked not to participate because of concerns about 'emotional competence'.

Bracketing

This skill involves suspending the classifications and constructs which we impose on our perceiving. This relates closely to reframing, but needs to happen first. Bracketing is further described in Appendix 3.

Reflection

I wrote the following entry in my research diary just before the first inquiry cycle began.

The need for skills like these raises a significant challenge to the inclusion

of people who have a history of institutional living, challenging behaviour, autism and learning difficulties. There are even more basic skills such as being able to listen to other people, being able to concentrate and being open to any kind of change. Is it unfair to expect anyone who has autistic tendencies to be involved in anything that requires a degree of change? Perhaps we need to develop a set of basic inquiry skills that might be developed within this inquiry.

[Research Diary: January 2001]

As a response to this, I include two extra inquiry skills which seem to be particularly important in the context of the community home inquiry.

Choice-making

In a literature review by Stalker and Harris (1998) they state that people with learning difficulties lack opportunities for choice. This situation is not related to ability but rather to the nature of the services provided and to the beliefs and attitudes of staff providing them. They say:

The presence of profound impairment need not prevent the identification of valid preferences and the facilitation of choosing (Stalker and Harris 1998: 73).

The most important approach would be to create many individualised opportunities for choice-making for each person. One suggestion is to develop some reflexivity in this:

It may be difficult for carers to offer someone an experience that they themselves don't like and don't think is in the best interest of the person (Jackson and Jackson 1998: 22).

Small choices might be most important. Phyllida Parsloe reminds us:

An elderly lady may not want to have a say in the way the care home is run or even whether or not she should be there but it may matter very much to her that she can choose when to go to bed, when to have a cup of tea and where to sit (Parsloe 1997:12).

When participants have severe learning difficulties, it seems important to pay attention to any detail relating to choice, but also to incorporate a process of critical subjectivity, so that our own assumptions about what form choices may take are challenged.

Imaginative listening

A very important criterion of validity in any action research project should be the ability to be self-reflexive and imaginative in the way that we hear others. Corbett talked about the importance of imaginative listening when researching with children or adults with disabilities (Corbett 1998).

In a project developing the education of disabled children in Lesotho, a visually impaired team member contributed 'aural observations' to the project, and noticed many aspects of interactive dialogue between participants which others missed (Stubbs 1999: 268).

Listening is arguably the most important skill a music therapist develops. The special listening skills of the music therapist may add an extra dimension to the inquiry. As the research design developed (see below) I began to recognise the importance of the music therapy process itself in the inquiry process. Music itself had become a form of inquiry.

4.6 The research design of the community home inquiry

Combining different action research methodologies

Reason suggested that participatory action research, co-operative inquiry and action inquiry⁷ could work well if they were integrated:

A PAR would be strengthened if the animators met together as a co-operative inquiry group to reflect on their practice; a co-operative inquiry would be helped if the members cultivated the interpenetrating attention advocated by action inquiry (Reason 1994: 335).

As I will describe in chapter seven, the inquiry began initially as a co-operative inquiry. However, the dominant form of communication within this was through words, and this excluded the participants who could not speak. Although we explored the avenue of advocacy (see chapter five), it became increasingly obvious that the main medium of the inquiry was the music within the music therapy sessions.

The music therapy inquiry

In the music therapy sessions, residents were free to decide when or whether to come in. They initiated contact with other participants and engaged in processes which involved listening, sharing, negotiating, expressing feelings, taking action and making personal changes.

Although I had experiential knowledge that this was likely to take place from my personal history as a musician and music therapist, it had not occurred to

⁷ Action inquiry, developed by Torbert (Torbert 1976, 1981, 1991) encourages intense first-person learning through dialogue with another.

me to develop a concept of the music therapy process itself as a form of inquiry. It was going to be very difficult to demonstrate formal inquiry cycles, for instance, and the lack of cohesion in the group meant that many processes occurred in the absence of several participants. However, with music as the medium, facilitated by the music therapist, the residents could be fully involved in creating the agenda. With the emphasis on thinking, feeling and action, there were similarities to a participatory action research design. The residents were in control of the extent of their participation and were involved in a process of inquiry through their relationship with Nick and each other. Anna and I participated by providing practical help in moving instruments and filming. This was my first experience of reframing theoretical assumptions within the inquiry.

The co-operative inquiry

Nick, Anna and I were involved in a co-operative inquiry with other care staff, daycare workers and managers. This allowed us to reflect upon our practice, and our findings brought in from the residents' inquiry helped the others to reflect on their own perceptions and assumptions. The co-operative inquiry enabled the music therapy inquiry to be supported through practical and ethical debate and discussion.

I met members of the co-operative team individually outside the co-operative inquiry to record our dialogues (see calendar, p6). We also met informally in the corridor, or when the minidisk was switched off. Nick and I met seven times during the year. All of these discussions were mutually balanced rather than being 'interviews'. I also met the residents to watch videos, and this sharing, although not very verbal, did allow some reflexivity, demonstrably with Steve, as described in chapter eight.

I was concerned at first that members of the home staff were not more involved in the PAR music inquiry. At first they were welcome, but early on in the inquiry it became clear to other participants that the residents simply would not be able to express themselves freely unless staff did not participate. The spirit of the inquiry was to foster as much openness about boundaries and exclusion as possible, and to encourage each participant to use the inquiry for his or her own first-person exploration.

Therefore the inquiry was divided into two parts, with a therapeutic boundary between the two. Aspects of confidentiality dominated the ethical debates in the co-operative inquiry, which related to the relationship between the two parts of the inquiry. The boundary became a focus of the inquiry, enabling a detailed exploration of the ethical aspects of using video, and an exploration of therapeutic boundaries. This design did enable the residents to have an equal voice in their part of the inquiry, and for the interests of different parties to be served. It did, however, preserve a conventional practice of therapy rather than initiating an ecological practice where all participants were involved in the music-making.

4.7 Aspects of first, second and third-person inquiry

All participatory approaches to action research should demonstrate first, second and third-person dimensions of inquiry (Torbert 1998). These are described in more detail in Appendix 3, p430. The first-person dimension involves self-reflexive processes within the inquiry, second-person inquiry involves dialogue between at least two participants which is what occurs in co-operative inquiry, and third-person inquiry involves the creation of reflexive inquiry within a wider community.

Figure 5 is a diagram illustrating these three dimensions of inquiry within the community home project.

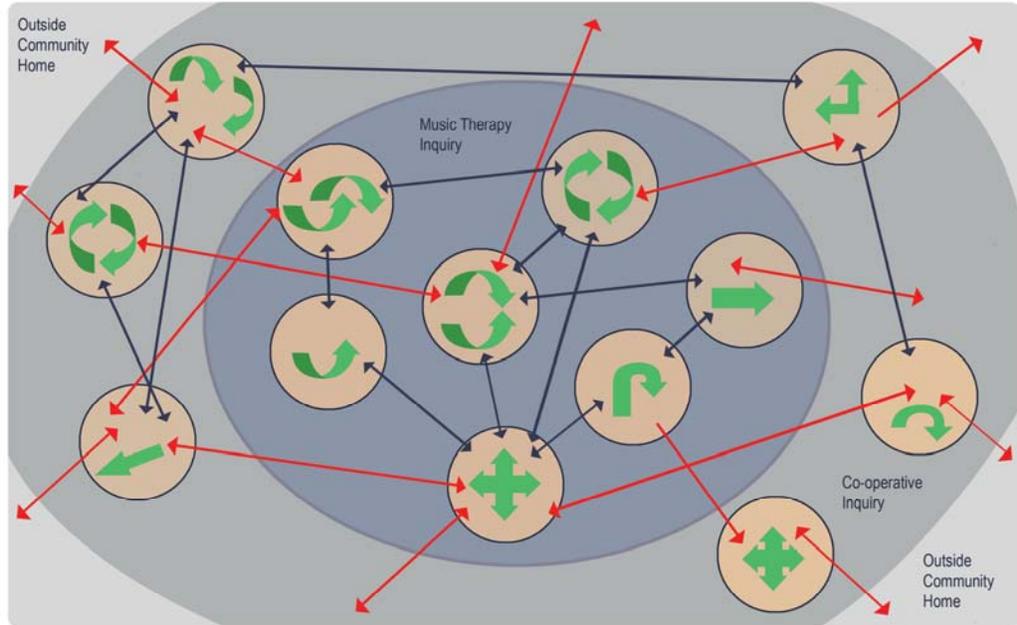


Figure 5 First, second and third person dimensions in the inquiry

In this diagram, the circles represent participants within both parts of the inquiry. The green arrows represent the first-person aspects of the inquiry, and because of the individual nature of first-person inquiry, the arrows are all different, representing different levels and types of critical reflexivity. The black arrows indicate the second-person dimension and are confined to dialogue within each part of the inquiry. The red arrows indicate aspects of third-person inquiry, where participants engage with a wider community. When drafting this diagram, it seemed important to indicate that when participants within the *music therapy* inquiry opened up questions to participants in the *co-operative* inquiry, this was already a form of third-person inquiry, as it expanded the scope of the music

therapy inquiry.

4.8 Aspects of validity

Schein makes a good point: if the initiating researcher in action research involves the 'client' to improve the quality of the *helping process* rather than the quality of the data, this will automatically have an impact on the quality, depth and validity of the data. By contrast, participant ethnographers will work to gain the trust of others involved in the project, but they may conceal the purpose of their inquiry and the way the data will be analysed (Schein 2001). It seems to me that he is saying that the *transparency of power relations* is the key to a developing validity. As inquirers move through the cycles, there could be a process of refinement because participants are able to challenge one another's assumptions as equals, even though in the world outside the inquiry the participants will not be of equal status to one another.

Heron introduces a number of procedures to ensure validity (Heron 1996). These include research cycling, the balance of reflection and action, reflection being balanced between presentational and propositional forms, challenging uncritical subjectivity (by, for example, the use of a 'devil's advocate' technique) and managing unaware projections. Another test of validity is the divergence and convergence of agreement amongst participants. For example extreme divergence of agreement would mean that participants could find no common ground, and extreme convergence would suggest the possibility of collusion. Validity is compromised if the design and implementation of the research is too rigid, and does not allow processes to come to a natural end.

Authentic collaboration (demonstrating how genuine the participation is)

was both the most necessary criterion and the most difficult one to achieve within the community home inquiry, because of the risk of coercing residents to take part. In chapter seven there are several examples of how we, as co-operative inquiry participants, were in danger of trying to research *about* rather than *with* the residents. However, I believe that by focusing on freedom of choice in relation to attendance of the music therapy sessions, we improved the level of authentic collaboration.

4.9 Summary

Action research methodologies have been a rarity in music therapy research. Although a few examples exist, a number of assumptions about the nature of clinical work make some of the methodologies difficult to implement. However, from this brief exploration of some of the types of action research, there are a number of qualities and advantages to this way of working which it might be healthy for music therapy to adopt. With careful attention to boundaries, and openness to re-examining our assumptions and theoretical frames, co-operative inquiry creates an opportunity for therapists to inquire alongside other professionals and clients.

Participatory action research offers vulnerable clients an opportunity to be involved in saying what is important for them in the therapeutic process. By making transparent the power relations which exist between different parties involved in the research, there may be opportunities to change therapeutic practice to suit clients better. Each participant may learn various skills which, although they relate to inquiry, can be applied to other settings and relationships. The repeated cycles allow us, as participants, to develop what we have learned,

refine our thinking, and return again and again to problems which are difficult to solve, attempting new framings. Finally, valuing ways of knowing through different media automatically enhances the approach of music therapy, which seeks to aid self-development and improved health through the activities of musicking.

CHAPTER FIVE

Ethical thinking within the inquiry

5.1 Starting a participatory inquiry

McArdle highlights the importance of telling the tale of the establishment of an action inquiry, as the thinking and decisions made in the very early stages determine the shape of the inquiry which follows (McArdle 2002). I found that it was possible to begin thinking about the research questions and design with potential participants. However, issues of power immediately became central. I could not contact any future participants who were vulnerable adults except by negotiating a complex set of gatekeeping procedures managed by a variety of organisations: the medical ethics committees, three local residential trusts and the university ethics committee. At this point I was hoping to set up a co-operative inquiry as described by Heron. His first defining feature of co-operative inquiry is that:

All subjects are as fully involved as possible as co-researchers in *all* research decisions – about both content and method – taken in the reflection phases (Heron 1996: 19).

The procedures designed to protect the vulnerable adults effectively prevented them from being involved at the earliest stages of the research. It seemed important to gain access to them as soon as possible by negotiating ethical approval.

Participatory research deals with situation-specific knowledge rather than

pre-existing knowledge. In order to process the application to the local ethics research committees, I needed to engage with some pre-existing knowledge in the form of research and guidelines on ethical practice. This situation was rather similar to the dilemma of how to engage with literature before the inquiry began (see chapter two).

5.2 Beginning ethical dialogues

By sharing some of the literature with the music therapist, Nick, we began to find helpful ways of thinking about the problem. We realised that together we could try to address some of the complex issues surrounding informed consent and confidentiality but that our conclusion need not be set in stone. Gaining a person's consent to participate in the research project was a process, and the cyclical nature of the inquiry design would allow participants to revisit the question every cycle. The ethical thinking developed in the early stages could be shared with other participants when the inquiry was fully under way.

We identified some common beliefs and values that would help us to tackle ethical questions. As a result of musical experiences we had shared with clients, we had both come to believe that people with profound learning difficulties were capable of making meaningful communication, forming close relationships, having opinions and making choices about certain aspects of their lives.

5.3 Gaining ethical approval: understanding the context

In order to prepare an ethical proposal which was congruent with the values of participatory inquiry but also conformed to the expectations of the ethics committees, I felt it was essential to explore the assumptions, concepts and

values which lay behind the required documentation. Rodgers (1999: 424) who had presented an ethics committee with a participatory research design, had challenged the requirement that before approaching a potential participant with learning difficulties the agreement of her parents and doctor (GP) should be obtained. In response the committee changed the requirement, so it seems that researchers involved in participatory or emancipatory research can enter into dialogue with local research ethics committees with positive results.

5.4 First ethical dilemmas

In the music therapy inquiry participants would be invited to become part of a research inquiry involving music. For the participants with learning difficulties, music therapy was also being offered as a healthcare intervention. They were vulnerable on three counts as identified by the Declaration of Helsinki (see Appendix 4: paragraph 8, p433) because they could not give fully informed consent; because they were likely to be put under duress; and because the research was combined with care. These reasons made them different from other participants in the project.

This difference raised various ethical questions. Were the people with learning difficulties we would approach as participants going to be able to consent? If so, how should we present the potential risks and benefits in a comprehensible form? How could we do this when we didn't know the participants and their communication needs?

Might music therapy pose risks or entail discomfort? Nick and I discussed potential emotional risks, particularly in the context of group work where group members might have difficult relationships with each other. The work could bring

to the surface emotional pain which might already be present in an unconscious form, or the participant might be upset if he were challenged by the therapist or another group member. There might be enjoyable moments and many benefits from taking part in music therapy, but there was no guarantee of a pain-free experience.

Conflicts of interest

Nick said he was aware that conflicts of interest might arise if he was working with people in a therapeutic relationship and also within a research project. His concern relates to another part of the Declaration where it says that: 'consent should be obtained from an independent physician not treating the patient' (see Appendix 4). I felt that this requirement reinforced the wisdom of choosing a design where two music therapists were involved. One person could be primarily responsible for focusing on the health care, whilst the other could act as an independent practitioner where consent was concerned.

At this early point we were already defining our roles and hence some of the boundaries of the research. The decision we came to was that Nick would be the music therapist and I would take a more facilitative role with regard to the overall research project while we both remained 'participants'. The roles and boundaries could be fully explored later when other participants were on board. The cartoon at the end of this chapter illustrates how the doctor's perspective on 'best interests' and the patient's may differ considerably. In practice, Turner found that the majority of doctors in his British study were ignorant of this aspect of the law.

5.5 Ethical thinking in music therapy, sociology and psychology

As yet there are no specific guidelines set down for music therapy research in Britain. (See Appendix 4 for details about ethical thinking in music therapy practice). For guidance on the intricacies of informed consent we consulted the ethical guidelines of the British Sociological Association (BSA 1995) and the British Psychological Society (BPS 1993). Sociological research embraces constructivism and the practices of ethnography and action research, where there have been many advances in thinking about the relationships between the researcher and the researched (see Appendix 4). I also expected that psychological researchers would have considered concepts of emotional harm with some sensitivity.

The challenge I set myself was to keep in mind the spirit of the Declaration while examining contemporary ethical interpretations and practice with a critical eye. In order to do this, there were three main areas I addressed: informed consent, anonymity and communication issues.

5.6 Informed consent

There are three factors determining informed consent::

- 1) The person must be *fully informed*;
- 2) Consent is *freely* given and
- 3) The person has the *capacity* to make the decision (Berghmans and Ter Meulen, 1995, Bartlett and Martin, 2000).

I felt challenged by all three aspects. How does one inform a person with no verbal understanding of what they are likely to encounter? Given the likelihood of some of the participants being compliant, how could I be sure they were not

consenting only to please? How easy was it to determine whether and when someone has 'capacity'?

How capacity is generally determined

According to the Law Commission Reports, capacity to make a decision depends primarily on the nature of the decision taken, and the particular circumstances of the person taking the decision at a particular time. There is no globally applicable definition (Law Commission 1991,1995). Therefore each decision must be considered on its own merits. This fits well with the idea that having the capacity to give informed consent changes over time, and giving consent is a process which must be continually negotiated. With the emphasis on the individual and the context in which the decision is being made, there seems to be a possibility of working towards at least partially informed consent for some decisions with any individual, regardless of disability. I agree with Carson when he says that we should be reluctant to accept that someone is incapable of making decisions (Carson 1996). However, it seems that this attitude is not always found within healthcare practice.

Gaining informed consent with the learning disabled community

Hart looked at current healthcare practice in the area of consent to treatment, or to medical procedures. Hart found that the participants reported varying and often poor practice with regard to consent to treatment.

Evidence suggests that consent is primarily being sought as a legal requirement and rarely as a strategy for ensuring people with learning disabilities understand the nature of their forthcoming treatment (Hart 1999: 20).

This poor practice was not always related to the person's ability to understand. Although he interviewed people with language skills, Hart depended primarily on non-verbal cues, such as body posture, to determine whether a person was truly giving consent to be interviewed. A study investigating whether people had the ability to consent showed that when a passage describing the research in simple language was read to a person with a learning difficulty, many of them failed to grasp the risks or benefits (Arscott et al 1998).

For someone who does not read, what does it mean that their contribution to research is going to be published? McCarthy argues that truly informed consent is unlikely in many scenarios involving people with learning difficulties and asks whether fully informed consent is actually needed. She suggests working within the limitations of what is possible and that good practice would involve consulting with participants at every stage of the research (McCarthy 1998).

5.7 Anonymity

A guarantee of anonymity for participants in any dissemination of the research was a prerequisite in my application for ethical approval. However, in some circumstances, research participants may prefer to have their identities revealed (see section about Grinyer's research, Appendix 4). This may be part of owning the research, and feeling a personal commitment to the findings.

In the dissemination of the findings of the participatory research, participants often jointly write papers. Marshall and McClean mention by name all the participants involved in their organisational inquiry in Gloucestershire (Marshall and McClean 1988).

5.8 Communication Issues

I decided to explore the relevant literature for ideas about using alternative forms of communication to explain ethical issues. Most of the material relates to people with mild disabilities, but notable examples included resources using pictures (Minkes et al 1995), maps to show distances between people (Wyngaarden 1981) and Makaton signs (Hollins 1996). If we wanted to use pictures or photographs to try to explain aspects of the research procedures, the materials had to be accessible to all the participants so we would have to know about any visual impairments. The positioning of visual materials could be crucial to their accessibility (Baumgart *et al* 1990). The use of objects of reference to explain what would happen next was another possibility, such as the use of a camera to indicate filming (Park 1995: 40-45). One study (McVilly 1995) used pictures of faces with different expressions but concluded that this communication system needed to be refined as he had still relied on proxy data from carers.

There are many aspects of communication to consider and address. The area of receptive communication is largely neglected in research, and in most studies with people with 'challenging behaviour' only expressive communication is considered (Kevan 2003).

There are very often mismatches between the language used by carers and the understanding of the person with a disability. This may also apply to people's understanding of visual images and music. Understanding of a research process cannot be taken for granted with articulate people without learning difficulties and careful attention needs to be paid to this throughout any participatory inquiry.

Very often communication needs are not fully understood or carefully assessed. In interpreting the communications of a person with a profound disability, there are number of problems such as assumptions about whether a person has an opinion, difficulty in understanding what is being communicated, assumptions about the meaning of a communication, and disagreements on interpretation (Porter and Ouvry 2001). In a participatory inquiry with verbal people with learning difficulties, Richardson (2002) emphasised the need for listening, the value of silence, taking time to reflect (and, I might add, to communicate) and the recognition of the significance of apparently trivial information.

Reflection

I wrote:

The difficulty of knowing whether information is significant or trivial is something I want to take seriously in our inquiry. Nick and I have both agreed that we want to take note of both small details and general patterns. Our understanding of the significance of a participant's communication is going to affect the inquiry considerably. Can this ever truly be a participatory inquiry?

[Field notes, November 2000]

5.9 Preparing an application for the LREC

Exclusion and exclusion criteria

The local research ethics committee (LREC) required information about people who might be excluded from the study ('exclusion criteria'). Although a participatory methodology rejects the principle of exclusion, in the practical case

of visual accessibility it did seem useful in this early stage to indicate that people with significant visual impairments would not be able to use the alternative information we were preparing for them. I had some experience working with people who needed to use augmentative and alternative communication systems. From previous work in a neurological hospital, there were, for example, people who were able to use eyebrow control to operate switches. I wanted to plan for the use of a range of communication materials and aids which would be versatile to fit the needs of participants with the severest of disabilities. When it came to the realisation of the project, we discovered that some of the participants did have visual problems that were either unknown to, or unacknowledged by, staff; and by that time it would have been unethical to exclude people on that basis alone. As the inquiry progressed therefore, the exclusion criteria were abandoned as unnecessarily discriminatory.

Materials prepared

Through discussion and reflection with Nick and engagement with the literature I developed a proposal and a number of forms, which were included in the submission (see Appendix 5, pp438-464). I needed to show that if vulnerable adults were involved in the research, every attempt would be made to obtain informed consent. The ethics committees gave guidelines including how to design 'patient' information sheets and assent and consent forms.

A photographic resource

For adults with severe learning difficulties even extremely simple information sheets were of no use. Instead we designed personalised information packs using forms of representation which were accessible to each individual. As we could not

yet identify the individual participants, Nick and I made up a sample pack to send to the committee. We took photographs of us playing instruments, talking to each other, filming each other, putting video tapes into a video cassette player and watching ourselves on television to illustrate different stages of the research process.

We used a digital camera because the image was immediately available. We proposed to include photographs of the participant in each pack to reduce confusion and the need to generalise, and we hoped that the experience of making the pack with each participant would go some way towards his having control over the process. Consent was an ongoing process and would form part of the changing relationship with me and the other participants. It was essential that participants felt able to leave, or change their level of participation.

5.10 Withdrawal of consent and the implications for the validity of the research

In chapter four Heron included authentic collaboration as an aspect of the validity of an inquiry. He said:

Individual viewpoints will not really be authentic unless each person is a fully-fledged collaborator, contributing at each stage of the inquiry about with a real grasp of what is going on (Heron 1988: 55).

In my research diary I asked:

Does this mean that involving participants, who are not able to have such a grasp, particularly in the early stages, leads the research to lose some validity? And if they are ambivalent about their level of participation, and often leave during a session, does this mean that the validity is

compromised? I am beginning to realise that the inquiry taking place within the music therapy sessions has a different validity. Although the men come and go, they are committed while they are in the room, and this is all we can hope for at this stage. To me this is authentic collaboration.

[Cycle 2: research diary]

In chapter twelve we will explore the themes of ambivalence and commitment further.

5.11 Exploring the notions of ‘risk’, ‘empowerment’ and ‘challenging behaviour’

During the co-operative inquiry, we often spoke of the lack of freedom of the residents, but also of risk factors. I was interested to read in another participatory research project involving participants who had dementia that the researchers had found that empowerment and risk were the key underpinning concepts they felt were in opposition to each other (Bartlett and Martin 2000).

The term ‘challenging behaviour’ raised a good deal of debate amongst participants during the co-operative inquiry. One participant said:

I hate the term *challenging behaviour* but I can’t think of any better alternative at the moment.

[Cycle 1: co-operative inquiry meeting]

I wrote:

By their very definitions these are labels that define people from the perspective of others. This in itself constitutes a lack of freedom.

These are labels that warn others, encouraging a negative

perspective of the person before anyone meets them.

[Cycle 1: research diary]

I have read the following standard description of challenging behaviour (CB) in a number of publications. CB is behaviour:

of such an intensity, frequency and duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit or delay access to and use of ordinary community facilities (Emerson *et al* 1987).

This description shows that here the emphasis is placed on the need to *predict* a likely behaviour and the degree of risk.

Research within more traditional paradigms shows that people with learning difficulties and challenging behaviour living in care homes are more at risk from physical abuse than those without these labels (Marchetti and McCartney 1990, Allen and Harris, 2000). Staff, too, may be at risk of injury, and are likely to experience a mixture of powerful feelings (Cottle *et al* 1995; Browley *et al* 1995).

The start of our inquiry coincided with a controversial documentary on television (MacIntyre Under Cover, BBC, 1999) where staff in a community home for people with learning difficulties were covertly filmed. At one point in the programme a resident was physically restrained in a potentially dangerous manner. I felt that the timing of this was likely to influence the way staff participants reacted to ethical discussions about the use of video. Would they have fears about potential covert use of the video in this inquiry, or would they see it as an opportunity to explore the complex nature of their jobs? Did the residents have any past experiences of abuse? What effect might this have on

their ability to trust any new relationships that the inquiry would bring?

5.12 Consulting people with learning difficulties

The best judges of whether an investigation will cause offence may be members of the population from which the participants in the research are drawn (British Psychological Society 1993: 34).

Although the specific population was inaccessible until ethical approval had been granted, there was nothing to stop us consulting with people who had learning difficulties. I approached a local branch of a well-known self-advocacy movement run by people with learning difficulties. Some of the members had been involved in participatory research already. Although the group was interested in our project, it was not possible to meet for several months so their valuable input influenced the inquiry rather than ethical thinking at the stage of application to a LREC.

Avoiding tokenistic involvement

My supervisors suggested asking people with learning difficulties if they were prepared act as employed research advisers and possibly advocates for the residents in the talking part of the inquiry. The university peer group were concerned that the involvement should not be tokenistic, and Nick was unsure about how relationships would form between the residents and the advocates. There was some anxiety about whether they might disrupt the therapy process. I wondered if potential advocates could meet the residents and play music together as part of the inquiry. Enough funding was available to employ two research assistants with learning difficulties.

Meeting potential advisers

Over thirty people attended the meeting. I had brought instruments so that we could start by sharing an experience by improvising music together. Some helped bring the instruments in from my car, and after we had all introduced ourselves the music started with no further discussion. To me there seemed to be great excitement and energy in the music, which was so loud that the recording was distorted. It lasted for only two minutes ending with one person taking the microphone and making a speech. We then talked about the experience.

First person: That was great!

Second person: Yeah, I enjoyed it.

Cathy: Does anyone have any questions?

First person: Can blind people play instruments?

Second person: I'm blind and I was playing the bodhrun all the time.

Third person: Do you have to be careful, you know, of sharp bits and things?

Second person: The Bodhran doesn't have sharp bits. I've played it before, you see.

Fourth person: Can anyone here play an ... a musical instrument?

Silence for about ten seconds

Cathy: Haven't you all just been playing instruments?

Several people: Yes!

Fourth person: Can people with learning difficulties learn to play instruments?

Cathy: Yes they can. You can. But I think it's sometimes difficult to find teachers.

Second person: I can play the bodhrun really well. Listen to this!

Fourth person: Yes that's good, I like it, but can people go to music classes?

The group was already generating questions for their own possible inquiry. The last question put me in mind of Knut's question (chapter four) 'may we too play in the brass band?' I wrote:

It seemed to me that raising the question of difference in a specific way i.e. focusing on a man who was blind, had enabled the group to move towards a more difficult question: were they excluded from mainstream music-making because of their difference?

[Cycle 2: field notes]

The way in which this particular inquiry unfolded is beyond the scope of my thesis but the conversation quoted above did help inform the inquiry in the community home. It encouraged me in the view that the use of improvised music as a form of inquiry was quite possible. People had thought of questions with apparent ease after the experience of being together in a musical improvisation. Furthermore, the group had raised the importance of the issue of being included in wider community music-making. They were concerned about the need for instruments to be accessible and safe for people with individual needs.

I explained that I was hoping to recruit people who would be able to help in our inquiry in the community home. We looked at some pictures of the building. I

explained that five men lived there who could not talk and that perhaps they needed someone to 'speak up for them'. The following conversation ensued:

Cathy: What do you do if someone in this group can't talk?

Person 5: J uses a picture book...

Person 6: ...to communicate.

Person 5: She points at the pictures ...like a drink.

Person 7: Everybody else can talk.

Person 8: Yeah but we mustn't ignore people who can't talk.

Cathy: I think some of the people in the project might be quite shy.

Person 9: (quietly) I'm shy.

I wrote:

This lively and energetic group recognises the need to support and include people who have more difficulty communicating, although they still seem to be at the beginning of thinking about this. One man seemed to have a strong empathic response to the community home residents; I thought he might be a good person to involve. Also B...she said that she had training in interviewing. Everyone was extremely positive about the value of playing music together. One woman said she had previously had a bad experience with one member of the group who had been asked to leave: playing music helped her express her feelings and she felt much better afterwards [Cycle 2: research diary].

Although seven people expressed interest in being employed in the research inquiry as advocates or advisers, in practice it proved impossible to meet

again because of their other work commitments and geographical factors. There may have been other reasons too. Aspis describes how people in self-advocacy groups seldom have the opportunity to grasp the importance of meeting with policy-makers or openly challenging the way services are put together (Aspis 1997). I realised in retrospect, that I did not emphasise the potential benefits for the advisers strongly enough.

Instead, I met with three of them individually. One had a support worker present, but the others preferred to meet me alone. I was able to take ideas raised by them for discussion in the co-operative inquiry group.

Working with advisers

The following extract is from a dialogue with one of these advisers, whom I will call Sharon. In this meeting we were looking at the possibility of her working as an advocate for one of the community home residents during the project. We watched a video about music therapy made in Holland as a starting point for discussion (Stichting Muziektherapie1999), which showed music therapy sessions between a woman with profound learning disabilities and a male music therapist.

Extract from the interview

[The woman is walking up some stairs physically supported by the music therapist.]

Sharon: That's wrong! She needs to be independent.

Cathy: Which bit is wrong?

Sharon: When he puts his arms round her. *[Mimes this.]*

[The film cuts to the woman, who is sitting in a wheelchair, waving her arms, not looking at the music therapist who is playing the

piano.]

Sharon: She's doing her own thing

[She watches in silence for several minutes. Now the therapist is singing a repeating song in falsetto. I think the woman seems interested. She is singing wordlessly.]

Sharon: He's playing music that is... *[She uses a sign with her hands that swoops upwards possibly indicating a rise in mood.]*

But she's distressed. It's the wrong music.

[More of the session – the woman is now making vocal sounds into a microphone.]

Sharon: I think music is very good for relaxing. She needs relaxing. I used to play music to my mum – CDs. She needed relaxing. She had a stroke. 'Bout six months ago. Her face was all... *[Pulls one side of her face down]*. She couldn't speak. She was very distressed. I helped her a lot.

Cathy: That sounds awful. What did you do to help her?

Sharon: She hit me with her fists. That's why I've moved to my new flat. I helped her a lot and she did begin speaking again. I had to hold her food for her. I didn't want to leave. But I had to. For my own good and my own independence. *[Indicates woman in video by eye pointing.]* She's more relaxed now. *[I agree.]*

This is my reflective note, written after the meeting:

In this interview Sharon was able to be mindful of the needs of others, even if they had hurt her. I was struck at how perceptive her observation was about the mismatch between the woman's mood and the therapist's music. She strongly believed in the woman's need for independence and respect rather than reacting to her obvious physical disabilities. Sharon's sensitivity to the boundaries of physical touch made me wonder about the impact of a lifetime experience of being vulnerable to disempowerment. Sharon has been able to hold down a job and care for her mother at the same time. Her experience of the conflict between caring for her mother and meeting her own needs too was very moving. She used the video to relate to her own personal experience. Interesting and important that she doesn't seem to relate to the woman in the video as someone who is like her. Sharon doesn't see her as a 'tragic case'. She is a person.

[Cycle 2: field notes]

Barriers, risk and emotional harm

On returning from this visit I spoke to the home manager about arranging Sharon's first visit to the home. The manager immediately raised the issue of risk assessments and locking procedures. It felt to me as though we were constructing barriers which made the place intimidating. We tried to explore how the place might be made more accessible to Sharon. We made a video of the home, explaining that the doors were locked so that one of the residents couldn't run out onto a dangerous road. When Sharon and I watched this together, she was very quiet. Later that week I contacted her. She said that she had been thinking about the locked doors and she said:

I think it will make me too sad even if I was helping them, the men who live there.

Reflection

Just because someone has the label of 'learning difficulties' does not mean they will identify with more disabled people with a similar label. The people from the self-advocacy group raised a number of different issues through their stories, but none of them was in the situation of the community home residents, living in a locked environment with no independent advocacy.

Sharon seemed to be saying that encountering the home might cause her emotional harm or distress. She has no other information than our portrayal of the home. Perhaps she would have chosen to come if we had told her less, although we felt that withholding information was unethical. She exercised her right to say 'no' to something she did not want, but the question remained: had the risk assessments created a barrier to access? This was something I hoped we would be able to address in the inquiry.

At this point there were no obvious candidates for working as advocates for the residents. The inquiry began formally with the first co-operative meeting, before Sharon's decision not to be involved. However, the picture and caption shown in plate 1, p 130, used by a similar self-advocacy group, helped the participants in the co-operative inquiry to agree that the voices of the residents themselves should be central to the inquiry findings, in whatever forms they presented themselves. The challenge to all the participants was how to hear the voices and dismantle our own barriers which prevented them from being heard.

SPEAK TO ME I AM THE ONE FEELING
THE PAIN NOT MY CARER



Plate 1

5.13 Summary

Ethical thinking is a complex process, and involves a balance between one's own intuitive response to moral issues and an attempt at understanding, incorporating and also questioning the ethical codes which have been constructed within the international community. Developing an ethics proposal involved a balance of freedom and risk on my part. I risked rejection from the committee by producing unconventional material such as the photographic resource and using an unconventional paradigmatic frame. Nick and I found some creative freedom in devising our own resource, and another strand of the inquiry was developed by my encounter with the self-advocacy group. Comparisons of different ethical

guidelines helped me to gain greater understanding of the origins and spirit of concepts such as informed consent and anonymity. Dialogue with participants and advisers helped us to question and develop these notions from more radical standpoints.

If I thought that preparation for the ethical committees had been rigorous, the work that we did during the inquiry was more so, and is explored in chapter seven. Informed consent, anonymity and making videos became highly complex issues about which most participants held strong opinions.

PART TWO

THE INQUIRY PROCESSES

Introduction

In this part I introduce a different way of representing the text in order to tell the story of the music therapy inquiry. In chapter six, the page is divided into two columns. This leaves the reader with some choices about how to read it. The observations, actions and comments of participants are in the first column, and I provide my own interpretation of events in the second column. The columns can be read across or down. Chapter seven is a summary of the process of the co-operative part of the inquiry.

CHAPTER SIX

The music therapy inquiry

Participants' voices in the inquiry

Words spoken by the residents who were participants are printed in red.

Nick wrote an account of each session immediately afterwards. His reports included his predominant thoughts about what participants had done, and what he felt were any significant aspects of the session.

Anna also wrote a brief independent account after each session in a similar way to Nick. She discussed the session with Nick before doing so.

Staff who participated by filming the sessions when Anna was away also wrote independent accounts after discussion with Nick.

I watched the video of each session independently and wrote a minute-by-minute account including analytic memos. These observations began as very 'thin' descriptions, in order to document the actions of the men, representing the sequence of events but leaving all my reactions to the analytic memos. As time went on these descriptions became 'thicker' with more comment.

My narrative of the 'music therapy inquiry'

The participants included the five men who lived in the house, namely Jack, Ralph, Bill, Steve and Pete; Aidan joined later as a new group member. Other participants were Nick, the music therapist working as the main facilitator, and Anna, the day care worker who filmed most of the sessions. There was partial involvement from various staff members who filmed if Anna was absent. No other members of the co-operative inquiry filmed at any point. This meant that Nick and Anna were the only two people who were full participants in both inquiries.

My involvement was partial: I was not present in most sessions but watched them alone on videotape afterwards. The co-operative inquiry team chose this role for me partly for pragmatic reasons: I was the only person who had time to look at the tapes one minute at a time. The group had decided that a description of the participants' actions from minute to minute would be one way of capturing the non-verbal actions, communications and decisions. I observed all the participants in the room including Nick and Anna. Clearly Anna made judgements about how to film each session and I made judgements about how I would record my observations. Both processes changed over time as did the way Nick and Anna chose to write their post-session accounts, and this became part of the reflexive process for us all.

Reflexivity on behalf of the men is more difficult to gauge, and is explored in more detail in the central chapters of this thesis.

6.1 Cycle One

Finding our feet and getting to know one another

At some points all of the men were in the room at the same time – I didn't expect that. [Session 1]

I think the men all responded and it was much more than I'd expected. I think when Steve started getting involved that really got things going. [Session 1]

I liked the way Nick was responding to what the residents were doing. By copying them he seemed to involve them. This is different from how we can be with them sometimes. [Staff member A: Session 1]

It was fantastic! [Session 1]

I was excited – I played the organ, played a tune. The men weren't interested. [Staff member B, Session 1]

I think she [staff member B] was probably using the session for her own needs rather than for the men's needs. She started playing instruments and blocking instruments. But I hadn't had a chance to brief her beforehand. [Session 1]

Leaving seems to be an important communication [Session 1]

These early sessions involved all the participants in fairly tentative exploration of the changes in the room, discovering new instruments, and above all, getting to know Nick. Connections with one another through music or physical touch were generally brief. There were many questions about the roles different people were playing and what was expected of them.

A number of participants expressed ambivalence about the process by not coming in, by hovering at the door or coming in only briefly. This included a range of participants. Plenty of enthusiasm was expressed too, within the music and verbally.

All four sessions took place in the lounge.

In the second session Bill wanted Nick to remove a chair from the room. He became upset and angry when Nick decided to challenge Bill by not removing it. Bill tried in different ways to communicate his wishes and Nick eventually removed the chair. This episode dominated the mood of the session for all the participants and formed the focus for future conflict within the co-operative inquiry team.

It's tricky. Sometimes he [Bill] goes on and on and ruins it for everyone else. So sometimes you just have to let him go on. [Session 2]

Come on Bill. Have a singsong.
[Staff member, session 2]

There was a point when I thought 'no I'm not going to take the chair out just because you [Bill] don't like it' because I felt that would have established a pattern. [Session 2]

Never! T-t-t...[Bill, session 2]

Steve comes in when the tension is quite high. Nick moves the chair. Bill goes to Ralph and tries to take his drum away – a change in tactic. [Session 2]

It raised a number of questions about the locus of power between the different subgroups of residents, staff and therapist. As a result Nick felt isolated and angry although he worked hard to prevent these feelings from affecting the therapy inquiry. He chose to deal with the issues within the co-operative inquiry team meetings instead.

The first cycle can be summed up as a period of careful exploration with much hovering on the borders, characterised by a variety of reactions to new experiences, sounds and ways of being together. Attitudes towards 'difference' (such as difference between 'the men' and staff, difference between staff and the music therapist and difference between those who engaged and those who didn't) sometimes became starkly evident. There was also a shift towards fewer staff coming into the room from the first to the fourth session. One participant was identified by others as a catalyst, another participant as a focus for some anxieties about the project. The music was generally made up of brief improvisations between the music therapist and another participant, rather than any larger numbers playing music together. Attendance was generally sporadic although there was a sense of surprise that it was going 'better' than expected.

6.2 Cycle Two

Adjusting and feeling our way

The change of room was significant. People are now more actively choosing to come in. [Session 5]

Steve hits a wall with a beater. He moves to the radiator, floor and chair, beating them. [Session 6]

Pete stood at the door wanting to come in but slammed door instead. [Session 6]

I noticed the TV was very loud from the lounge and felt this as competition. [Session 6]

Steve and Nick play together with Pete watching. Ralph enters leaving ten seconds later. Pete and Nick then play together by rolling drums on the floor. [Session 7]

Pete's presence seemed to dominate the room. Do Ralph and Pete compete for my attention? They avoid each other. [Session 7]

Steve played on many instruments, seemed fine and then got a little moody. When he came back he seemed concerned or sad. Is there something on his mind? [Session 6]

Nick sits in silence alone. There is a sense of despair. [Session 6]

Illness affected the attendance of two participants, and this was keenly felt in such a small group.

The sessions had been moved to the dining room and this resulted in fewer staff interruptions, but more noise from them instead. The move seemed to unsettle Pete who generally stood outside the door rather than coming in. The participants in the room found a number of new ways of playing together and began to explore relationships a little. There was a move from focusing on becoming familiar with one another to operating on a more emotional level. For example, Anna noticed and thought about Steve's moods and Nick began to experience feelings of despair. There were differing reactions to Bill's absence since the room change: Nick felt Bill was being prevented by staff from coming in; Anna and I reflected more on Bill's terminal illness. There were signs of jealousy and rivalry between participants, especially between Ralph and Pete, and between the care staff and Nick.

In general, this brief cycle involved further exploration in terms of relationships, the musical environment and ways of being together, but involved adjusting to the room change and generally the attendance of some participants decreased.

Jack found ways of being with Nick, using the instruments for brief periods of time, but both Ralph and Bill showed ambivalence in terms of their participation. Bill did not come in at all. Ralph came in more often than before, but missed session 6 by choice. He expressed quite a lot of aggression in his instrumental playing and towards Pete. Only Steve stayed for long

periods of time, playing duets with Nick.

Nick was concerned about the amount of noise made outside the room by non-participants and wondered if some of the residents were being kept out.

6.3 Cycle Three

Growing confidence and commitment

Pete was calmer than I expected even though he was causing havoc. He really took part – maybe not in a conventional way. [Session 10]

Steve sang with me at the beginning and carried on singing outside when he left. [Session 10]

Ralph tries to get hold of the trombone. Pete throws the metallophone and the bars come off. Ralph leaves. Nick says ‘what chaos!’ Anna is laughing (with shock?) [Session 11]

Ralph wanted to hold the trombone. I felt too unsure to let him – pity! [Session 11]

I had a hunch Ralph wanted to take part all along but was surprised at how much he has changed. His confidence has seemed to have doubled. [Session 10]

Before the start Pete, Jack and Ralph are standing at the door, apparently anticipating the session. [Session 11]

The focus in this cycle shifted towards noticing each other. Pete and Nick started to find different ways of playing with instruments, such as rolling drums and moving them about, and Pete’s attendance increased noticeably. Nick brought in some different instruments, experimented together with others to find new ways of playing and started to write more reflectively about his relationship with each of the five residents. Ralph spent more time in the room and played some instruments spontaneously.

He expressed difficulties in his relationship with Pete, drawing attention to his problem. Steve and Nick continued to develop their musical relationship through longer and more varied improvisations, the sadness Steve expressed became more evident. In response, Nick explored more of Steve’s background through the co-operative inquiry in order to understand Steve better. Jack still made only brief contact with others in the session but left whenever there was a loud sound or any hint of conflict with another person. He appeared to be the least powerful participant. Nick struggled to make what he felt was meaningful contact with Jack. With Ralph, Pete and Steve, while their commitment to participation with Nick

Bill was outside the door vocalising, becoming present in the room, extending the boundary space beyond the dining room.[Session 12]

grew, an element of competition emerged between the three men, particularly Pete and Ralph, who were less confident than Steve.

Bill's physical distress started to affect participation in the room, although Bill did not come in. He was often heard outside in some distress. Nick, very conscious that Bill was effectively an outsider, decided to work outside the normal therapeutic boundaries of the session and started to leave the room when other participants were in it, so that he could contact Bill. This was quite a radical move in terms of his practice, and seemed to be made possible by the growing confidence and commitment of the other participants.

Staff support for the session primarily involved setting the room up and accepting the privacy of the session, so there was little intrusion within the session from non-participants.

6.4 Cycle Four

Challenge, trust and death

Pete sat down in a chair as I played with Steve. We became a group of three. Then Pete became difficult – he pushed Steve. [Session 14]

Steve enjoyed playing. There was close interaction between Steve and me and we played the conga and tympanum together – there was smiling and eye contact. [Session 16]

Pete has thrown instruments very aggressively today. He drew blood from Nick during an altercation with the cymbal, probably by accident. Nick managed to distract him quickly by offering him another drum. [Session 15]

Cycles 4 and 5 were the longest and represented the periods of greatest reflection, challenge and change for most participants. The practical difficulties of setting up the sessions had been settled and the staff had accepted that private space was needed for the residents with Nick and Anna. The way was clear for deeper inquiry.

There was a growing commitment to musical participation from both Steve and Pete. The trust between each of them and Nick grew stronger, and there were many periods where there was mutual music-making between the three men. Pete at this stage was not playing instruments, but his listening, awareness of other people's music

If you'd put a knife to my throat I wouldn't react so immediately. [Session 15, referring to the same incident]

This session would have been very difficult for any music therapist to contain. [Session 15]

You say that, but I think it would be difficult for anyone to cope with. [Anna, in response]

Ralph enters, goes to the camera and grabs it. Steve is standing next to him arranging the beaters in line. Ralph takes a rainmaker but does not play it. Thirty seconds later he leaves. [Session 15]

Ralph came in first. He couldn't quite engage with me. He played the conga with a beater then threw the beater down. [Session 19]

I felt Ralph wanted to join in more. [Session 19]

Bill was agitated and very vocal in the hallway which seemed to change the moods of the other men. Bill carried on for most of the session, unsettling the others. [Session 17]

There was silence in the session. Bill shouted out in the lounge and Nick, in the dining room, sang a response at the same pitch. Bill then vocalised more loudly, then Ralph (in the lounge) threw a box of crayons all over the floor. [Session 18]

Bill engaged with me throwing the vine leaf shaker in and out of the room. He threw with considerable force. Steve watched all this as he played the congas. This was the most contact I have ever had with Bill. Bill sang and I answered with the trombone. [Session 19]

and interest in it increased continually. He spent most of each session in the room whereas in cycles 1 and 2 he spent a lot of time standing outside the door.

Pete and Steve's relationship became a focus of interest for both of them and Nick. Pete was drawn to Steve's music but often became jealous and threw instruments in a way that Nick could not ignore, as part of his role was to protect the safety of others in the session. Nick spent some time reflecting on Pete's actions and coming up with action strategies of his own for maintaining the safety of the room while keeping Pete involved. This continued to be a very challenging task indeed.

Nick was also preoccupied with how to facilitate involvement with Ralph, Jack and Bill, who were apparently not forming the same strength of attachment to him as Steve and Pete were.

Ralph was entering the room as frequently as before, but he seemed to be communicating some unease about the presence of the camera. He was most involved at the beginning and end of sessions when he helped carry instruments in and out. During sessions he handled instruments but rarely played, even though he had shown he knew how to.

Bill's health began to deteriorate rapidly from the time of session 17. The next three sessions were dominated by Bill's distress which he showed by shouting out. In session 19, Bill was playing with Nick for most of the session, but standing outside the door, never coming in. This was the most contact Nick ever had with Bill within the inquiry.

Bill's distress clearly affected all participants in different ways.

Bill is in his bedroom. He is dying. When Nick and I arrive, all four men stand at the door waiting for us to come in. [Session 23]

Jack paced around the room. He stayed for longer at the beginning than usual and in a different way – he leaned against the window. Steve – there was a close connection between us as we played guitars together. The music had a sombre quality. I drew closer to Steve and he held my hand. He seemed to fall asleep. [Session 23]

Things will be very different now that Bill is no longer with the group. [after funeral]

Between session 19 and session 23, the day of his death, Bill was too weak to want or to be able to be involved, but the others showed how strongly they were affected in various ways. Pete sometimes became agitated in the session as Bill cried out. On the day of Bill's death, Steve was very upset and had a seizure during the session. Nick put him to bed.

At the beginning of the cycle, Jack started to spend longer periods of time in the room. In cycles 1 to 3, he had spent on average less than three minutes at a time in the room. Jack missed sessions 18 voluntarily and was on holiday in session 19. When he returned, Bill had become very distressed. Jack almost disappeared from the inquiry for some time, reappearing briefly on the day of Bill's death.

Nick spent some time with Bill before session 23. Nick, Anna and I were all invited to Bill's funeral. None of the residents were involved in the funeral, despite having known Bill for years. The cycle ended with all the participants in a state of grief or bewilderment.

6.5 Cycle Five

Growing awareness of self and others

In the middle of the session, Nick leaves to ask Ralph in. A member of staff who is filming makes Steve wake up and says 'bang the drums'. Pete leads Nick into the room. Steve, as instructed, starts playing. [Session 24]

I thought it was significant how much the men reacted or took part; either if it's just listening and watching or actually playing. [Session 24]

During the period of this cycle, participants who had developed close musical relationships began to inquire into them. Anna and Nick were struck by the positive change in Ralph when Nick forgot the camera. Anna was forced to reflect on her role as the person behind the camera.

Some participants became aware that they had developed particular ways of being in the session. This awareness was prompted by the member of staff

Ralph played of his own accord and spent longer in the session than all the others put together. This may have been because we had NO CAMERA. [Session 25]

Not having the camera, Ralph seemed to be more interested in the session. Is this due to not being filmed? [Session 25]

Pete's jealousy of Steve is most apparent by him throwing instruments. Steve's music has acted as 'commentator' in the background. Nick has drawn some clear boundaries with Pete. Pete seems receptive to Nick's communications and acts more 'sheepishly' after being banned from the room. Pete refusing to leave at the end is significant.
[Session 26, analytic memo,]

I felt irritated by Pete's behaviour.
[Session 26]

Pete threw the instruments around the room so much that Nick got a bit angry! Pete pushed it a little too far.
[Session 26]

Steve is looking at the camera smiling then starts to play every instrument in sight as fast as he can.
[Session 27]

Nick starts playing the trombone. Pete enters and hits a drum. This is first time he has used an instrument in a conventional way. [Session 27]

Jack takes the buffalo drum from Nick and hums with him. [Session 27]

Jack seems to be more present musically.
[Session 27]

Ralph stopped Pete from throwing the xylophone by taking his arm. [Session 28]

who, not having been present before, filmed session 24 while Anna was away. She expected Steve to stay awake, and play when he did not want to. On the other hand she was surprised at how involved the residents were.

Steve developed ways of staying in a creative space despite Pete's attempts to disrupt it. As Nick and Pete got more emotionally involved with each other, Pete began to realise how his behaviour could have a negative effect, and could get in the way of relating with Nick. Previously, he had used the strategy of throwing instruments in order to divert Nick's attention away from others to him. Pete wanted to be with Nick and found he had to adjust to Nick's needs for this to happen.

Steve continued to perform to the camera occasionally, mainly trying to stretch the limits of what he could do. Pete and Jack both began to develop their musical self-expression through making sounds on drums (Pete) and humming and exchanging instruments with Nick (Jack). Ralph began to play *with* Nick rather than for short bursts on his own, which characterised his earlier playing. He also began to let Pete know that he was not happy about him throwing instruments.

Ralph decided to convey this by physically stopping Pete, whereas Steve communicated anger through drumming, gesture and words. So a number of participants were challenging Pete to change his actions which endangered and annoyed them. Pete was finding more ways to develop his relationship with Nick, including dancing to his music and choosing instruments from Nick to play.

Steve starts singing exactly like Nick. Pete gives Nick a drum upside down. Nick rights it. Ralph enters and shares playing a drum with Nick. [Session 28]

Steve hit a drum beater on Pete's head when he tried to throw stuff. [Session 29]

Aidan, a new resident living here temporarily, appears at the door. Pete approaches Nick's trombone and tries to pull it off the table. Is Pete jealous or upset? [Session 29]

Aidan played a few instruments very well. [Session 29]

It's significant – a new resident has moved into the group. [Session 29]

Pete laughs and snorts. Jack taps his feet. Steve plays the conga continuously and Nick is on the xylophone. The music stops naturally after a couple of minutes. There is a silence together. [Session 30]

Jack stayed in the room for most of the session, humming pitched notes corresponding to my singing (around D). He picked up a guitar and strummed as I sat next to him. Afterwards he seemed to be watching me and the others out of the corner of his vision.[Session 30]

Steve played the drums for a long time and discovered some interesting rhythms which made me want to dance! Jack moved the tables and instruments around and sat in a chair for most of the session. [Session 30]

I left three tables in the room so as to change it as little as possible for the men who live here. [Session 30]

The appearance of a new group member, Aidan, only five weeks after Bill's death, threw the participants into confusion. Anna was unsure whether to film him or not, Pete became angry at the sight of him, and Jack left the room whenever Aidan was present. Although Nick tried to include him from the start it was not clear whether the residents regarded him as part of the inquiry. Staff members initially believed that Aidan would only be at the home for a few weeks. He was usually out at daycare when the session took place on Thursdays. However, when he did attend, Aidan's appearance was threatening, particularly because he appeared to be considerably more musically and communicatively able than any of the other resident participants.

Towards the end of the cycle musical trios and quartets happened in every session and with increasing frequency. Jack stayed in for an entire session, which was a major change from his usual choice of brief participation. He spent most of his time participating in the music, either by humming or tapping his feet, and sat close to Nick.

Anna started to comment in more detail on the quality of each person's playing and spent more time reflecting on her observations and intuitive responses to the music of various participants. This was a change from the very brief observations in cycles 1 to 4.

Nick reflected more on the room layout and reverted to using the original dining room layout that the residents were used to, rather than trying to impose change.

*Steve played the drums aggressively followed by soft? sad? thoughtful? playing of guitar. Pete appeared affected by sounds, particularly soft xylophone playing where he relaxed totally. When Steve left the session he became agitated, pushing chairs around.
[Session 31: new staff member]*

It seems as if a triadic relationship/pattern has been established between Steve, Pete and me in which I connect with Steve in the music and Pete tried to get in and break the connection and in the process connects with me.
[Session 31]

Ralph came in more because I challenged him to engage and spent time encouraging him to come in the room. [Session 32]

Nick is clearly working hard with Ralph and to some extent does get somewhere although it is causing Ralph some discomfort. [Session 32]

Ralph seemed interested in putting parts of the xylophone back in the box. Maybe this is because he likes to put things away. Seemed interested but wary. It is important that people get something out of the session for themselves even if it is not the norm of playing them (i.e. instruments.) [Session 32]

Steve looks out of the window as Nick and Pete battle over instruments. Nick plays in a frustrated way on the xylophone. He says to Pete 'I'm tired of this' Pete quietens but continues to move instruments. Nick asks him to leave and physically guides him to the door. Pete reappears fifteen seconds later and sits quietly
[session 33]

When Pete returned after being sent out he was very calm, and moved his leg to the music Nick played for him.
[session 33]

Being like Pete is like being with a baby.
[session 33]

The peer relationships between Pete, Steve, Ralph and Jack were explored in depth within the music. Rather than making connections through Nick, they began to relate more directly to each other, although Pete continued to express any discontent by throwing instruments when he did not want to share Nick with anyone else. Another member of the care staff (filming for one session) noticed aspects of Pete's and Steve's thinking and feeling that were not evident to him before the inquiry. Generally there was more music, and musical interaction, in the session, which is reflected in all our written accounts. Nick continued to work to challenge and involve Ralph, who was his main preoccupation at this stage of the inquiry.

Ralph's ambivalence at this stage was palpable. He had communicated clearly about the video camera but it was still there. He was interested in the instruments but was unhappy when Nick attempted to keep him in the room. This approach was questioned by other participants and by Nick after reflection. Ralph continued to be described by staff members as someone who liked to 'tidy away'. Nick and Anna began to realise that until the camera was removed they would not know if this was the main factor in his reluctance to attend. They were determined to continue the music therapy beyond the formal end of the inquiry.

In this way they began to look beyond the end of the year and to plan. Anna said she would like to be using instruments rather than filming; and so sought a more active musical role. Nick and Pete continued to work on their relationship, which they both found quite tiring. However they both seemed very committed to working

There is some interesting negotiation between Pete and Nick which seems to have enabled Pete to be in the session without challenging others too much. He has listened to Nick's frustration and seems to be listening to what is going on. He also seems to know when it is the end of the session.
[session 33]

some things through. By the end of the cycle there was progress as they were able to be more relaxed together in sessions.

This in turn had an effect on Steve and Jack. Steve was sensitive to Pete's anger and Jack was highly sensitive to any anger expressed by Nick in the music, leaving the room whenever Nick played loudly. It was important that both Pete and Nick inquired into the effect that they had on others in the room.

6.6 Cycle Six

Looking beyond the inquiry

Aidan puts on a pre-programmed 'demo' on the keyboard which is complex and rapid. Jack enters immediately and starts slapping his face. Nick turns off the demo and Jack leaves. Steve and Aidan play a duet and are joined by Nick musically. Pete moves a chair and Aidan puts on the demo again. [Session 34]

Aidan was present for twenty minutes, which is new. Steve was dominated by Aidan a bit too much in the music and became tired. Aidan made a difference (disruption) to the dynamic.[Session 34]

Jack was very high. He and Pete wanted Nick to leave and go into their bedrooms instead. Jack threw instruments like Pete! When Nick played 'Somewhere over the Rainbow' on the keyboard, Steve looked away and seemed affected by it. Then he bashed the keys aggressively.
[Session 35]

Nick became more of a keyboard 'expert' who played music for Steve. Nick accepted that Steve might just want to sit with him rather than doing anything and that this was an acceptable way to be together.

Power issues, always a factor in this inquiry, came to the fore during this period. Aidan, the new participant became more active and dominant within sessions in which he was present (sessions 34 and 38). Jack and Steve both developed a more assertive presence in the room, but both did this primarily by behaving like other participants.

Jack began to throw instruments whereas Steve and Aidan both adopted the tactic of locking other unwanted participants out of the room. They both had experiences of locked doors in the home. They were able to do this because there was a manual lock on the inside of the kitchen door.

Nick said he felt self-conscious as this was not usual music therapy. [Session 36]

The music I played today was different from usual – I improvised on pre-composed songs. Jack sat on a chair next to me and he seemed to want to come in more because of wanting to hum with the songs. [Session 36]

When Pete tried to move the windchimes out of the room, Steve locked him out! Steve said he wanted Pete to stay out. [Session 37]

Nick asks Steve why he has locked Pete out. Steve says **Because I have!** [Session 37]

Jack is much more musically engaged this session than usual and shows his knowledge of carols. [Session 37]

Aidan told Jack to leave the room and then locked him out. He tried controlling who was in the room. Anna unlocked the door. [Session 38]

Both Pete and Steve try to take instruments out of the room when Aidan is in. Most of the session was dominated by Aidan who has hardly ever attended. This is quite a shift in focus for the last inquiry session. [Session 38]

The other men didn't come back into the room when Aidan was in. [Session 38]

Nick experimented more with the use of songs, particularly in the last two sessions approaching Christmas. He found that both Steve and Jack had particularly strong emotional responses to this. Nick was extending his practice in this final cycle: he experimented with using less improvisation (the model he was trained in) and he worked with receptive techniques as well.

We discussed the fact that he felt self-conscious about this.

My involvement in the project lessened. I was now not able to meet some of the participants because I was pregnant and risk assessments determined that I should not have contact with Steve, Pete, Jack or Ralph. I felt bereft and did not agree that I was at significant risk. However I could not bring myself to take the bold step of ignoring them because I felt protective towards my unborn child.

Meanwhile, Jack and Pete continually tried to lead Nick out of the room, possibly because they wanted to avoid Aidan.

Not only had Aidan taken Bill's place (literally, he inhabited his bedroom) but he was controlling, dominating and ordering weaker residents around, very much against the ethos that had developed during the inquiry. Aidan, who had verbal skills, tried to explain why he wanted to lock others out; he did not want to be identified with them and it was not his choice to be living in the home. Pete, Steve and Jack appeared to feel that he threatened their relationship with Nick so they tried to take Nick into their own territory.

Nick reflected on this and he began to question the therapeutic model he had worked within, with its emphasis on maintaining strict boundaries.

The music therapy was to continue the following year. This was one of the outcomes of the project. Nick and Anna started to plan the changes they wanted to implement. All participants ate a meal together after the final inquiry session.

6.7 Further Developments

Nick and Anna continued to provide a music therapy session on Thursdays for a further eight months after the end of the sixth cycle.

Ralph's attendance did increase and he became more interactively involved in the music. Steve developed the way in which he expressed himself on the instruments and began to share his worries verbally with Nick more often. Anna became involved in using the music to develop her relationships with other participants. Jack and Pete continued to attend with significant change. Aidan accepted individual therapy instead and moved to the adjoining house. Two new men joined the group from the other house joined the group.

By August, Nick felt the significant developments in group interactions and dynamics had 'reached a plateau'. Nick made arrangements to continue working with each of these four participants individually a weekly basis and this still continues.

CHAPTER SEVEN

Narrative of the Co-operative Inquiry

7.1 Preliminary meeting

In chapter four I described the inquiry as being divided into two parts. In fact it began as a single inquiry. Potential participants met together in the lounge to discuss what form the inquiry might take. In preparation for this meeting I had given the literate participants copies of Reason's *Layperson's Guide to Co-operative Inquiry* (2000). In the meeting I introduced the idea of an inquiry where the main inquiry medium was music rather than words. Although this was appealing because it allowed residents more opportunities for inclusion than a verbal medium, staff members were reluctant to accept this. Apparently residents and staff had recently been involved in non-research project that they felt had a similar design. This had involved the creation of a sensory stimulation environment in which they could all play together. This project had been withdrawn early, staff had not often attended and most people perceived it as a failure. Nick and I thought that an approach where everyone participated in some music would be the ideal option, but both of us were concerned that we had not yet tried an approach like this in our clinical practice. We were doubtful whether either of us at the time had the skills to facilitate a highly complex process, in musical or dynamic terms.

Content of preliminary meeting

During the preliminary meeting, residents often walked in and out of the room. In the end the verbal participants were talking over the residents, and it

seemed difficult to find a way we could hold together the conflicting needs for attention.

Some staff members said that they were interested in following Heron's model of co-operative inquiry, as they thought it could work well as a way of inquiring into professional practice. Inquiring together by talking effectively excluded the subgroup formed by the residents. From our experience with the residents in this meeting, we were not certain whether and how they might be prepared to participate in any type of inquiry. Therefore we settled on the idea that the music therapy inquiry would run as a music therapy group, facilitated by Nick. A daycare worker, Anna, would film the sessions. Other staff would support residents in the group, and could film if Anna were away.

The other interested participants would form a co-operative inquiry group concerned primarily with supporting the music therapy inquiry. Nick, Anna and I were to be involved in both groups, allowing aspects of each inquiry to be shared. This would allow for the possibility of reflecting on music therapy practice through inquiry with both residents and care staff, whilst offering residents a confidential therapeutic experience. However, reframing perceptions of therapeutic boundaries and confidentiality could also form part of the inquiry.

7.2 The participants

There were six co-operative inquiry meetings in all, each scheduled for 90 minutes. They took place in the activities room, a shed-like building in the community home garden.

A number of practical difficulties affected participation. Some participants were unable to join us because of shift patterns. Staff shortages meant that in the first

cycle two meetings were cancelled at very short notice. After the second cancellation we agreed to continue meetings even if the numbers were as low as three. Despite interest from over thirty staff members, practical considerations meant that eleven participants formed the core group of the co-operative inquiry. The group worked well with this number. The group included an unqualified daycare worker (Anna), her manager (Frank), three home support workers (Dave, Kate, Madge), two qualified nurses (Sarah and Chris), the home manager (Rose) and her deputy (Claire) both of whom were qualified nurses, and two music therapists (Nick and myself).

Among the staff of the community home, the home manager held the most authority and accountability, and the home support workers the least. The residents had no occupation. There were two levels of hierarchy represented within the day care team: Anna and her manager. The music therapist was a clinician accountable to his clinical manager who was not involved in the project. I was accountable to both my university line manager and academic supervision team. Within the inquiry participants understood that they were accountable to each other but also had to manage their place within the complexity and demands of the relevant power structures outside the inquiry. Because of the entrenched hierarchical roles it took time and careful facilitation before some of the less powerful verbal participants began to speak out.

7.3 Cycle phases

Each meeting marked out the beginning of a new research cycle within the co-operative inquiry. Heron and Reason describe four phases of the research cycle (2001:180). Phase one involves meeting together to identify the focus of the

current cycle of the inquiry. This phase was incorporated into each meeting in order to kick-start the next cycle. In meetings 2 to 6, this discussion took place naturally after participants had presented their findings from the previous cycle and had collectively reflected on them.

Phase two is where the participants engage in the actions they have agreed. In this inquiry, most of the actions were carried out between meetings, for example in cycle 1, an ethical protocol was drawn up in consultation with the wider staff group.

Phase three is where the co-researchers become fully immersed in their action and experience. This occurred both within the meetings and in between. For example, Nick, Anna and I met to review the contents of their session questionnaires in each cycle, deciding what to present to the co-operative inquiry participants and how it could be done. Much happened informally through mutual discussion and reflection.

Phase four is where the co-researchers reassemble to share their findings in a variety of ways, perhaps in different presentational forms such as music or images. Phase four took place during meetings 2 to 6. The findings of the cycle were discussed collectively and the group agreed on the reframing of research questions, research focus and actions.

7.4 Cycle 1

Meeting 1

During the process of introducing one another, Nick and I were given a brief history of the home. One participant said:

I've found the setting up process pretty awful to be honest. They just arrived in a minibus! I found it a bit much really: they visited three times and then they moved in.

Other people seemed to be keen to talk about what had been good in their experience but interspersed with this were a number of admissions that the home seemed 'chaotic', and some events had been 'a nightmare' or 'horrendous'.

I suggested that we set an agenda for the rest of the meeting together, and displayed it on a flipchart. We agreed on:

- What did participants expect from the inquiry?
- What did we understand by 'research'?
- What do we want to find out?
- How will we define our roles in the inquiry?
- Discussion and action on practical aspects of setting up music therapy sessions.
- What forms might the data collection take?
- Ethical considerations

The bullet points were indicative of the culture of the group at this point: the list of 'things to do' seemed organised and efficient with an emphasis on democratic decision-making and careful time management. All the points were addressed, although this was not a linear process.

When we tried to identify areas of interest within the inquiry there were confusions about whether the research was *on*, *about* or *with* the residents (Heron and Reason 2001). One absent participant had requested that the inquiry measured the amount of time each man chose to spend in the music therapy room.

Another wanted the research to concentrate on how residents were able to make choices in the sessions. Another wanted to look at the significant moments in the sessions and a fourth was interested in a way of researching the interaction between the men.

Reflection

I was concerned that the division into two inquiries had allowed the dynamic to move back to more traditional forms of research where the residents became subjects. My role was to move the inquiry into the here and now, and help participants recognise their own place in the inquiry.

I asked the participants how they felt about the residents not being involved in this part of the inquiry. One person was glad to be in a space where they were not interrupted, and others felt concerned that we were excluding the residents by 'hiding' in the activities room, explaining that some residents were afraid to cross the garden:

In the hospital where they used to live, the patio area was used for punishments. Maybe they think we'll do something nasty to them if they go in the garden.

A number of people made comments about whether the men had any relationship with each other. Opinion was divided: some people thought the men had 'no interaction' with each other, and others thought they did communicate. One person thought it might be possible to find out what the residents had felt about the resettlement process. There was silence after this exchange, as if something had been uncovered that was not easily expressed. I wondered aloud if the differences between our perceptions of the residents made it difficult to think about how we

might approach the inquiry. There seemed to be an air of resignation around.

A practical exercise with a video camera allowed the group to work together in a more cohesive way. The camera had a small screen which could be pulled out and viewed as the filming took place. There was laughter as people filmed each other and then shared experiences. There was some exploration of the sensitive nature of filming, especially in the community home context where a camera might represent a covert form of surveillance in order to expose poor working practices.

The discussion then became more focused on the ethical issues. If residents were being filmed, how could they understand what was happening, and give or withhold consent? Could they play with the camera in the way that group members had just done? Would the camera be safe from damage?

One participant raised the question of what would happen if a staff member needed to restrain a resident because of actions that posed a risk to others. Would they want this to be filmed? Should the camera be turned off sometimes, and if so, by whom?

Nick raised the question of therapeutic confidentiality. Who would watch the video? There was general consensus that only the people who had been filmed could watch. This would mean that some of the co-operative inquiry participants would not see the videotapes. There was a discussion about my role too; it was felt that as I was the one participant who had dedicated research time, I could make detailed observations of the sessions by watching all the videotapes retrospectively. This would provide a different perspective on the sessions from the participant-observer experiences of Nick and Anna. I would also copy tapes for all the music therapy inquiry participants for their own viewing.

Nick's preference was to work only with the residents and Anna in the music therapy sessions, enabling privacy and preserving a therapeutic confidentiality for the residents. Some staff members were disappointed not to be involved in the sessions, and we agreed that as we would be meeting after four sessions, staff could be involved in the sessions initially, but we would revisit this decision. Rose and Claire were concerned about the safety of the videotapes if all the residents, as well as Nick and Anna, had their own copies: they could be watched or even taken off the premises by agency staff.

This discussion produced the first research question:

How do we ensure that this project is ethical?

Collectively we agreed on the following actions: each member of the group would keep his or her own reflective diary; before therapy started, I would spend time with each resident individually, playing with the video camera; and when Nick and Anna started the weekly therapy they would reflect on whether, and to what extent the participants seemed to be affected by the presence of a video camera. The group also devised a brief questionnaire Nick and Anna would complete after each session. The questions were:

What did participants do in the session?

And:

What did you think was significant in the session?

After the first two sessions, I would watch the tapes with the residents and write about any reactions or comments the men might make. The managers would consult with home staff about current ethical issues, write a draft ethical protocol and bring this to the next co-operative inquiry meeting.

Discussion moved on to how a music therapy session could work practically in the men's own home. This resulted in the generation of a second research question:

How can we support the music therapy in practical ways?

The group next discussed where they thought the sessions should take place. The main problem was that the home did not have an obvious place for a therapeutic venue. Eventually there was mutual agreement that we should try the lounge in the residents' own home, which was a place where both residents and staff spent much of their time. Nick, Anna and I would bring in the instruments every week. Staff on duty would be involved in the session as participants. If residents chose not to be involved, I would stay outside the session and notice what happened when residents left the room. No person was to encourage or discourage any resident from choosing whether or not to be in the session. Staff who had taken part in the session would meet afterwards to reflect together on what had happened. I would do this later in the week with the residents, by watching the videos with them.

Reflection

There seemed to be a particular tension in the group between staying within the constraints of our own professional roles (such as accepting conventional therapeutic boundaries or exercising the nurses' duty of care), and enthusiasm for creativity and exploration. Excitement about the opportunity to understand and challenge the viewpoints of others was tempered by an anxiety about being accountable to others within the healthcare environment. Immediately after the meeting I regretted not

introducing some experiential musical improvisation. The exploration of instruments and the experience of communicating together non-verbally would have been an excellent way of giving all the participants in this part of the inquiry a sense of what the residents might be entering into.

Furthermore, there might have been opportunities to talk about the power relationships within the co-operative inquiry group. Examining them within musical play might have been a creative but safe way to bring such issues to the surface.

I felt that it had been a struggle for the group to identify research questions which did not involve research 'on' or 'about' the residents. I received a strong challenge from my supervision team about the membership of the co-operative inquiry group, particularly on account of our failure to identify anyone willing to be an independent advocate for each resident. One supervisor suggested I should exclude staff involvement altogether in order to empower the residents' voices. I felt uneasy. Exclusion seemed to be a point of high sensitivity. Did I have an unconscious agenda to protect the professionals in this inquiry? Was I not able to take up a sufficiently radical stance? A discussion with a peer group of researchers helped me to clarify that dialogue was a key concept in both reflexive inquiry and music therapy. I should respect my desire to keep the dialogue open with as many different participants as possible. I was aware of a strong sense of commitment to 'the men' from the participants. My supervisors and contemporaries were interested in the idea of the music therapy process as a form of inquiry, and so the main area of debate was

concentrated on how the staff fitted in as participants. I thought that the co-operative inquiry was an opportunity to challenge all the verbal participants to inquire into their own motivations and assumptions about the residents, and that keeping the music therapy inquiry separate but linked might allow more autonomy for the residents.

When I met residents individually to explore the camera, Steve showed some interest in filming us and was able to operate the 'on/off' button independently after a demonstration. He smiled while doing this, although I wondered how compliant⁸ this was. Ralph, similarly, operated the camera on his own but was reluctant to watch himself and seemed to me to be self-conscious. Pete consistently pushed the camera away on three different occasions, but when I replayed a sequence I had recorded, he listened and laughed in response to his voice and mine. Bill refused to hold or look at the camera, but stilled his movement as if listening when I played the film back. Jack did not stay near the camera and did not appear to attend to it.

Reflection

I felt there was the possibility of working towards partially informed consent with Steve and Ralph. Pete and Bill had showed signs of awareness that something familiar was being played back to them, but their understanding of what was actually represented seemed unclear, and also entirely dependent upon sound. Were Pete and Bill reacting to the recording as if it was happening in real time? Jack's participation in the filming event was so

⁸ The work of Sigelman *et al* (1981) explores the way in which people with learning difficulties may often smile in compliance rather than risk showing their true feelings, or lack of understanding.

limited that I concluded that he was probably unaware of being filmed or what that might mean. The justification for using the camera was solely based on whether I could use it to gain a greater understanding of the meaning of Jack's actions. This put a strain on the meaning of 'participation' and 'voice' in his case and felt like I was researching 'about' Jack. An important question within my own inquiry became 'how might I find a way of inquiring with Jack, Pete and Bill?'

7.5 Cycle 2

Meeting 2

This meeting began in a state of high tension. Participants had been busy carrying out their inquiry tasks, and had encountered problems which were perceived as serious. Although they had received information sheets and consent forms, many staff members were still unaware of the details of the inquiry because of the lack of communication within the home. One staff member participant had attempted to cancel a session because of low staff numbers. Rose and Claire had received some strong communications from home staff who were concerned that Bill might be adversely affected by participating in the inquiry. Questions included the wisdom of using the lounge, because Bill usually rested there and might not have the energy to leave if he chose. Another staff member felt the music therapy was distressing, and another participant, that Bill's dignity was compromised by hearing playback on the video.

Rose and Claire presented the draft ethical protocol, tellingly entitled *video control*. Rose focused on Bill's health needs and stressed the qualified nursing staff 'had a duty of care' to him overriding any interest in the inquiry. Nick said he

needed to be trusted with the welfare of the men. After discussion, most of the group felt that the sessions should be moved out of the lounge. This was most uncomfortable for Nick, who explained that he felt challenged because it was usually up to him to decide where the therapy should take place. Dave suggested that different people in the room had different experiences of Bill's illness, and different senses of responsibility, but everyone did seem to be feeling responsible. I asked if the difficulty of not really knowing what Bill felt had anything to do with this. Some participants felt strongly that they did know how Bill felt.

Nick agreed to move the session to the dining room so that it was clear Bill had a choice about whether to attend or not. This concession shifted the atmosphere of the meeting to a less confrontational dynamic. Participants then discussed the details of the protocol: a process of softening and clarifying. A third question was added to the post-session questionnaire:

Do you think anything was filmed which might cause distress to any participant watching it?

One sticking point was that Rose and Claire wanted to hold the residents' videotapes in their office in a locked box. If residents wanted to see the tapes, they would have to ask for them. Although a number of us felt that this restricted the autonomy of the residents within the inquiry, there was little actual resistance to the idea within the meeting.

Nick and Anna raised concerns about staff involvement. One staff participant had dominated instrumental play in the sessions without really listening to the residents. The sessions had been unnecessarily interrupted several times by other staff members, and the one resident's private viewing had been interrupted thirteen

times. The group agreed that staff involvement in and out of the session should be the focus of the inquiry for this cycle, and we would also inquire into how the change of room affected the residents. Inquiry questions for cycle 2 were:

How has the change in venue affected the therapy?

And:

How can staff members most usefully support the music therapy?’

At this point I suggested we could draw up some shared values as part of the protocol. One suggestion, which was incorporated, was this:

All work undertaken in the project is done so in a way that enables ownership of the project to be felt by the residents and those others involved.

[Cycle 2: statement of inquiry protocol]

This gave the inquiry team the opportunity to revisit the concerns about the storage of videotapes at a later date.

Participants agreed that meeting 3 should take place fairly soon as there were several issues which needed further development.

Reflection

The emphasis in this meeting was on action rather than reflection and the atmosphere had been so tense that I found it difficult to think. The difference in professional status between participants became obvious and some of the weaker participants were silent. In my research diary I used metaphors of warfare:

This seemed to be a battle over the emotive territory of the rights of different professional groups to determine what was best for Bill. What

fears are behind this? How can I open up the process to help participants develop their own individual inquiries? [Field notes: March 2001]

This time a most helpful reflexive process for me was meeting with a critical friend: a music therapy colleague who knew my work well. Together we realised that my desire to make the project a success was contributing to an atmosphere of anxiety within the inquiry. Reflecting on my style of facilitation, I decided to facilitate by saying less, but to intervene more strongly when necessary. Before the next meeting I took part in dialogue with all participants individually to support them in identifying some of the main challenges to their work.

It transpired that home staff were encountering a number of difficulties: the unpredictability of the residents, a lack of confidence in understanding the men (for all staff members had known them for less than a year), and fears about how well they could support a dying man. Developing rigid protocols and cancelling meetings were signs of dealing with uncertainty by being controlling on the one hand, and avoidant on the other. Nick felt like an outsider (an experience I also shared) and was not confident that he had the skills to work with a group of residents he saw as exceptionally demanding.

Dialogue with Anna and Claire provided some of the solutions. Anna decided that she could take an active role in mediating between Nick and the home staff informally on the days when the sessions took place. The deputy home manager and Nick decided to meet to explore the details support that participants needed within the inquiry. Practical measures like turning off the lounge television and not

having a tea break just before the session helped all the participants to focus on the music therapy.

Nick watched the sessions on the video with me and we recorded our discussion. He wondered whether some members of staff felt the lounge was *their* space rather than that of the residents as they spent rather a lot of time in there watching television. There was clearly plenty of work to be done in order to develop mutually trusting relationships.

7.6 Cycle 3

Meeting 3

In a move to develop individual reflexive processes, I had circulated transcripts of the first meeting to all participants before we met. We began the meeting simply by asking how they were feeling about being involved in the inquiry. One person spoke about her experiences of seeing her words in transcript and another about how vulnerable he was feeling as a result of the experience of the previous meeting. A third described her discomfort of being filmed. This led to a discussion about what it might mean to read transcriptions or see oneself on video. One participant said:

It gives you insight about how your actions and about how you may come across. You may not have noticed.

This part of the meeting was characterised by personal sharing of feeling, and an acknowledgement of the effort that group members were putting into the project. Rather than a need to demonstrate personal commitment, rather there was a tendency to appreciate the commitment of others in public.

The conversation turned naturally to the question of how the residents might

be able to access the video and understand it better. Ideas included thoughts about each resident's need for a private space, and choosing clips from the video which showed residents clearly so that they would be motivated to watch and listen.

Nick, having not invited staff into any of the sessions in cycle 2, began to think about ways in which they could be involved. He recognised that members of staff had an interest and a need to know what was going on. This shift in his thinking had taken place because of his dialogue with Claire.

Other participants talked about their growing recognition that it was important for the residents to have their own relationship with the music therapist and day care worker. One acknowledged the irony that she could best support the residents by not being involved.

Nick highlighted a number of other changes in his practice instigated by the co-operative inquiry such as involving residents in helping to set up the session, not putting any expectation on them to attend, and his exploration of non-conventional ways of using instruments with participants, such as rolling drums along the floor.

Some home staff in the group wanted to inquire into the possible use of video to help tackle two distinct problems of staff recruitment and communication with distant relatives. The fears of being accountable on video had now been tackled so that instead of being an object of fear, it was now a tool to use in a positive way. They suggested making a starter pack video for new employees so that they did not find their first visit too shocking. An honest discussion followed about how people reacted negatively to the residents initially; one group member saw this as opening up a 'taboo subject'.

Anna told the story of how difficult she had found her role when she had first

started working at the home. The participants agreed to reflect on this among themselves to see if they could come to a clearer understanding of why it was so hard to be new in the home.

Reflection

It was only during this meeting that I felt confident that the project would survive. Some obvious learning and insights had been developed through collaborative sharing. However, we still seemed to be struggling with the responsibility of full access and to ownership of the data.

Between meetings Nick, Anna and I prepared some of the more formal data for discussion, including attendance charts and a content analysis of our session observations. I developed a more detailed dialogue with one resident, Steve, who watched some of the video sessions in detail.

7.7 Cycle 4

Meeting 4

The first task the group tackled was to look at the attendance charts together (see Appendix, chapter ten). Some people wondered why Nick and Anna were omitted: did that mean that there was some difference in status for them as participants? This indicated another move away from researching *about* people. The second comment was that the graph did not reflect the quality or the significance of the experience. Nick asked:

Could the lines that represented the attendance of each person meet on the paper like the people met in the session?

The group agreed that space between participants was important, and perhaps

they could find a way of representing proximity and distance in relationship and in actual space. A group agreed to work on this for the next meeting.

One person noticed early graphs suggested busyness in the sessions, which fell away after the fourth session, coinciding with the change of venue. One interpretation was that Bill wasn't coming in any more and 'was voting with his feet'. Nick thought that when people were in the session, they were increasingly engaged. The discussion widened to include different interpretations of the graph: we each had our own version of 'the truth'. Instead of worrying about differences, participants began to see how multiple perspectives could help them understand more about what might be happening in the music therapy inquiry. Home staff participants made connections between some of the discoveries in the music therapy inquiry and changes which they were seeing in the residents outside the session.

Home staff in the inquiry team reported on their inquiry into the staff culture, based on informal discussions with a selection of different staff, including temporary workers. The main finding was that the residents were experienced as being unpredictable and a source of risk. Any additional considerations, such as new people coming in who were unaware of risk factors caused extra strain for staff. The music therapy was now seen as a regular, consistent structure, and therefore was welcomed. Claire said:

We are now proud of the way we are able to prepare for music therapy. Before, staff [sic] were coming to me saying, 'Music therapy's happening this morning. OH MY GOD! The residents are going to be out of the door, the instruments are coming through at the same time!' That's where the panic was coming from. Now we have a system

everything is fine.

The fear that residents might escape (the term used was *abscond*) was a central fear.

Members of staff had also reflected on systems of communications and some of the problems of operating a shift system. They were going to present their findings to the next staff meeting.

A video had been made to introduce potential staff recruits to the home, and some verbal residents in the home next door had watched videos made by staff applying to be their key workers, thus avoiding the pressure of a face-to-face interview system for the residents.

Plenty of confidence was expressed in the relevance of the findings of music therapy inquiry. We decided that Nick, Anna and I would continue to compare our perspectives of the experience and bring those to the inquiry, without revealing details which might compromise the confidentiality of the residents. We would also explore ways of disseminating these findings to others in the co-operative inquiry group and the home as a whole.

Reflection

Although there had been plenty of research activity during the previous cycle, there was pressure in the meeting to return to researching on the men. Nick, Anna and I needed to think about how to present aspects of the music therapy inquiry in a way that moved the focus onto the co-operative inquiry participants. We needed to do this by developing our reflexivity together.

We met several times to watch videos together and deepen our understanding

of what was happening in the sessions. Nick became interested in the way in which participants used space in the music therapy, and he developed a way of drawing diagrams to represent the changing space between participants.

Throughout this time Bill became increasingly ill and he died in August. During this period, home staff members were not actively involved in carrying out inquiry work. Instead, this was an exceptionally reflective phase where many people sought to find meaning of the experience of Bill's death. During the days that followed the funeral some participants told me that the residents were part of 'a second family'. Rose said that she was sometimes called 'Mum' by some of the staff.

7.8 Cycle 5

Meeting 5

As the home staff were immersed in the aftermath of Bill's death, Nick, Anna and I met to consolidate our recent inquiry work. We looked at the summaries we had made of each participant's session reports, observations and reflections up to this point, and identified six main thematic areas: *music, relationship, new events, emotions, control, and space*. These formed the starting point for my development of a more detailed analytic framework for all the empirical sources. This framework is described in chapter eight.

Our explorations allowed us to reflect on the different ways we constructed meaning about similar events, and how we identified different areas and factors of significance. The comparison led to an exploration of what 'being in the music' meant to us, why it was so difficult to find ways of talking about music and how knowing the residents in music had altered our perceptions of them.

We shared our findings with other members of the co-operative team individually and asked for comments. As a result two new themes were added to the framework: *ways of thinking* and a special *video* category.

Then, only a few weeks after Bill's death, a new resident was moved into the home (see chapter fourteen). The focus of the music therapy inquiry shifted to include the impact of this change following the bereavement.

7.9 Cycle 6

Meeting 6

This cycle began in November, six weeks before the formal close of the inquiry, so participants arranged to devote a whole morning on the inquiry. We began the meeting by reviewing what we had learned so far. Nick, Anna and I presented our learning from each resident. We had brought a book of photographs depicting various human relationships. In order to stimulate reflection about what Pete had brought to the inquiry, I asked all the participants to choose a photograph to represent the main issue in each cycle. These photographs and the reason for their choice are shown in chapter nine.

This activity stimulated a reflective period where participants began to consider how the findings from the music therapy inquiry challenged their own perceptions of themselves and the residents. A range of issues emerged. Personal lack of confidence and the limitations of the medical model were identified as the main factors preventing participants from trusting their intuitive knowledge of the residents. The residents had a right to private relationships with people outside the home, such as Nick. The residents did have much more awareness of each other than staff generally recognised, and by sharing musical experiences, some

residents had been included and involved in ways that a number of participants scarcely believed possible. Some people found it difficult to accept that the residents were communicating clearly and that they might hold strong opinions. However, when the majority of participants shared examples of when they had not listened carefully, one participant seemed to make a radical shift by admitting that when a resident did something she found disturbing, she always put it down to his autism, rather than recognising that he might be communicating something to her that she did not want to hear.

The lack of opportunity to play with objects was seen as an important area that participants felt needed further reflection and action. Nick was asked to work with the staff team on strategies to develop play with Pete and Jack. I was asked to join a working party for developing trust policy on non-verbal service user involvement.

The music therapists recognised that a traditional therapeutic stance with tight boundaries and a lack of communication with care staff helped stir up hostilities because it evoked a culture of exclusiveness around the therapy. Nick and I arranged to present some of these reflections together at a national music therapy conference the following year. The group talked about how participants coped with new events and how they felt that they should continue to embrace new experiences.

We discussed in what form the inquiry could take beyond the year. There was a strong consensus that the music therapy should continue. A suggestion was made that there could be a series of meetings and presentations involving residents, carers and family. There were plans about how to pass on our findings to

other staff groups in community homes,

As I was due to go on maternity leave, the group identified a link person who would follow up the initiatives that were being continued in the inquiry and arranged to meet again three months later.

Reflection

Although I felt sad to be leaving, it was also satisfying to think that the inquiry had generated a life of its own. I had begun to feel that I was carrying less responsibility by the sixth month of the inquiry, as participants grew in confidence in their own judgement. I worried that although there were signs of a shift in perceptions and some reframing of models of thinking, there was still a great deal of resistance to major change in nursing practice within the community home, but I felt that the co-operative inquiry was likely to make a greater contribution to music therapy practice. However, Nick and I believed that if the co-operative inquiry had not existed, the music therapy inquiry might not have survived more than two cycles because of the differences between the home staff culture and the therapeutic culture. Having the opportunity to meet several times during the process had allowed potential conflicts to be resolved, and the development of mutual understanding and respect.

I left at a stage where the third-person dimension of the inquiry was just beginning to develop. It was the time to continue my own particular line of inquiry, which was to complete a more detailed analysis of the music therapy inquiry for this doctoral thesis. This leads us to Part Three.

PART THREE

ANALYSIS

CHAPTER EIGHT

Data, analysis and representation

8.1 Introduction

This chapter first addresses some of the main issues relating to the analysis and representation of the data collected during the course of the inquiry. It was important to think about how the data and the layers of analysis could be represented in the text to provide accessible meaning, whilst retaining the depth and complexity that the findings demand. The second part of the chapter deals with how I attempted a meta-analysis of the data: my attempts to organise and interpret data which came from every aspect of both inquiries, and how this related to the original research question ‘What are the benefits of group music therapy in this setting?’ The third part explores issues of representation within the text.

The main challenge has been working with both the larger picture and minute detail, making meanings by involving a wide variety of perspectives. There was a multitude of decisions to be made along the way, in which all participants had their share. The guiding principle has been that the data set was not limited too early in the process because it was difficult to know what we as participants would ultimately find significant. This involved a greater workload for both the transcription

and the analysis. I had to accept that it was not possible to include all the information, interpretations and insights. Deciding what to exclude from the thesis has continued to be part of my inquiry throughout the process of 'writing up'.

8.2 What the analysis is not

I do not propose to analyse the music created during the music therapy sessions.. My intention was to explore multiple perspectives on the important issues which were raised through the musical play. For example, Pete often threw drums. Nick at first heard this as disrupting the music but later started thinking about it in terms of Pete wanting to organise the drums in space. I heard this as an exploration of the weight and sound of the instruments and later as a way of protesting against feeling left out. Anna at first saw Pete's throwing as challenging behaviour, but later as a way of Pete teasing, or expressing hurt.

8.3 Forms of data

Video and audio recordings

The raw forms of the data were based in sound and images. Every music therapy session was recorded on digital videotape using a small camcorder on a tripod. The voices of the residents can be heard on audio recordings taken from the videos, and extracts from these are on the accompanying CD. I decided against attempting to transcribe the sounds, because I was not seeking a structural analysis of the music. In any case, it would have been problematic to represent the sounds in Western musical notation, or in some kind of graphic form, and would have been reliant on a number of cultural assumptions. Hearing the sounds on CD captures something of the emotional experience of the music, although inevitably recorded

sound itself loses some of the essence of being in the room.

Transcriptions

All the dialogues (13) and meetings (6) were recorded on audio minidisc before I transcribed them. I chose to represent the language used as accurately as possible, to indicate pauses laughter, and where several people spoke at once. Some participants found these details disconcerting, and asked for the 'laughs' to be removed. This reminded me of an ethnographic study where a woman with learning difficulties became frustrated with the researcher because she felt that the transcriptions of her words did not accurately reflect how she wanted to say things (Goodley 1998). This taught me that dialogue in response to a transcription can be a useful process of reflexive inquiry.

Others found reading their own words a novel experience. One participant said:

It's a bit like coming face-to-face with your own personality.

[Cycle 3: co-operative inquiry]

Recording our words helped us to develop a greater sense of accountability to ourselves and to each other within the research process.

Descriptions of residents watching the videos

Although this is a relatively small part of the data, it is important. It represents to me a way of enabling residents to make some sense of being a participant in a participatory research inquiry. The descriptions are primarily my own participant observations of what happened when each resident watched himself on video, but they are developed by the perspectives of others present. Here is one example.

When Steve saw a tape of himself playing drums with Nick, he stared and said nothing. I felt that he had been quite shocked by what he had seen and had not been able to talk about it. (Steve was one participant who could be verbally articulate.) His keyworker was present at the viewing and thought his silence might mean he was unhappy about some aspect of the experience. She was unsure whether he had understood the process. I discussed this with Nick who had not been present. He wondered about the implications for his relationship with Steve and introduced the idea of using video might be a betrayal of trust. In the following session, several days later, Steve surprised us all by running into the session and playing all the instruments in the room very fast, smiling at the camera.

Post-session questionnaire

As the questionnaires were completed straight after the session, they included immediate partially-considered comments and descriptions. Participants used the questionnaires in different ways. Nick sometimes added extra reflections a few days after the sessions, and often wrote analytic memos. In early cycles, Anna wrote briefly on the questionnaire sheets, and sometimes failed to fill them in. By the sixth cycle she filled them in with attention to detail. This showed a shift in her commitment to and involvement in the inquiry and followed the detailed evaluation she had shared with Nick and myself in the previous cycle.

The first question, 'What did the residents do in the session?' helped provide different perspectives on the actions of the residents. Nick and Anna isolated the main actions they could recall immediately following the session, sometimes writing in note form, and sometimes in richly thick descriptions.

The second question, 'What do you think was significant in the session?' involved another layer of interpretation, with 'significance' allowing a range of possibilities. Comments such as 'group dynamics were particularly significant in this session' allowed Nick and Anna to connect their observations within the broader context of the inquiry process. There were as many as 355 different aspects of significance described by Nick, Anna and additional staff.

Video descriptions

These were the minute-by-minute observations that I made for each session by watching the videotape retrospectively, and were an attempt at a more detailed record of all the participants' actions. This was not participant observation except when I was present (four sessions).

The nature of my observations changed as the inquiry developed. At first, when my main focus was on patterns of attendance I chose to notice and record to the nearest five seconds who was in the room, and wrote very little else. This was essentially what Geertz would call a 'thin' description (Denzin 1994). These observations were balanced with a descriptive narrative, which ran to several pages, of the sessions in cycle 1. I included few of my own emotional reactions. The descriptions were influenced by the tradition of ethological descriptive analysis, which had formed part of my music therapy training. My aim was to focus on what the residents did rather than involve my own interpretations. Of course, I was still making interpretations but, at the outset, I was anxious to avoid the kind of assumptions referred to in chapter one.

In discussion with my supervisors, in peer debriefings, and in dialogue with other participants I began to question the nature of the descriptions. I tried to

develop the discipline suggested by Kelly's mother (Nowikas 1999) in chapter one. This involved being honest about what I could not interpret, but also included thoughts about the meaning of sounds made and actions taken in the session. Comments relating to the meaning of events or recognition of patterns could be represented in analytic memos. Over time, the session descriptions become richer. Here is an example from session 34:

Minute 8: Nick leaves to find Ralph. Steve hits Pete with a beater. The staff member filming chastises him. [I think Steve is quite affected by this and quite conscious of him.]

Analytic memo: Steve was told off because Nick was out of the room. I wonder how Steve feels, as he is normally free to express himself in the session. Steve is beginning to show Pete that he doesn't like his throwing.

[Session 34: observation]

This kind of description contains as much information about residents' actions as in the earlier descriptions but much more about how different people are reacting to the situation.

As I was not a participant for much of the process, my experience and perspective is likely to exhibit a degree of detachment or removal from the people in the session. However, I often registered strong feelings when I was watching. In most of the music therapy research reviewed in chapter two, music therapist researchers studied their own music therapy work. As our design involved two music therapists with different motivations, I believe that the possibility of dialogue between the two perspectives enriched the research.

Dialogues

The main dialogues were between Nick and me while watching the videos. I also recorded dialogues with Anna and Rose in cycles 1, 4 and 6. Transcribed, these unstructured⁹ dialogues caused much less concern than the co-operative inquiry meetings. They involved in-depth mutual explorations, including reflections on our own relationships and therefore were distinct from a more traditional research interview.

Communication reports

However, I included extracts of communication reports written for each resident by a speech and language therapist because they were helpful in planning the individual photographic resources mentioned in chapter five. Chapters nine to twelve include brief extracts in order to introduce the residents but they are not included in the analysis.

8.4 Cycle 7 – further analysis

As described in chapter seven, participants were involved in the analytic processes in the first six cycles. I then undertook a further period of analysis attempting an overview of the data as a whole, after the inquiry had finished. This forms the basis of the thesis.

My intention with the overall analysis was to discover patterns and themes which ran through all the data.

⁹ Rather, the only structure introduced involved watching videotape.

Deciding on the mode of analysis

What is analysis in participatory inquiry? Analytic processes occur throughout the cycles, involving many layers of interpretation and decision. Insights developed from reflexive inquiry are themselves the outcome of an analytic process. However, in order to identify patterns across a large collection of data, I needed a systematic, qualitative, analytic tool which had been tried in other situations.

As the main research question focused on identifying the benefits of the music therapy, this helped discount the option of grounded theory, as the purpose of the research was not to generate theory. Phenomenological analysis focuses on the nature of experience, and is essentially descriptive, but it does not acknowledge that our experiences may be part of our own history, personality and culture. As Smeijsters asks:

Who among us can be sure that our emotions and sensations are grounded in the experience we are studying, and not in our own individual personalities?

(Smeijsters 1997: 52)

In chapter four, one of Heron's criteria of validity was to manage unaware projections which result from a participant's unprocessed distress of earlier years. A phenomenological approach would not necessarily incorporate such aspects.

The chosen analytic method needed to be flexible enough to incorporate different ways of knowing. I explored the option of discourse analysis by joining a discourse analysis group and sharing some of the raw data to be analysed. The insights gained from this experience were helpful. Even so, the insights gained would mainly have been in relation to the people who had produced the texts.

Narrative and thematic analysis were possibilities. Eventually I decided on a form of thematic analysis called *Framework* because I felt confident that it would allow me to identify patterns across the wide range of the data. The danger of this type of content analysis, however, is that as the data is segmented, important processes get lost. Therefore I needed to reflect on how the method might be adapted to allow the processes to remain visible and intact.

8.5 Thematic analysis: *Framework*

Framework (Ritchie and Spencer 1994) is a system of qualitative analysis, developed by the authors within the context of applied policy research.

Framework has the following key features:

It is *grounded* or *generative*; that is, strongly based in the original data.

It is *dynamic*: it can be changed throughout the process, for example, if new data becomes available.

It is *systematic*, and methodically applied so there is rigour.

It enables easy retrieval.

It *allows between- and within-case analysis*, so that patterns between different data groupings may be made.

It is *accessible to others*; and therefore could be used as a shared system of analysis between participant-researchers

(Ritchie and Spencer 1994: 176).

The application of the method for participatory research

The authors emphasise that although the method consists of distinct stages and is systematically applied, each stage is highly dependent on the analyst for making

meanings, connections and interpretations. As the process is clearly documented, it allows backtracking and the reworking of ideas, keeping the process creative and transparent. Ritchie and Spencer criticise many qualitative methods for not outlining the rigour of their analytic processes adequately. In applied policy research, they argue, the data are generally unwieldy, mainly text-based and contains a vast amount of detail. *Framework* allows the possibility of gaining a sense of structure and coherence without losing the sense of the raw data.

Ritchie and Spencer do not give accounts of situations the method has been used in action research. However, in participatory action research, any participant undertaking analysis is accountable to the other participants. A rigorous method of analysis ensures that each participant's contribution is contained within the analytic process. A transparent process with easily identifiable stages allows other participants to access the method and challenge any interpretations and assumptions made.

8.6 The stages of *Framework*

There are five key stages:

1. *familiarization* with the data
2. *identifying a thematic framework*
3. *indexing* the themes
4. *charting* the data in two dimensions
5. *mapping and interpretation* (Ritchie and Spencer 1994: 178).

After a description of each stage, I will summarise how it was applied within our inquiry.

Stage One: Familiarization

This involves immersion in the material such as listening to tapes, reading data and taking notice of the accounts collected by other researchers. It is important to become familiar with the data set as a whole. The authors suggest that if the data set is too large for the time available at this stage, a selection of each data type could be made, including different cases, times and sources.

Over the period of the inquiry and for three months beyond this, I became familiar with all the recorded texts by transcribing and transferring them to Atlas ti, a computer data management programme. The material incorporated 145 different texts, which included the data types described earlier, as well as field notes, my research diary, and all the documents produced by the co-operative inquiry team.

As mentioned earlier some of these empirical sources were steeped in analysis, either through reflective dialogue or in the form of analytic memos. Therefore, the process of applying *Framework* represented a form of meta-analysis: a thematic analysis of the various analyses made collectively and in dialogue throughout the research cycles.

Stage Two: Identifying a thematic framework

At this point, the researchers return to the notes made during the first phase to identify recurrent themes, issues and patterns which emerged, including the researchers' own responses to the material. The researchers decide on the key concepts or issues and construct a thematic frame within which all the data may be held. This process is a combination of intuitive and logical thinking, making interpretations about meaning, relevance and how ideas are connected. In order to refine this complex process the researchers move through a number of drafts

(Ritchie and Spencer 1994: 180).

I found that this was one of the most intellectually demanding parts of the analytic process. There seemed to be innumerable connections between the different parts of the inquiry and I found it difficult to hold them all in mind. The process was complex because the participants had been assigning meanings to the non-verbal/textual parts of the data. I drew up six drafts before finalising the Framework. Some of these drafts are shown below to illustrate how my thinking developed throughout this process.

I played with different ways of generating categories. In the first draft I tried to generate a 'new events' category formed from multiple accounts of the first two sessions in the music therapy inquiry. Here is an extract from draft one, showing quite a mixed range of categories.

New Events

- 1.1 Relationship in music
- 1.2 Individual musical events
- 1.3 Relationship pre-musical
- 1.4 Individual pre-musical events
- 1.5 New sounds – therapist
- 1.6 Giving and accepting
- 1.7 Therapist direction (includes boundary setting)
- 1.8 In/out of room
- 1.9 Doors and locking
- 1.10 Absence
- 1.11 Verbal

1.12 Furniture arrangement

1.13 Video

1.14 Staff and outside influence

This first attempt includes a number of elements and ways of making meaning incorporated in the final Framework scheme, but here they are all contained within one unwieldy and disparate theme.

For the second draft the main categories were arranged around participants in the inquiries (see figure 6, p184), in an attempt to make the residents' issues central. It also incorporated aspects of first, second and third person learning. One of the problems of this system was that many of the categories were duplicated. The conceptual framing was grounded in action research theory rather than emerging from the data.

Draft Framework 2

| 1 Pete | 2 Jack | 3 Ralph |
|--|---|--|
| 1.1 Actions over time | 2.1 Actions over time | 3.1 Actions over time |
| 1.2 Relationship with others | 2.2 Relationship with others | 3.2 Relationship with others |
| 1.3 Changes in thinking | 2.3 Changes in thinking | 3.3 Changes in thinking |
| 1.4 Staff perceptions of 'challenging behaviour' | 2.4 My learning from him | 3.4 My learning from him |
| 1.5 My learning from him | 2.5 What the organisation can learn from him | 3.5 What the organisation can learn from him |
| 1.6 What the organisation can learn from him | 2.6 Other | 3.6 Other |
| 1.7 Other | | |
| 4 Bill | 5 Steve | 6 Nick |
| 4.1 Actions over time | 5.1 Actions over time | 6.1 Actions over time in therapy |
| 4.2 Relationship with others | 5.2 Relationship with others | 6.2 Actions over time in co-operative team |
| 4.3 Changes in thinking | 5.3 Changes in thinking | 6.3 Relationship with others |
| 4.4 My learning from him | 5.4 My learning from him | 6.4 Changes in thinking |
| 4.5 What the organisation can learn from him | 5.5 What the organisation can learn from him | 6.5 My learning from him |
| 4.6 Other | 5.6 Other | 6.6 What the organisation can learn from him |
| | | 6.7 Other |
| 7 Anna | 8 Home staff | |
| 7.1 Actions over time in therapy | 8.1 Actions over time in co-operative team | |
| 7.2 Actions over time in co-operative team | 8.2 Changes in thinking | |
| 7.3 Relationship with others | 8.3 Relationship with others | |
| 7.4 Changes in thinking | 8.4 Changes in role | |
| 7.5 My learning from her | 8.5 Barriers to changing | |
| 7.6 What the organisation can learn from her | 8.6 My learning from them | |
| 7.7 Other | 8.7 What the organisation can learn from them | |
| | 8.8 Other | |

Figure 6

Draft Framework 3

| 1 Music | 2 Relationship | 3 Psychological Issues |
|--|-----------------------------------|--|
| 1.1 Changing relationships within music | 2.1 Changes in relationship | 3.1 Forms of emotional expression |
| 1.2 Instrumental play | 2.2 Significant relationships | 3.2 Jealousy and rivalry |
| 1.3 Vocal play | 2.3 Communication issues | 3.3 Attachment issues |
| 1.4 What is music? - idioms and boundaries | 2.4 Cross-cultural issues | 3.4 Grief |
| 1.5 Noise and silence | 2.5 Group dynamics | 3.5 Assigning emotions to others |
| 1.6 Other uses of music | 2.6 Teamwork | 3.6 Confusion between thinking and feeling |
| | 2.7 Perceptions of relationships | 3.7 Other |
| | 2.8 Other relationships | |
| 4 Changes in thinking | 5 Power and control | 6 Space and time |
| 4.1 Attitudes toward music therapy | 5.1 Choice | 6.1 Practical difficulties |
| 4.2 Impact of the new | 5.2 Exercising power | 6.2 Inside and outside |
| 4.3 Changes in roles and skills | 5.3 Predicting the future | 6.3 Space in terms of relationship |
| 4.4 Attitude towards self | 5.4 Disabling barrier | 6.4 Session boundaries |
| 4.5 Attitude towards others | 5.5 Barriers preventing access | 6.5 Space between objects |
| 4.6 Constructions of 'challenging behaviour' | 5.6 Other | 6.6 Perceptions of time and space |
| 4.7 Perceptions of 'normality' | | 6.7 Issues surrounding home |
| 4.8 Other | | 6.8 Other |
| | 7 Video | 8 New Events |
| | 7.1 Experience of watching videos | 8.1 New sounds |
| | 7.2 Issues of consent | 8.2 New actions |
| | 7.3 Issues of confidentiality | 8.3 New group member |
| | 7.4 Attitudes towards video | 8.4 Changes in attendance |
| | 7.5 Practical issues | 8.5 The shock of the new |
| | 7.6 Limitations of video use | 8.6 Newness versus familiarity |
| | 7.7 Practical issues | 8.7 Other |
| | 7.8 Other | |

Figure 7

Moving from draft two to three was probably the most difficult part of the analysis as it involved experimenting with a number of ways of thinking of the main categories, trying to hold what was most important in mind and finding a way of including all the data. Musical aspects were more strongly emphasised this time.

The third draft (see figure 7, p185) incorporated all the final category headings, at least in essence. Within the sub-categories, the emphasis was on the changes that had come about through the music therapy. For example, category 1.1 emphasises how relationships change within music, and theme four is entirely devoted to how participants' attitudes had shifted. Data relating to all the participants could be included equally. At this point I made the decision to present the findings in chapters named after the residents, thus ensuring that they remained in the centre of the picture.

Some of the categories in the final working version came directly from participant questions: they included *instrumental play* (Anna's main interest) and *new sounds* (Jack and Steve). Others were apparent only when I became fully engaged with the data, such as perceptions of time and space, and predicting the future. These categories included patterns emergent across all levels of the inquiry. Some illustrated how the participants changed their perceptions and assumptions, indicating first-person learning.

The final three drafts were stages of refinement of the Framework scheme. I relied on feedback from my supervision team for this process. To me this marked a move from being a participant to making my own voice and understanding of the process more central.

Final Working Framework

| 1 Music | | 2 Relationships | | 3 New events & patterns | |
|---|-----|--|-----|--|-----|
| 1.1 Musical relationship | 641 | 2.1 Important relationships | 753 | 3.1 New sounds | 151 |
| 1.2 Instrumental play | 691 | 2.2 Group dynamics | 373 | 3.2 New actions | 396 |
| 1.3 Vocal play | 143 | 2.3 Communication issues | 301 | 3.3 Attendance | 433 |
| 1.4 What is music? | 57 | 2.4 Attachment issues | 69 | 3.4 New group member | 27 |
| 1.5 Interpretations of music | 142 | 2.5 Cross-cultural issues | 300 | 3.5 Perceptions of patterns of behaviour | 243 |
| 1.6 Perceptions of listening / awareness | 221 | 2.6 Perceptions of relationships | 100 | 3.6 Responses to newness | 95 |
| 1.7 Other aspects of music | 82 | 2.7 Other relationships | 23 | 3.7 Other | 0 |
| 4 Emotions | | 5 Ways of thinking | | 6 Power and control | |
| 4.1 Range of emotional expressions | 328 | 5.1 Responses to music therapy | 113 | 6.1 Choice | 153 |
| 4.2 Jealousy and rivalry | 93 | 5.2 Perceptions of 'significance' in therapy | 355 | 6.2 Exercising power through action | 344 |
| 4.3 Loss | 56 | 5.3 Identity and roles | 272 | 6.3 Exercising power through non-action | 65 |
| 4.4 Attributing emotions to others | 185 | 5.4 Self-awareness | 154 | 6.4 Predicting the future | 129 |
| 4.5 Diparity between thinking and feeling | 13 | 5.5 Perceptions of others | 211 | 6.5 Not knowing | 156 |
| 4.6 Other forms of emotional expression | 27 | 5.6 Constructions of 'challenging behaviour' | 80 | 6.6 Disabling barriers | 85 |
| | | 5.7 Constructions of 'risk' | 56 | 6.7 Ownership | 83 |
| | | 5.8 Other ways of thinking | 192 | 6.8 Perceptions of power relations | 127 |
| | | | | 6.9 Conflict | 44 |
| 7 Space and time | | 8 Video | | 9 Health | |
| 7.1 Inside and outside | 406 | 8.1 Responses from watching videos | 62 | 9.1 Aspects of illness | 49 |
| 7.2 People in physical space | 314 | 8.2 Responses to the use of video | 103 | 9.2 Aspects of medication | 11 |
| 7.3 Instruments in physical space | 219 | 8.3 Ethical issues | 101 | | |
| 7.4 Boundaries in therapy | 344 | 8.4 Benefits of using video | 35 | | |
| 7.5 Perceptions of time and space | 146 | 8.5 Limitations of using video | 16 | | |
| 7.6 Issues about home | 132 | 8.6 Practical issues with video | 100 | | |
| 7.7 Practical difficulties | 144 | 8.7 Other | 0 | | |
| 7.8 Other | 31 | | | | |

The figures in red refer to the number of textual segments assigned to each category during the indexing stage

Figure 8

In one discussion the need for 'change' to be represented within the themes was questioned. As change was a pivotal dimension both in therapy and social action research any category should be able to demonstrate it in some way. Therefore I rethought all the categories relating to change, and also used the more universal term *emotion* in place of *psychological issues*. I felt this was more in the spirit of this inquiry. These changes resulted in draft six which became the final working framework (figure 8, p187).

Stage Three: Indexing

Indexing involves applying the thematic framework systematically to the data by linking themes to portions of the text. This involves making decisions about the size and meaning of the textual portion. Ritchie and Spencer suggest annotating transcriptions with the category numbers to show how the decisions have been made.

The use of the *Atlas ti* software programme allowed me to select large portions of text. It was possible to apply multiple categories to one portion. This helped to prevent excessive segmenting and fragmentation of the data. Here is an example of how I indexed a long paragraph

Anna: Pete kept moving the instruments around like the drums, especially putting them upside down. I was really wanting to know what he was meaning by that. Because sometimes I thought he'd move the instruments around because he wanted Nick to play them.

Cathy: Right.

Anna: That did cross my mind a few times. I was thinking 'well maybe he just wants you to play that one'.

[Cycle 6: Dialogue with Anna]

In this extract I applied musical relationship (1.1), instrumental play (1.2), important relationships (2.1), new actions, i.e. upending drums (3.2), perceptions of others, i.e. Anna's perceptions of Pete's motivations and wishes (5.5), choice, i.e. Pete's choice of action (6.1), not knowing, i.e. Anna's wondering about the meaning of Pete's actions (6.5) and instruments in physical space (7.3).

Indexing 250,000 words of text was made less onerous than it might have been because of the ease and speed which *Atlas ti* made possible. *Atlas* was also able to sort each theme and category, and print out a list of all the textual segments relating to any category I wished to explore. As the layers of coding were quite dense, the complexity of the cross connections became ever more apparent. The brief descriptions of resident's actions in the session observations were especially rich in potential meanings. Here is an example of this:

Pete takes the windchimes out of the room. Nick stops him. Steve goes over to the windchimes at the door and strokes them. Steve then locks the door. Nick says 'why have you locked Pete out? Steve says 'because I have!' Steve then plays the windchimes.

[Session 37: observation]

Ten categories applied to this piece of text: musical relationship (1.1), instrumental play (1.2), important relationships (2.1), group dynamics (the triangle of Pete, Steve and Nick) (2.2), communication issues (because I thought Steve spoke fluently and with wit following what might have been an empowering action for him) (2.3), perceptions of significance in therapy (I had marked it as being particularly significant) (5.2), exercising power through action (6.3), ownership (Pete then Steve claiming ownership of the windchimes) (6.7); inside and outside (applies to

taking instruments outside, and locking Pete outside) (7.1) and instruments in physical space (7.3).

Reflections on the process of categorization

Initially I was reluctant to use coding techniques because I was concerned that fragmentation of the data might lead to a superficial analysis, and that underlying meanings and insights might be lost. However, the *Framework* method allowed unusual and interesting links between seemingly disparate data.

One metaphor that I have found useful is to conceive of *Framework* as a large building, with the themes as particular wings and the categories as different rooms. Sorting data between rooms allows data of all shapes, sizes and qualities to occupy the same space. The analogy begins to break down, however, if we consider that *Framework* allows the same data to occupy several rooms at once. Nevertheless, within a room many interesting connections can be made between disparate types of data. Some rooms may contain mainly Ralph's possessions, say, Pete's may dominate another. In some rooms there may be an equal mix, such as for the categories 'self-awareness' and 'communication issues'.

Five more sub-categories emerged during the indexing process: *conflict* which was subsumed into theme 6 ('power and control'), *non-verbal communication* which became part of 3.2 (*communication issues*), *interpretations of session atmosphere* which became part of 5.1 (*responses to music therapy*) and *aspects of medication* and *aspects of illness* which were presented within a new theme of 'health'.

Stage Four: Charting

This is a vital part of the process and involves lifting the data from their textual

sources and rearranging them in two-dimensions on large charts. Each chart corresponds to one of the themes, which have subheadings on one axis relating to each category. Every entry in the chart needs to be abstracted from the data and summarised and presented in a form chosen by the analyst.

Figure 9 illustrates the way in which the axes worked for each chart. It was possible to read across each chart to see how any aspect of any category changed over time. In order to follow the process of a particular person within a category I used coloured 'Post-it' notes. For example, to follow the progress of Bill all I needed to do was isolate the green notes within each cycle. Some of the main processes over the year of the inquiry became clearly visible using this method. The charts were A1 size and each contained several hundred stickers and as one friend remarked, they looked like a piece of modern art. Charting was the most time-consuming part of the analytic process and took several months.

| | CYCLES | 1 | 2 | 3 | 4 | 5 | 6 |
|-----|-------------------------------------|---|---|---|---|---|---|
| | THEMES | | | | | | |
| 1.1 | Musical relationship | | | | | | |
| 1.2 | Instrumental play | | | | | | |
| 1.3 | Vocal play | | | | | | |
| 1.4 | What is music? | | | | | | |
| 1.5 | Interpretations of music | | | | | | |
| 1.6 | Perceptions of listening/ awareness | | | | | | |
| 1.7 | Other aspects of music | | | | | | |

Figure 9 Chart representing theme one: music

Stage Five: Mapping and Interpretation

This is the final stage described by Ritchie and Spencer, where the analysts ‘pull together key characteristics of the data’ (Ritchie and Spencer 1994: 186). They suggest a range of interpretation methods, namely:

- Defining concepts
- Mapping the range and nature of the phenomena
- Creating typologies
- Finding associations
- Providing explanations
- Developing strategies.

In the following six chapters I hope to demonstrate some of the ways I have chosen to make meaning from this process, and some of the patterns that have felt important to explore. I have mainly chosen to make structures from processes discernible to me through the cycles. Each chapter is named after one of the residents.

An important aspect of interpretation concerns representation of the data and analysis. In the remainder of this chapter we will consider aspects of representation, including the problems of representing different players in the inquiry, the relationship with the reader, and alternative forms of text.

8.7 Hypertextuality

Hypertextuality theory, as informed by literary theory (Bakhtin 1996) explores ways of thinking about text as a non-linear experience. One example is the information on a CD ROM, where sections of linear writing, pictures and video files may be accessed according to the choice of the ‘reader’. Stige points out that *text* in

Greek originally meant *web*, so that portions of text act as nodal points with many interconnections (Stige 2002: 158). Foulkes used a similar metaphor to describe how groups work: the term *group matrix* is a way of describing how different individuals in a group connect to each other, and the *unconscious matrix* denotes the links each individual has to their culture and personal history (Foulkes 1984). Stige, whilst accepting there may be problems about considering actions and music as texts, has explored hypertextuality as a useful metaphor in music therapy (Stige 2002: 155-178). He presents the example of a woman in music therapy that uses music to explore meaning in her life on a number of different levels. She uses songs as links to her culture, to her personal history, and also to her world of feelings. She herself embraces the idea of hypertext as a metaphor for her therapeutic journey.

Music therapy allows many different links between music and words, and links between actions and music. It also allows us to move between different time frames: the 'here and now', past events or feelings, the possibility of trying something new. As I said in chapter one, time itself need not be thought of only as a linear process.

8.8 Representational validity

Lather has suggested that for a text to have representational validity in action research it must have four facets: situated, rhizomatic, reflexive and ironic validity (Lather 1993). Situated validity occurs when the text contains a reflective and emotionally connected voice of the author. The rhizomatic validity concerns representation of the multiple voices of the co-researchers. Reflexive validity relates to the degree to which the text questions its own validity. Ironic validity

occurs when the reader is involved in interpretation and decision-making within the text. In order to explore the reflexive validity of the thesis, I will explain how I struggled with some of these issues of representation.

Situated validity: representing personal selves in the text

How does one represent the multiplicity of cultural and experiential influences on one's thinking without disorientating the reader? In chapter one I identified over fifteen 'selves'. Representing them as separate voices runs the risk of being cumbersome and confusing. Richardson (1994) talks of how we suppress or silence certain parts of ourselves of necessity when we write. My personal voice within this thesis is primarily there to present reflexive aspects of self: the parts of me that make meaning.

These parts are informed previous experiences, as represented by the imported selves of mother, musician and so on, and are reformed by reading, and my development of critical subjectivity through encounter with others during the inquiry.

Judi Marshall writes:

As I inquire, I am partly making choices about when to move from action into reflection and vice versa, and what combinations of inner and outer attentions to hold...Tracking these movements between states and forms of activity is a key aspect of self-reflective questioning (Marshall 2001: 434).

Marshall's narrative is characterised by alternating paragraphs headed 'action' and 'reflection'. In contrast, when attempting to represent the 'multiple realities which dance and collide', Susan Weil identifies three first-person voices: the voice of the post-positivist researcher occupying the main body of the text, an actively reflective

voice (indented text), and a context-situated voice from field notes (Weil 1996). Her second, reflective voice is free from linear representation of time, but as with Marshall's paragraphs of reflection, this works because it interacts with the main body of text representing events as they unfold in linear time.

Marshall and Weil emphasise the importance of establishing a discipline of reflexivity, clearly communicated to the reader. Given that reflexivity may occur at any point during an inquiry, and may be brief, as in a flash of insight, or over a prolonged period of reflective time, it would be impossible to capture every example. But examining the nature and quality of reflexive thought so that the reader is aware of how it develops should contribute to the trustworthiness and validity of the inquiry.

Reflections on the complexities of reflection and reactivity

I have found it useful to indent reflexive writing in italics within the main body of the text. Although I experience reflection as separate from action, sometimes the movement back and forth is rapid. There are different types of reflective space. The time immediately after an event might be a combination of reactivity (unprocessed action or feeling) and reflection. The act of communicating this helps me move through a further process of reflection. Heron warns of the dangers of reactivity without reflection, but I have found that even if I have explored my own reactions to distressing events in my past, I am not always free from reactivity. Sometimes reflecting on my unprocessed reactions can be enlightening: it is useful to have them in the first place.

Psychotherapeutic concepts such as projection may be cultural constructs, but using them is one way of acknowledging that our emotional reactions to events affect our reflection. Furthermore, others involved in the encounter will have

feelings that may further affect what happens in my reflection. Perhaps part of the process of reflection is a way of separating out my feelings from those of others, and providing me with constructs that enable me to decide what to do next.

Rhizomatic validity: representing multiple voices in the text

The multi-voiced text is the most straightforward: representing the words of participants who were able to communicate using spoken and written language. In a participatory project, the voices of the participants must be heard, and the juxtaposition of these voices may indicate the specific dynamics within the group: for example where one participant's contribution influenced a change in another's perceptions. Chapter six is presented in two columns. The juxtaposition of participant quotations is governed by linear chronology to a certain extent. However, the reader is free to read the page in whatever order she chooses.

On reading the first draft of chapter six one of my supervisors commented:

The contrasting perspectives left me free to make meanings that were not explicit in the text.

[Hazel Morbey: personal communication]

By implication then, there is some ironic validity in this text. Through interpretation of the spatial representation, aspects of power, influence and change may be implied and interpreted by the reader. In chapter six I chose participant quotations before writing the narrative in the second column and this enabled the commentary to be slightly more participant-led. I have needed to critically reappraise some of these decisions several times.

The use of different media in the representation of voices

Richardson (1994) asserts that writing itself is a form of inquiry, and that

postmodernism has freed the researcher to write in experimental ways. She mentions forms of representation such as the use of pictures, and dramatic and poetic textual forms. Music is not included in her list, but, by implication, could be.

Music as text

Music has been treated as text in a number of research studies in music therapy. Accompanying CDs can be found in the doctoral theses of Lee and Ansdell, and Agrotou's thesis was later disseminated as a video including many musical and visual extracts.

Although participants in our inquiry collectively decided that the video data were not to be made available to anyone outside the music therapy inquiry, audio recordings from these videos was allowed, because it was still possible to preserve anonymity.

Images as text

The use of images has been important in this inquiry, so this should be reflected in the thesis. We used photographs, videotape and even created a collage as part of the inquiry process. This allowed participants to select significant parts of the data and critically reflect on our perceptions of the residents, and ourselves.

The use of photographs in qualitative inquiry has been established for some time (see Appendix 6).

Reflexive validity: how valid is the text of this thesis?

The greatest challenge in the thesis is the representation of voice which is not in spoken or written form. This leaves the responsibility for assigning meaning to actions to others. Further analysis is not open to the actors themselves. In this way, the thesis is limited. Presenting Pete's music as text on the CD does

improve this aspect of validity, although the use of video would have helped more. However, protecting the confidentiality of the vulnerable participants became a more important concern in the research. Nevertheless, I have sometimes wondered if keeping confidentiality might be an excuse sometimes for suppressing that which is hardly audible in the first place.

This dilemma is not restricted to people with learning difficulties. Clough asks:

How do we give voice to those – the differently articulate – whose words will not be heard? How do we understand that which is suppressed?

(Clough 1998:131).

In this case, he is writing about being with boys who use language which is full of swearing and colloquialisms.

Ironic validity: the autonomy of the reader

Situated validity is related to ironic validity because it deals with the relationship between writer (representer) and reader. I am interested in learning how readers find this text ironically valid. One music therapy colleague wrote the following in response to a reading of chapters nine to fourteen:

Very thought-provoking and moving to read. The use of photos as a way round confidentiality/consent issues seemed often very enlightening. However two photographs selected as part of the inquiry process in Pete's chapter seemed rather bizarre choices! For example, the two little girls: so odd that I found it distracting. I was impressed by the subtlety of body language and miniscule interactions it was possible to analyse due to the video – for a long

time I was **sure** Cathy had been in the room in the sessions from the descriptive immediacy and sensitivity to the emotional atmosphere. Video seems especially useful in a group situation. However, it did seem an intrusion, distressing to at least one resident. How does one ethically weigh up the huge benefits against the intrusion? Very interesting how Aidan's arrival showed there was indeed a group identity which I, too, had questioned. Reading this reminds me how complex the simplest music therapy 'event' or interaction is. We owe it to ourselves and to our clients to think about our work in detail (Lisa Otter-Barry: personal communication).

The unusual nature of the representation of the data does seem to provoke strong views and reflections, which are quite varied. Clearly though, the text allowed this reader to form her own views, which seems to have been quite a dynamic process.

8.9 Summary

I began this chapter by looking at the main data forms and taking the reader through various decisions I made, initially with the other participants, and alone during the further process of analysis. There followed a discussion of different aspects of representational validity, and an exploration of the creative options available to us through different media. We are now prepared for the following chapters which contain audio and visual material as well as multiple reflexive voices.

PART FOUR

THE RESIDENTS

Introduction

In the following six chapters the format is generally the same. I start with a vignette introducing each participant. For the first four men, I provide information from communication reports provided by a speech and language therapist employed as an educational consultant by the Trust, so these are not officially from healthcare records. I explain which categories I have drawn from Framework for each person, as retrieving information from every category would make for unwieldy chapters. Then I present the empirical sources, with some examples from 'raw data'. In the case of the chapters entitled 'Pete', 'Jack' and 'Ralph', I have found patterns by examining quite fragmentary data owing to the nature of their participation. For them, I have summarised the main findings in a table of the cycles for ease of reference. With 'Steve', 'Bill' and 'Aidan' I have been able to base my findings around fewer main themes so have not felt the need for summary tables.

I present overviews of each aspect the empirical sources address and present summaries that link to the concluding chapter.

CHAPTER NINE

Pete

9.1 Vignette

Pete hangs his head slightly to one side and does not look to either side. He stands by the window, occasionally dipping slightly by bending one knee. He puts his open palm just in front of his eyes and moves it away then slowly returns it. He repeats this movement, with an occasional knee bend, over a hundred times. At the same time he pushes his hand closer to his face again, holds it there for a few seconds then moves it slowly away in the same repetitive pattern. Pete appears to be uninterested in anything in his environment, and may stay for an hour in the same pose. The other residents leave him alone. Slowly he turns, without looking, and shuffles noisily towards the kitchen. Someone has left a chair in the corridor. Pete starts to push it and in a sudden, unexpected burst of energy knocks it right over with a resounding crash. He resumes his knee jigging and palm gazing.

9.2 My Impression

Pete is forty but looks younger. This youthful impression is exaggerated by his loose-fitting tracksuit and square shoulders. He has a jaw and forehead which jut out unusually. His skin is quite pitted, so he appears rough-hewn. Pete moves around carefully, giving the impression that he is almost blind but he will suddenly stop and look carefully at a person or object. He has small hands and uses them delicately. He will sometimes slap his chest hard while he chuckles. He has often stood in front of me with his head bowed,

expectantly. If I do not react he will gently take my wrists and place my hands on his cheeks, waiting to be patted. I feel pleased when Pete comes along; I like his careful curiosity.

[Field notes: January 2001]

9.3 Background

Pete had lived with Steve, Ralph, Bill and Jack for fourteen years in two long-stay institutions. His mother kept in contact, but Pete had not visited her at home for fourteen years. Living in the community home had opened up this important possibility and Pete went to visit his mother for the first time just as the inquiry began.

Pete had tuberous sclerosis, resulting in many small brain tumours which caused epilepsy and profound learning difficulties. He had very limited communication available to him.

Pete does not use speech, signing, pictures, eye pointing, symbols, objects of reference or gestures to communicate. He does use whole body movements like going towards someone he likes. If he does not like something he moves away. He does not initiate moving towards any object he wants and does not reach out. He needs increased opportunities to initiate choices and people who understand him well. He understands when he is excluded, and can understand the word 'no' when accompanied by gesture/intonation.

[Communication report November 2000]

Pete had found settling in the home difficult, and after six months was still not sleeping through the night. When members of staff tried to hang curtains up to make the home more 'normal', Pete tore them down again. He also behaved quite

unsociably at home, sometimes throwing large objects. As a result, the television had been bolted to the floor and no moveable objects were left lying around. The kitchen was locked so that Pete could not get in to throw the crockery, or worse, a kettle of boiling water. However, this meant that none of the residents had access to the kitchen. Pete would often stand outside the kitchen door, waiting for a cup of tea, or perhaps because he knew he could not get in.

One participant gave an account of visiting him when he lived on a hospital ward.

He just reminded me of pictures you used to see of Rumanian orphanages. He just stayed in the corner of the room rocking. No interaction. He didn't like people. He used to take his clothes off and stuff. You could never get him to be part of anything. And over here now, he's got social skills coming out of his earholes.

[Co-operative inquiry: cycle 1]

Expectations of Pete in the inquiry were low. One experienced participant said:

To get him to take part at all would be nice.

[Co-operative inquiry: cycle 1]

9.4 Issues about participation and assent

Staff members were concerned that Pete's mother, as the next-of-kin, might refuse assent for Pete to be involved in the inquiry because of a fear that he might have exposure on the Internet. I wrote a letter assuring her that there would be no possibility of this, and explaining in detail the processes the research was likely to involve. She returned the signed form with a letter saying that she was glad he had the chance of some music therapy. This taught me the value of addressing individual circumstances when setting up the inquiry.

9.5 Organisation of the data

Despite expectations, Pete's involvement in the inquiry was so rich that a large number of the Framework categories apply to his data. Participants in the music therapy inquiry identified the following categories as 'significant' in relation to Pete: instrumental play; perceptions of challenging behaviour; and perceptions of risk (categories 1.2, 5.6 and 5.7; see figure 10). In addition I have chosen: musical relationship; vocal play; perceptions of listening and awareness; important relationships (both peer and therapeutic); and attendance (categories 1.1, 1.3, 1.6, 2.1 and 3.3) as the categories most strongly associated with Pete. In order to show the links between each of the themes, they are presented alongside each other as we move through the cycles. I include some audio examples so that the detailed changes he made in his vocal play can be experienced by the reader. General trends are summarised in figure 11, leading on to a discussion of how they interrelate; I conclude with a summary of how Pete contributes to the inquiry.

9.6 Cycle 1 (sessions 1- 4)

Attendance

According to Pete's communication report, the choice to come into the music therapy room towards instruments and participants was a communication of intent. On the attendance graphs (see Appendix 7) the line that represents the minutes when Pete was in the room shows that at first he was in the session very little. From my field notes, it appears that he spent most of the time standing just outside the door.

Instrumental play

When Pete did come in he threw and kicked instruments. In session 1 he picked up a drum to give to Nick. Nick thought Pete was interested during the session, but later questioned this in reflection.

In session 4 Pete takes beaters outside, although no instruments. I reflect:

Perhaps he wants the music for himself.

[Session 4: analytic memo]

Perceptions of listening and awareness

Pete laughs in response to sound when a video of Nick singing is played and also laughs in response to other sounds in the sessions.

Vocal play

No data.

Important relationships

I notice that Ralph gets up exactly when Pete leaves the room in session 1 and I wonder whether there is some connection between the two of them. Nick says in reflection outside the session:

There's something *different* about Pete. Somehow his presence is going to be disruptive.

[Cycle 1: dialogue with Nick:]

Representing musical relationship using photographs

Towards the end of the project, in cycle 6, participants in the co-operative inquiry team developed an experiential activity where they selected photographs depicting Pete's progress through the cycles. The choice was from a wide range of images (source: Marsh 1988) and helped us as participants to reflect on our learning from

Pete and Nick. I include here the photographs that participants chose, including alternatives when there was not complete agreement, a summary of why each choice was made and examples of the reflective learning which took place.



Plate 2 Photograph 1: cycle 1

Participants chose this picture to reflect on the first four sessions because we felt this man's hesitant but expectant pose illustrated some of what Pete might have been feeling. One participant said:

He hovered, he was interested, but he still needed the security of the wall.

Others said that other figures in the background reminded them of how staff members left participants free to decide whether to go in. This led us to reflect on how residents often stood at thresholds in the home. One person saw this as a metaphor for 'exclusion or inclusion' and another commented on the importance of having an open door when so many others were locked.

9.7 Cycle 2 (sessions 5-7)

Attendance

In session 7 Pete decided to come in and stay for a longer periods of time, and this continued throughout the inquiry. From the attendance graphs (Appendix: chapter 9) it is evident that Pete would be in the music therapy room for up to twenty-five minutes at a time.

Instrumental play

I write:

Pete and Nick play by Nick pushing drums over and Pete replacing them upright.

[Session 7: observation]

At times Nick finds this affects the group dynamic:

He immediately picked up the drum and dropped it over his head...the energy level of the group seemed to go up then.

[Session 7: questionnaire]

Nick begins to adopt a similar approach to Pete's in his handling of instruments in order to find a way in which they can play together.

I started rolling the drum around on the floor. You wouldn't normally do that. And that got his attention.

[Co-operative inquiry: meeting 3].

Anna comments:

Pete also holds instruments with Nick, not making a sound.

[Session 7: questionnaire]

Vocal play

There are no examples of Pete using his voice. Nick starts to use his own voice more often than in cycle 1, particularly when participants are outside, by singing the men's names and imitating their sounds.

Perceptions of listening and awareness

I describe Pete as 'watching', and a staff member filming when Anna was away writes that 'Pete only observed'. Both observations imply that we are placing a low value on his receptiveness.

Perceptions of risk and challenging behaviour

The words that Nick uses about Pete throwing drums relate more to the effect he has on the group dynamic. For example:

After Pete threw the drums the energy level of the group went up.

[Session 6: questionnaire]

Important relationships

Nick comments on how Ralph responds to Pete's presence:

I felt he was put off by Pete being in the room; he seemed angry and aggressive.

[Session 6: questionnaire]

Nick also reflects on whether Pete and Ralph possibly compete for his attention. Pete and Steve, by contrast spend time together in the session, and are quite physically close. Pete often opens and shuts the door into the therapy room. Nick spends some time working with him to encourage him in when he does this. Pete also tries to take Nick out of the room, although Nick resists this.

Representing musical relationship using photographs



Plate 3

Plate 4

Photographs: cycle 2

Participants chose the first image to represent what Pete was doing in cycle 2, as it depicts a father-son relationship, where they both focus on an object, in this case a cricket ball. In the music therapy, the focus between Pete and Nick was on the drums, with Pete continually knocking them over. He began to show signs of watching and listening, and the image captures this quality strongly. Pete was not engaging with instruments by playing with them and the boy in the image is not engaging with the ball by touching it. The second image shows the father leaning towards the son, and was chosen to emphasise the effort that Nick is putting in, despite a lack of response from Pete.

9.8 Cycle 3 (sessions 8-13)

Attendance

Pete spent periods of several minutes in the room, also leaving a number of times in a session, reappearing shortly afterwards.

Instrumental play

Anna notes that Pete is more active:

Pete responded and took part a lot.

[Session 8: questionnaire]

In session 9 he tries a number of new ways of using the instruments in order to make connections with Nick: he plays the keyboard then gives it to Nick; he stands upright the drums which Nick has put down; and he arranges instruments on the floor. He also gives Nick more space around instruments and pushes less often than in cycle 1. However, he stops other people's music by throwing small instruments such as seedpods.

Vocal play

Pete responds to Nick's singing, and laughs in response to Nick's vocalisations. Nick begins to respond to this by matching some of Pete's laughing in his own singing. Some of Pete's other vocal sounds, such as snorting, actively stop the music.

EXAMPLE ONE

Session 10 (minutes 46 – 47) CD TRACK 1

Commentary

Nick is singing to Pete and starts tapping a rhythm on the chair next to him.

Pete, standing facing him, is putting his hand in front of his eyes and

moving it alternately further from and nearer to his face. He starts his

laughing vocalisations and slaps his forehead. Nick responds by hitting the

chair. Then Nick claps a rhythm, stops, and claps every time Pete slaps his

forehead: this becomes effectively an anticipation game. Pete continues to

laugh. Nick sings, Pete laughs, there is a silence and then Nick sings again. Almost immediately Pete laughs. It seems to me they are playing with the silence and waiting to see who will start next.

Nick writes:

We had some moments of closeness.

[Session 10: questionnaire]

Anna writes:

There have been a lot of changes in the two weeks I was away.

Before Steve was the only one really taking part. I have been pleasantly surprised how much Pete has been taking part! Pete may still be throwing stuff around but he is having a go. I know he can be a lot worse than he is when throwing. He is still gentle with it.

[Session 10: questionnaire]

Perceptions of listening and awareness

The language in the participant observations shifts from 'watches' to 'listens'.

Perceptions of risk and challenging behaviour

Pete grazes Nick's wrist by knocking a cymbal over, and there are several occasions when he throws instruments.

Important relationships

Nick notices a connection between Pete's absence and Ralph's increased presence. He writes:

Pete became difficult (i.e. throwing an instrument) when I was playing with Ralph, so Ralph left.

[Session 12: questionnaire]

Home staff in the co-operative inquiry describe the relationship between Pete and Ralph as 'not easy'. Pete and Ralph appear not to want to be in the room together, and Pete controls this situation by intimidating Ralph.

For the first time there are observations about Pete and Jack. Pete shuts Jack out in session 11, throws a seedpod when Jack enters in session 12 and in session 13, when Pete leaves, Jack comes in immediately. Here it seems that Pete is effective in keeping Jack out, and again does not want to share the space with him.

Anna, Nick and I all observe in different sessions that Steve stops making music and goes motionless when Pete comes in. We reflect on the meaning of this: is Steve apprehensive of what Pete might do, or is he afraid?

Within the therapeutic relationship, there is some change. Pete puts Nick's hands on his face in a quiet moment (session 9) and takes his hand in session 12. He laughs and sits with Nick when Nick sings his name. Nick is able to persuade Pete to come in to the room when ambivalent. I reflect:

Therapy has moved from 'not sure if I want to be here' to 'when I come in something happens between me and Nick'.

[Cycle 3: dialogue with Nick,]

Musical relationship in photographs



Plate 5 Photograph: cycle 3

This image was chosen because it captures aspects of Pete's relationship between people and objects during the sessions. Neither baby looks at the other but they both want to have the same object. Some participants thought of the child reaching over as representing Pete.

9.9 Cycle 4 (sessions 14-23)

Attendance

Pete missed session 13 because of a hospital appointment, and for the next five sessions his attendance was sporadic, as if he had lost a connection which he had been slowly building. A holiday meant he missed session 19 but he appeared to re-engage more fully afterwards, staying in for periods of over twenty minutes in the next three sessions. He did not come in to session 23, the day that Bill died, but stayed close by, outside.

Vocal play

There are several examples of Pete using vocalisation interactively. In session 22

Steve and Pete vocalise together for the first time. Pete's vocalisations develop and he seems sensitive to Bill's vocal sounds outside, as demonstrated in the following extract.

EXAMPLE TWO

Session 20 (minutes 14-16) CD TRACK 3

Commentary

Nick is singing (slow modal melody) and Pete starts his 'laughing' vocalisation in response to his name. He slaps his side. Outside, an octave higher, the sound of Bill crying out is audible. Pete continues the vocalisation, looking more distracted. As Bill cries out for the second time, Pete's laughing grows more intense, as does the volume of Nick's singing. On the video recording it can be seen that Pete develops a slightly pained look. He slaps his side more. Then it is quieter outside, and Nick continues singing in a sustained manner. Pete begins to vocalise a little more gently with shorter, repeated high-pitched sounds, and at one point makes a longer vocal sound, which is unusual. He and Nick make more rapid slapping and clapping noises. Bill cries out again. Pete moves away and pushes a beater off a table quite deliberately so that it falls to the floor with a new sound. Nick stays where he is rather than stopping Pete, continuing to sing.

At the time I reflected:

Pete responds to so little in some ways, but I think he is alert to feelings expressed in people's voices. I felt strongly when I watched the tape that he was sensitive to Bill's distress and wanted to respond. He will have been used to Bill's voice for fourteen years. Bill

is dying, and I think that is somehow communicated by him.

[Session 20: field notes]

Nick takes his interpretations in a different direction:

Bill was vocally audible in the room. I felt that Pete might be stopping him coming into the room. There are some connections between Bill and Pete to explore.

[Session 20: questionnaire]

Instrumental play

Pete begins to arrange and move the instruments in more complex ways:

Cathy: Why do you think he moves all the instruments out?

Nick: I don't know. Sometimes he puts instruments around the edge of the room. But sometimes he takes them all back to the middle.

Cathy: You mean he undoes what he's done?

Nick: Yes, and then he puts them in order again.

[Cycle 4: dialogue with Nick]

Anna notices a wider repertoire in Pete's instrumental play:

Pete rolls, kicks, lifts and carries the drum outside the door.

[Session 18: questionnaire]

Pete's use of instruments also becomes more extreme: he runs outside with beaters Nick chasing him. In sessions 14 to 18 he throws the larger instruments. In session 20 he plays the windchimes. At one point Anna thinks that Pete is taking instruments outside to annoy Bill who is outside. I wonder whether Pete has a sufficient level of insight to do this. Anna has noticed that Pete is now throwing

other participants' instruments and believes that Pete is becoming more aware of his disruptive power within the session.

In session 21 there seems to be a significant change. Pete moves instruments, stopping to listen to their sounds, rather than throwing.

Nick adapts his play to engage Pete. He throws instruments gently to him. He takes instruments out of the room to engage with Pete in the corridor. He catches drums when Pete throws them and takes Pete out when he thinks the play is becoming dangerous. Pete often comes in when Nick plays the trombone.

EXAMPLE THREE

Session 21 (minutes 20-21) CD TRACK 2

Commentary

Nick is quietly singing in much the same way as in the previous extract.

Pete is standing. Nick sits down and begins to play a repetitive rhythm on a tongue drum. Pete begins to move round the room until he comes to some windchimes on a stand. He touches the top and it makes a slight sound.

Then Pete reaches down and begins actively to play the windchimes with his hand, moving it backwards and forwards across the chimes, making a

new louder sound. He starts to lift up the chimes singly. When he is not making the sweeping gesture with his hand, he jigs his legs in time to

Nick's drum rhythm. As Nick's 'verse' begins again, Pete uses his other hand to play the chimes. He stands back to look at the chimes for a few

seconds and then begins to jig again. Then he walks away and his feet can be heard swishing along the floor.

Nick writes:

This was a remarkable session for him. He was gentle and quiet and affectionate for a long time at the start. Then he played the windchimes looking and listening to them as he has never done before.

[Session 21: questionnaire]

Anna writes:

When Pete first came into the session, instead of throwing everything around as usual, he just sat clicking his fingers and jigging his leg to the music. Also Pete appeared to play the standing windchimes. Instead of just throwing it he pushed single chimes with a finger.

[Session 21: questionnaire]

Perceptions of listening and awareness

There is an explosion of references which describe Pete as listening. He also looks more closely at objects such as the camera and the instruments.

Perceptions of risk and challenging behaviour

Nick describes Pete as 'difficult' (session 14) but later says:

His throwing was not so rigid as it was before.

[Session 16: questionnaire].

Anna writes more casually about the throwing, such as in session 20:

Pete threw a bit.

[Session 20: questionnaire]

as if this was completely normal. I note in one analytic memo that his throwing, pushing and so on are more extreme in the week following a session where he developed some closeness with Nick. I note this again three times in this cycle.

This suggests to me that Pete might be developing expectations of Nick, and

becoming disappointed or jealous when the same closeness is not there the following week.

Important relationships

Nick thinks Pete stops Bill from coming in; Kate, a carer, sees Pete barring Bill's entrance and Anna thinks Pete is 'winding Bill up'.

Jack seems specifically to avoid contact with Pete. There are three examples of Jack entering as soon as Pete leaves and sitting on the chair Pete was occupying. There are no examples of Pete showing aggression to Jack.

Ralph seems to come in more and avoids Pete less in the sessions. On the other hand, Pete shuts Ralph out of the room in a rather aggressive way. In the next session he shuts him *in*. Pete is in the room both times.

There are similar examples of Steve 'freezing' when Pete throws instruments or pushes past him, and he is wary of Pete. Pete, however, watches Steve, and listens to his music. There are examples for the first time of musical trios and quartets involving Pete. Nick comments:

Pete, Steve and Ralph are coming together more in the music. Pete and Steve tolerating each other in the session is significant.

[Session 20: questionnaire]

Pete continues to play with shutting doors and leading Nick out of the room. There are many more comments about Pete having affectionate contact with Nick. Pete often now sits with Nick. Anna, too, becomes involved in 'giving face pats'. In session 21 Nick describes Pete as being 'gentle and affectionate'.

In the next session Nick and Pete play together with instruments and body movements throughout the session. Early on, Nick tells Pete that he is becoming angry about his throwing and chair moving. I write:

This leads to a freer, more affectionate exchange near the end of the session.

[Session 21: analytic memo]

Musical relationship in photographs



Plate 6 photograph: cycle 4

In cycle 4 Nick needed to be clear about where the boundaries of acceptable behaviour lay. Some participants of the co-operative inquiry thought that Nick was acting rather like a referee, and Pete was beginning to understand that rules might apply to him. We chose this photograph because we saw it as depicting a referee physically holding one player away from another. Nick had explained how he used touch to guide Pete out of the room. I was interested in this interpretation because I had seen the 'referee' as a player in black strip. This difference of view led to a realisation that the choice of images is complex, and involves participants in interpreting what they see and appropriating what is relevant for them. The identification of Nick as a referee implied a conception of him as 'other', and this realisation led participants to examine their own perceptions of his professional role.

9.10 Cycle 5 (sessions 24–34)

Attendance

From session 24 onwards Pete is in the room for most of each session. In session 33 he does not leave at all.

Instrumental play

Pete starts to examine the damage caused when he throws an instrument. He plays more instruments, including a drum. He listens to Steve and Nick play and dances more. His throwing is extreme but it is more rare. He actively fights Nick for a drum. Nick tries teasing Pete by moving drums away, which results in Pete becoming quite angry and agitated. Nick begins to notice when he needs to listen to Pete's vocalisations more specifically. He finds new ways of encouraging Pete in; for example, leaving a drum for him in the doorway. Nick still reinforces boundaries at times, but he inquires into the meaning of Pete's throwing much more. Pete decides very precisely where he wants instruments.

Rose (home manager) comments that Pete's desire to arrange instruments in a particular way seems quite autistic. Nick sees it as imposing order and taking control.

Vocal play

Pete creates unusual vocalisations, which are used as part of the music and has the experience of others in the group responding musically to his own contributions. This is illustrated in audio example four (following page).

EXAMPLE FOUR

Session 30 (minutes 14-15) CD TRACK 4

Commentary

Steve is playing rapidly repeating notes on two drums with a beater in each hand. Nick is also playing the xylophone with two beaters at the same speed. Nick begins to sing a simple pentatonic melody to 'aah'. Jack is sitting next to Nick, tapping his foot at the same speed. Pete is standing in front of all three, watching Nick. He begins to laugh and then vocalises in a higher pitch, sliding downwards. Nick begins to vocalise to 'mmm' and Pete begins to move around much more vigorously. As Nick returns to 'aah' or 'orr', Pete moves to stand by the door, and jigs his knees in time to the music, still looking at Nick. This continues as Nick begins to play a more prominent xylophone tune. Pete snorts loudly (to clear his nasal congestion) and the music stops abruptly. There is silence, then Steve and Nick start again, but at exactly the same time Pete snorts again and the music stops again. Then Nick starts to sing gently once more and all the others listen for a little. Pete makes no more sound and eventually Steve begins to join Nick again in the music by playing the drum.

Jack is sitting next to Nick and jiggling his knee too. All the participants in the room seem to be acutely aware of Pete. An unexpected sound is enough to break the atmosphere and it takes quite a time for it to be gently re-established. Pete is very powerful in this situation, but by stopping the music that he is dancing to, he is able to learn that he needs to be more still to allow it to carry on. He is finding ways of being part of the group sound.

Nick writes:

Pete, Jack and Steve were all in together and interacting – that is significant. Pete had long periods of quietness and passivity, and he seemed to have more space to be interested in the guitar. There were a number of interactions between Jack and Pete with the table and the drum.

[Session 30: questionnaire]

Anna writes:

All three men (Jack, Pete and Steve) were in the room together for a long time.

[Session 30: questionnaire]

I write:

Pete, Jack and Steve are together for most of the time, which is completely different from any previous session. There is a lot of mutual or shared silence that surrounds the music.

[Session 30: observation]

EXAMPLE FIVE

Session 31 (minutes 13-14) CD TRACK 5

Commentary

Steve is playing the windchimes and Nick is playing gentle drum beats. Pete starts to vocalise, laughing at first, and Nick hums quietly with this. Pete begins to vocalise brief sounds at a higher pitch and starts to swoop upwards in pitch. Steve responds to this by playing the windchimes and hitting the side of a cupboard with a beater. Pete continues, and at this point Nick starts to move instruments around rather than responding

directly to Pete. There are random sounds in the background from Nick and Steve moving the instruments. Pete goes to the door to leave, but Steve starts playing the drum, and, from the first drum sound, Pete turns back and soon begins to vocalise with a new sound 'orrr', again swooping upwards in pitch. Nick and Steve begin a drum duet and Pete jigs his knee to this, smiling.

EXAMPLE SIX

Session 31 (minutes 19-20)

CD TRACK 6

Commentary

Nick gives Steve a guitar. Steve begins to strum and Nick sings quietly with him. Pete quickly plays the windchimes and starts to laugh/vocalise, sometimes in pitch with Nick, rising up a minor third and then a perfect fifth. Pete then gently pushes a beater off the table onto the floor. Nick gets up to retrieve it, the music gets much quieter and then Pete vocalises to a deep 'orrr', standing close to Nick in what seems to me to be a slightly aggressive stance. He is using his voice to express displeasure at Nick's action rather than by throwing something. As Nick's own voice matches Pete's sound, he appears to lower his head and relax his posture. He then lets Nick move some instruments further away, turns to Steve and listens to his guitar playing, jiggling his knees in time, making slightly more gentle vocal sounds. Nick resumes his own singing and the music continues with Pete in a more actively listening involvement.

Steve is playing the guitar by repeatedly plucking the same chord in

continuous rhythm. As he plays, Pete begins to vocalise and again the sound is different (ORRR).

The staff member filming writes:

Pete appeared affected by sounds, particularly soft, melodic guitar playing and the xylophone, when he relaxed totally. When the guitar playing got harsher, Pete became more agitated. When Steve left the session, Pete became even more agitated, pushing chairs around.

[Session 31: questionnaire]

Nick reflects:

It seems as if a triadic relationship has been established between Steve, me and Pete in which I connect with Steve in the music and Pete tries to get in – or to break the connection and in the process he connects with me. Pete left the room at one point but when he came back he sat down with me and stopped competing for a while.

[Session 31: analytic memo within questionnaire]

I write:

Pete was very vocal but not always heard by Nick because he was focusing on the more able and interactive Steve. Pete did make sure attention was diverted back to him by throwing drums and moving chairs. There was some quiet interaction between all three. The man filming affected all three men and the atmosphere was very different – is this to do with his personality or is it gender?

[Session 31: analytic memo]

Perceptions of listening and awareness

Pete starts to vocalise much more: I feel he is becoming angry or frustrated when he is not listened to. Are his expectations of what the session offers

increasing? He spends increasing amounts of time listening to Steve and Ralph when they create music, and there is more shared silence.

Perceptions of risk and challenging behaviour

Observations and questionnaires have fewer references to Pete throwing. However, when he does throw, others experience this as more violent and upsetting. Nick shows annoyance, and sometimes asks Pete to leave when he thinks his throwing is getting out of hand. Pete's behaviour seems to be clearer in terms of communication and affects others. Negotiation is now more possible with Pete. He wants to be with Nick and seems to be able to suppress his desire to push objects around at times.

Important relationships

Jack leaves when Pete enters the room. Once, Pete shuts Jack out. In session 30 Jack challenges Pete by returning a table Pete has moved. Pete moves it again, apparently to intimidate Jack, but this time Jack does not leave.

Pete stops his own music and stops moving objects each time Ralph enters. He does occasionally try to intimidate him into leaving. Ralph, like Jack, begins to stand up to Pete. Anna notices that he holds back Pete's arm to prevent him throwing a xylophone.

Pete and Steve spend most of their time together in the sessions. When Pete tries to intimidate Jack or Ralph, Steve plays loudly on the drums, as if using the music to express the tension he feels. Pete prevents Steve from playing like this by taking his beaters away. When Nick holds Steve's hand, Pete pushes Nick's hand away, as if jealous. However, a member of staff notices that Pete becomes more agitated when Steve leaves, as if Steve is a calming influence on him, or as if

Pete is disappointed that he has lost the contact. I notice a number of examples of the 'triadic relationship' Nick has mentioned. When Pete and Nick sit together, Steve comes and sits between them. When Steve and Nick play music together, Pete leaves and slams the door. When Steve and Nick leave the room to get a tissue for Steve, Pete throws beaters around.

Pete tries to take Nick outside several times. In this cycle he also begins to lead Nick into the room. Nick says:

I'm being more affected by Pete. I get more angry with him.

[Cycle 5: dialogue with Nick:]

Nick communicates to Pete that he does not like his intimidation of others. When Nick asks Pete to leave the room, Pete consistently returns in a calmer mood.

Musical relationship in photographs



Plate 7 Photograph: cycle 5

As a group we found it difficult to identify an image which we felt was suitable for this cycle, and some participants took the view that this was not the best choice. However, the image of the two majorettes reminded us of

how Pete was beginning to learn from others, just as the girls seem to watch each other. We felt that this was extremely significant for Pete, and some participants said that they had not believed such a change was possible.

9.11 Cycle Six (sessions 35-38)

Attendance

In session 34 Aidan comes in at the beginning, and Pete leaves soon afterwards. Pete's attendance after this episode dwindles. In session 38, when Aidan next returns, Pete stays for less than one minute.

Instrumental play

Pete spends most of his time listening to other people's music, but in session 37 becomes very angry and throws drums around. It seems that Pete is finding Aidan very difficult to be with.

Vocal play

Pete makes considerably fewer vocal sounds.

Perceptions of listening and awareness

Nick focuses on Pete and his emotional needs; perhaps more than he did in cycle 5. Pete is quieter.

Perceptions of risk and challenging behaviour

Nick puts forward the idea that Pete takes instruments away from others not because he is upset but mainly from a desire to reposition instruments. Anna (and other staff members) think about why Pete throws instruments.

Sometimes with Pete I do think that he's just doing something to wind

everyone up! Being a bit cheeky. Because he's laughing. He'll be laughing and then he'll do something really destructive and push or whatever, and then he'll be laughing again. So there are two sides. But there's the side where he's genuinely annoyed and he seems a bit angry, and then I start thinking 'what is that reason?'

I felt at the time I could tell whether he just had something he was doing because he was angry...or whether he was just being a bit mischievous.

And Nick gets to the point where he says 'Right Pete! I've had enough. Out!' And then Pete's come back in and he's known he's pushed it a bit too far. I think that sometimes he's been doing it just because he's got something on his mind, or upsetting him or whatever.

[Cycle 6: dialogue with Anna]

Important relationships

Nick challenges Aidan when he intimidates Pete. When Pete moves a chair, Aidan immediately moves it back. Nick then says to Aidan 'Pete can do what he likes': quite a contrast to the message he gives to other group members.

Anna reflects:

It's been very different since Aidan's joined the group. He [Aidan] is just ...really nasty! He's always pushing the other men over, giving them a sly punch and things like that. Pete doesn't like him but Aidan might be all right with Pete because Pete laughs a lot.

[Cycle 6: dialogue with Anna]

Ralph and Jack continue to challenge Pete. When Pete moves a chair,

Ralph hits the back of it. When Pete moves a drum, Jack hits the congas hard and stands up, expressing his feelings in music to Pete for the first time.

Steve locks Pete out of the room. However, on another occasion he seems to appreciate that Pete is feeling upset, and reaches his hand out to him. However, when Pete knocks over the windchimes, which makes a considerable noise, Steve leaves.

Nick continues to admonish Pete when he makes him angry, and Pete again quietens in response.

Nick writes:

I felt irritated by Pete's behaviour and this signifies that I am being more affected by him.

[Session 35: questionnaire]

This connects with Anna's experience of *feeling* more for Pete.

Musical relationships in photographs



Plate 8

Plate 9

Photographs: cycle 6

We chose the first image as a way of discussing the relationship between Nick and Aidan. The third man standing between the two fighting men represented Nick.

Some participants did not agree with this choice, as neither Pete nor Aidan showed physical aggression to each other. Moreover, the man in the middle seemed too detached to represent Nick who was more sensitively involved in recognising Pete's feelings. The second photograph illustrates the intensity of pain and hurt we thought Pete might feel when he became jealous of Aidan. A number of other incidents involving both men had occurred in the home, suggesting to care staff participants that Pete might be envious of Aidan.

Figures 10 and 11 summarise the main changes Pete made during the inquiry.

| CYCLES CATEGORIES | Cycle 1 | Cycle 2 | Cycle 3 |
|--|--|--|---|
| Attendance | P comes in very little | Starts to stay for longer periods | Pete stays for long periods but leaves several times/session |
| Instrumental play | Touches instruments carefully. Throws and kicks instruments | Pushing and rolling instruments. Interactive play. Holds instruments with Nick | More active with instruments Arranges instruments Shares instruments 'Gentle' throwing Throwing stops the music |
| Perceptions of listening and awareness | P laughs to N's voice on video | 'Watches' in session | 'Listens' in session |
| Vocal play | No data | Frequently uses his voice | Increase in vocal play Snorting stops the music |
| Perceptions of challenging behaviour and risk | No data | Nick describes Pete's throwing in emotive terms | Throwing causes harm to Nick |
| Important relationships | Do Pete and Ralph avoid each other? | Do Pete and Ralph compete? | Pete and Ralph avoid each other. Pete intimidates Ralph. Steve looks apprehensive of Pete. Pete keeps Jack out of the room |
| Therapeutic relationship | Nick gets Pete's name wrong. Nick anticipates disruption from Pete | Nick and Pete play more together. Pete uses door opening to interact | Pete more affectionate and trusting of Nick Pete enters when Nick asks him to |

Figure 10 Summary of the changes Pete makes in cycles 1-3

| CYCLES CATEGORIES | Cycle 4 | Cycle 5 | Cycle 6 |
|--|---|--|---|
| Attendance | Missed session then sporadic attendance. Attendance increases before Bill's death. | In nearly all the time | Attendance seriously reduced when Aidan is in session |
| Instrumental play | Plays instruments Arranges with increasing complexity. Throws large Instruments. Nick takes instruments out into corridor to play with P. Music is more exploratory | Pete notices when he damages instruments Takes instruments outside Makes clearer choices of instrument | Pete throws instruments more |
| Perceptions of listening and awareness | Many examples of Pete listening | Pete has higher expectations of being listened to - angry when not. Listens to his peer's music More silence in session | Pete is quieter and Nick is aware of this |
| Vocal play | Uses his voice interactively in music. Sensitive to Bill's voice outside | Creative vocal sounds Pete experiences peers responding musically to his own sounds | Decrease in vocal play |
| Perceptions of challenging behaviour and risk | Throwing is worse in the session <i>after</i> he has had close contact with Nick | Pete throws less More violent when he does throw | Participants inquire into the meaning of Pete's throwing |
| Important relationships | Ralph tolerates Pete and avoids him less. Pete shuts Ralph out. Pete less aggressive with Jack. Pete distressed about Bill. Pete listens to and shares music with Steve. Involved in trios and quartets | Ralph stands up to Pete Jack challenges Pete Steve uses music to comment on Pete's aggression. Pete shows envy of Steve's prowess and jealousy of his relationship with Nick | Ralph and Jack challenge Pete in music Steve locks Pete out but is also sympathetic Nick protects Pete from Aidan |
| | More affectionate exchange between Nick and Pete. Nick clear about acceptable boundaries when Pete throws instruments | 'Triadic' relationship between Pete, Steve and Nick. Nick talks to Pete about how he makes him feel | Nick is sensitive to Pete's reaction to Aidan |

Figure 11 Summary of the changes Pete makes in cycles 4-6

A number of patterns and connections are evident from this summary. I will present an overview of Pete's changes through the year, and then look at changes within each category in order to explore different ways of connecting and conceptualising

the findings.

9.12 An overview of Pete's changes

In cycle 1 Pete engages very little in any of the ways suggested by the categories. However, there are indications of a potential for development in his brief explorations of the instruments. The difficult relationship between Ralph and Pete is also evident from the outset.

Pete's reaction to Nick's recorded voice is the only hint that Pete will find his use of voice the route to developing connections with others.

In the brief cycle 2 there are changes in all areas which suggest Pete is becoming more involved in the music therapy experience. This happens most noticeably through vocal and instrumental play. No other peers are involved with Pete at this stage.

By cycle 3 Pete becomes more aware that he might affect the music, although this is mainly by preventing its flow. Pete is both more involved with and intimidating to his peers, and increasingly affectionate to Nick. He seems to develop a sense of power in two directions. The first is through communication and exploration and the second by throwing instruments and making violent sounds.

In the fourth cycle Pete's receptiveness increases. There are numerous examples of him listening, changing his vocal play to match others and listening to Bill. His peer relationships start to change and other participants comment on his feelings. The several occasions on which he seems to be disappointed with Nick following the weeks when he has had a particularly close engagement with him.

The fifth cycle shows the most positive change within the year. Pete's peers respond both to Nick's example of setting boundaries with Pete, and also to Pete's

increased awareness of them and himself. Even Jack, the most vulnerable of the participants, has the courage to move tables back when Pete moves them. The music changes: Pete allows many more silences, and his vocal contributions connect to the group music in terms of pitch and timing. His vocal expressions seem more creative. He throws instruments as a specific response to a situation, and the moods he expresses are more marked. Pete becomes increasingly involved with Steve and Nick.

There is almost a catastrophic end to the year for Pete in cycle 6 as the result of Aidan's arrival in the group. Nick prevents Aidan from intimidating Pete. Despite this, Pete attends and participates musically in a restricted way. Both Nick and Steve seem concerned about this.

Attendance – an overview

Pete's attendance appears to depend upon events that are significant for him in the sessions. His reluctance to come into the room in cycle 1 could be an indicator of ambivalence but is probably due to shyness. He chooses to come in increasingly as the therapy progresses, but certain events affect this pattern. After missing a session in cycle 4, it takes several weeks for Pete to re-engage. The communal distress which builds up before Bill's death, and the subsequent aftermath, appear to bring him in for long periods. However, Aidan's replacement of Bill is the factor that makes Pete the most reluctant to attend. All the benefits provided by the therapy seem to have disappeared.

Instrumental play – an overview

There is a fascinating sequence of changes in the way Pete relates to instruments. At first he hardly touches them, but soon he starts to investigate their weight or

gravity. The idea of them as sound-making objects, so obvious to us, does not yet seem to occur to him. However, instruments are objects that can be shared, and soon Pete discovers that he can be jealous of other people's use of them. His throwing suggests a sense of possessiveness: at last he has objects to play with that he is interested in. They become the focus of power for him. They make different noises if dropped, and he discovers ways of dramatically stopping music that he is not part of. Arranging the instruments in rows, and making noises as he moves them may give him a sense of control and exploration. This is also a way for Nick to start to make games with Pete. By cycle 4 Pete occasionally plays instruments, a fact that astounds Anna. If this means that Pete is consciously producing music with his hands in the way that others do, it is a departure from his earlier involvement. Pete seems aware of more instruments, but is more threatening with them too. He starts to damage instruments, but begins to notice this in cycle 5. I believe this is connected with his growing awareness of his impact on other people and represents a developing sense of the consequences of his actions.

Reflection

Taking desired instruments and people (Nick) out of the therapy space may symbolise Pete's desire to keep them for himself. He explores a sense of room space by standing on the threshold, opening and shutting doors, playing outside in the corridor, taking instruments outside and shutting others out or in. These examples suggest to me that he has some understanding of the significance of the room as a group space. My interpretation is that Pete is exploring his feelings about whether he wants to be included in the group or not by choosing to be in or out. Taking instruments outside is his solution when he wants to play with them

(or to possess them) but not to share. He organises instruments in lines to create a sense of order or control over his environment. His dynamic method of moving instruments by dragging or throwing is expressive, and musical; it is much more intense by cycle 5, and seems specifically linked with feelings of jealousy.

Vocal play – an overview

We as participants felt that Pete's changes in this area were the most striking. He moves from making no sound to becoming aware of how he can use his voice within group music. He begins to learn how he can develop his vocalisations by exploring and experimenting with different sounds. This is important for his personal development, as he has so few expressive resources. From his changes in listening, it seems that he is interested in the sounds that Nick and Steve make, and he wants the music to continue. In cycle 3 there are a number of occasions when Pete snorts, but finds other ways of making vocal sounds when the music resumes. Pete snorts because of nasal congestion, so he has to choose whether to inhibit his habitual snorting or not. The exercise of choice adds to his growing self-awareness, and the impact he has on the music. In short, Pete begins to connect with the music, and so experiences more direct reactions from others. In turn, this allows participants to react to Pete in ways that do not involve avoidance.

Perceptions of listening and awareness - an overview

Pete shows evidence of listening from the first cycle, and reports and observations of him listening increase throughout the year. One interesting change between cycles 2 and 3 is in the language: 'watching' becomes 'listening'. 'Listening' implies an involvement in the music; 'watching' suggests a degree of detachment. It is difficult to tell whether Pete actually does listen more: it is mainly in the perceptions

of those around him that a change is indicated. In cycle 5 Pete starts to listen more to his peers and not solely to Nick. It is as if he has needed to gain confidence with Nick before he is able to begin to relate to the people he already knows so well. Pete now allows there to be more silence in the music. As a music therapist, shared silence in this context indicates to me that the music created in the group is more mutually communicated than if there is constant noise.

Pete begins to show dissatisfaction if Nick does not respond to his vocalisations, implying that he expects Nick to listen. Nick listens most at a crucial time in cycle 6, when Pete seems to be particularly isolated.

Perceptions of challenging behaviour and risk – an overview

Nick is concerned from the outset that Pete's throwing has an effect on everyone present. Nick is the recipient of much of the throwing in cycles 2 and 3, and at this point it seems to be his responsibility to manage the risk element. By cycle 4, Pete's throwing has been recognised as having meaning: he throws when he is upset, or perhaps disappointed that he does not have the same closeness with Nick as he had in the previous week. Nick is beginning to deal with throwing by making very clear statements to Pete about what is acceptable. Taking Pete out of the room may be a punishment for not behaving in a safe way, but it has the function of keeping the others safe.

By cycle 5, this appears to have made a difference, and Pete is throwing less. However, when he is upset, he throws very vigorously. Ralph, perhaps following the example of Nick, has the confidence to intervene and hold Pete back from throwing. Anna writes about Pete's throwing in a light way: 'Pete threw a bit but is gentle with it.' The general pattern is that others begin to view his throwing with more discrimination. There is a move from the idea that Pete's throwing

disrupts everything to the attitude that Pete is throwing for different reasons and in different ways. Participants also develop the perception that Pete can take some of the responsibility for this. He wants to please Nick, so he stops throwing because Nick does not want him to. Then when Aidan appears in cycle 6, Pete's genuine distress has more impact when he throws. It seems that Pete is no longer 'crying wolf' by throwing. Pete begins to appreciate that others do not like his throwing, and he learns that he can control it. Others discover that Pete is expressing feelings when he throws, these feelings are important and need to be listened to. Pete is beginning to find different ways of expressing his feelings, particularly through his voice.

Peer relationships – an overview

I use the term peers to describe the people with whom Pete has lived for a number of years. The data cover every possible relationship Pete could have. Participants cannot afford to ignore Pete, and Pete himself relates to each person in some way. The relationship that is present throughout the cycles is the one between Ralph and Pete. By cycle 4 each man is more tolerant of the other. Pete's bullying relationship with Jack has some parallels with Aidan's bullying of Pete. Steve freezes in anticipation when he sees Pete in the room in cycle 3. Eventually Steve and Pete become musical partners; Steve is someone who can express both frustration and sympathy towards Pete. Pete begins to experience his peer relationships in a more complex way than through bullying or avoiding others. By cycle 5, the other participants have found that they can communicate with Pete through the music. Long-term relationships which may have fallen into fixed ways of relating are the most difficult to change, but there is some evidence in the inquiry

that through musical relationships and the therapeutic setting, these changes are beginning to take place.

Therapeutic relationship – an overview

Pete is able to build a trusting relationship with Nick from around session 7 and this quickly becomes both affectionate and charged. Nick works hard with Pete to establish boundaries and make the space safe. He often talks about his irritation, although rarely despair. There is something vital about Pete's presence, and his interest in Nick and his music. Nick sings much of the time to Pete, often using a style that is similar to Gregorian chant, simple but meditative. Pete begins to listen to this. Nick increasingly talks to Pete, and although it is unlikely that Pete understands his language, he may benefit from non-verbal aspects of this communication.

9.13 Summary

Pete showed positive changes within every area that I have explored in this chapter. From the multiple perspectives of the participants in the music therapy inquiry, there seemed to be a gradual development of his relationships with others, of his confidence, of his use and understanding of his own musical contributions, and a refining of the communicative use of his 'challenging behaviours'. All participants gradually develop a more sophisticated relationship with him. His communications widen in range and complexity, and well beyond the abilities outlined in his communication report.

From the actions of his peers, there seem to be two areas of note. First, all his peers are involved with him, although apparently through relationships that are dominated by power, intimidation and avoidance. The second finding is that during

the inquiry, particularly through the use of music or instrumental play, Ralph, Jack and Steve find new ways of relating to Pete. In addition, these men find ways of making music with him.

The most striking and worrying aspect of the data is the way in which his involvement, learning and gains all appear to fall away in the final cycle. Although therapy continued beyond the inquiry timetable, it is not within the scope of the thesis to follow whether Pete recovered from this. The possible effect on an established group of residents of a peer bereavement followed closely by the rapid appearance of a considerably more able and intimidating new resident is a question that I will discuss in the concluding chapter.

CHAPTER TEN

Jack

10.1 Vignette

Jack walks diagonally across the room with a quick shuffle, never looking from side to side. He is slightly built with a gaunt, lined face and anxious expression. Ralph gets up from his chair quickly and Jack immediately turns in his tracks and leaves. He takes a staff member by the hand and urgently drags her to the garden door, putting her hand on the latch. He repeats this until she takes out her large ring of keys and unlocks it for him. He does not look at her at all. As soon as the door is open he shuffles out and makes what seems to be a planned circuit round the garden, again not looking around. He repeats this circuit several times. Pete comes into the garden and Jack then goes straight back into the house, humming.

10.2 My impression

Apart from his face, I think Jack looks younger than his fifty-three years. However, his facial expression (for there seems to be only one) strikes me every time we meet. It is not quite vacant, but in it there seems to be such resignation, lack of expectation and lack of animation that my mind starts racing with questions. What has his life been like to warrant this expression? Autism cannot be the sole cause: I have worked with many people with autistic spectrum disorders who are animated

and vital. Jack, gives an impression of being rootless and is perhaps looking for something he may not find.

10.3 Background

Jack was fifty-three at the time the inquiry. He had no known living relatives and the information on his history was patchy. He was institutionalized from an early age, but details were unavailable. He was addicted to eating cigarette ends, an inheritance from institutional life, but was slowly being weaned off by nicotine patches. Jack did not speak, although sometimes hummed under his breath. He rarely looked into people's eyes. If he went outside the house Jack would simply run without stopping, putting himself at risk near roads. Because of this, the front door had a locked keypad, and the garden a secure fence. In the previous hospital there were extensive grounds. Jack had been free to wander over considerable space. The day care workers at the home took Jack for long country walks to compensate for this. One staff member said that if Jack was upset he could punch care workers very hard indeed. This did not happen during the music therapy inquiry.

Jack uses no speech, signing, use of pictures, eye pointing, symbols or gestures. He indicates 'yes' through his body and his use of objects. Attends for only a few seconds. His movements carry direct meaning i.e. standing by the door to go out. ...He reaches out to things of interest... He has potential for developing objects of reference. Does understand if he is included or excluded from the interaction. Seems to have no understanding at all of spoken language. He needs an increased range of choices, freedom of movement, and plenty of gestures and physical behaviour to explain

what is happening. Has a history of otitis media (hearing problems).

[Communication report, November 2000]

10.4 Issues with participation and assent

As Jack had no living relatives, the home manager gave assent for him to participate in the inquiry. Jack's keyworker did not want to give assent, as there was no independent advocate or family member who could object. This raised again the invisibility of Jack's past.

10.5 Organisation of the data

Jack's data are more scattered than Pete's. To make the connections and frame the questions Jack raises, I have found it useful to draw from a wide range of categories within Framework. Participants in the music therapy inquiry identified the appropriate categories as being: attendance (category 3.3); vocal play (1.3) and instrumental play (1.2). I have added 'inside and outside' (category 7.1) which works well with 'attendance'; 'new sounds' (3.1); 'not knowing' (6.5) and 'important relationships' (2.1). As in the previous chapter, I present the detailed data, summarise them on a chart and discuss and interpret the main findings and emergent patterns.

10.6 Cycle 1 (sessions 1-4)

Attendance

In cycle 1 Jack attended the session for less than fifteen seconds every time he came in. Jack chooses to be in the session for considerably shorter times than any other resident (see graphs 1 and 2, p236). He visited several times in the first session but slightly less frequently after that.

[Session 1: questionnaire]

Nick notices an important point from the beginning: Jack is only prepared to walk across the diagonals in the room, which need to be free of instruments. While watching session 1 and 2 on video he comments:

He has to see a way through [the room] before he comes in. See, he's hesitating and then I thought he might leave.

[Dialogue with Nick]

Listening and Awareness

No data.

New Sounds

The data refer only to drumming sounds. For example, Jack first comes into session 1 after the bongos are played. In session 2 he enters, approaches Nick after picking up the buffalo drum (see instrument glossary in Appendix) and hits it. Then he leaves. He later returns but leaves again when Nick plays the drum.

Jack makes his own sounds by hitting the strings at the back of a buffalo drum inside and dropping it on the floor.

Vocal play

No data.

Instrumental play

From the first Jack seems to identify Nick as the person with whom to relate. He holds drums for Nick and gives them to him. He hits drums that Nick holds and exchanges instruments with Nick. Nick says that:

Jack is communicating by doing this.

[Session 3:questionnaire]

Jack explores small instruments he takes from a box. When Nick tries saying to Jack, 'No, I don't want that instrument,' Jack puts it next to him on the floor. Jack also plays the metallophone briefly. When watching the video Nick says:

I'd forgotten that. Jack actually played! So he plays from the start.

[Dialogue with Nick]

Not knowing

I have included this category because so much uncertainty and puzzlement surrounds our understandings of the meaning of Jack's actions. In this cycle there is a question about whether Jack knows what he is doing; for example:

I don't think he knows what to do with the instruments.

[Session 3: Nick's questionnaire].

Anna raises this question in relation to most of the residents:

Steve loves his music. [*He has been dancing to CDs.*] But the others – they don't know what to do. They're just too embarrassed – not embarrassed, I wouldn't say...it's more like being encouraged to do things like that. I don't know.

[Dialogue with Anna, cycle 1]]

In a wider context, confusion and 'not knowing' arose many times during the first cycle. For example, in the co-operative inquiry, some participants discussed the general confusion residents were likely to be feeling, following their move to the home. One woman questioned whether the music therapy inquiry might help participants to make sense of their move.

Claire: I wondered when the penny was going to drop. It's difficult to assess that with them.

Rose: Can they ever be certain they're not going back?

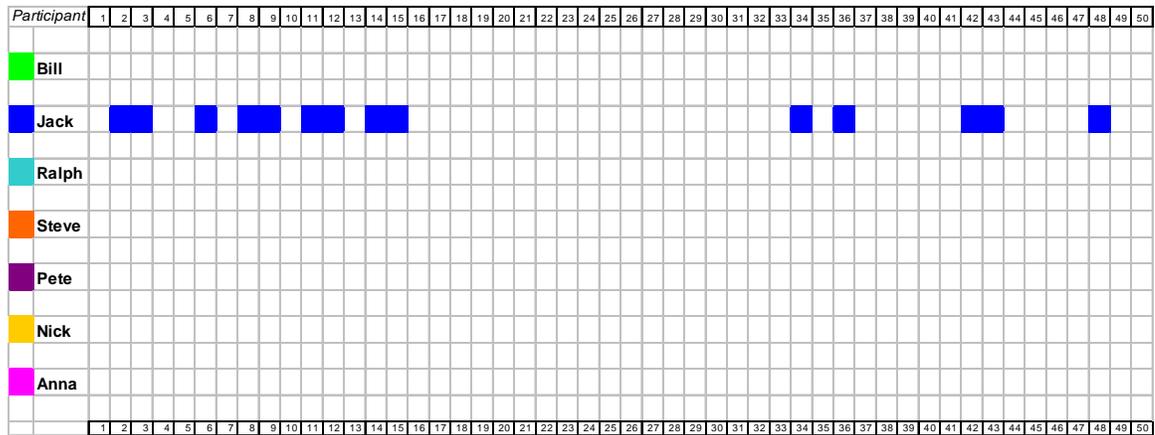
Important relationships

There were no data about Jack's relationship with anyone except Nick in this cycle. This is noteworthy in itself, emphasising his isolation.

10.7 Cycle 2 (sessions 5-7)

Attendance

Jack stays in for longer periods (between two and three minutes). He also enters on average nine times per session. Graph 3 shows when Jack was in the room during session 7.



Graph 3 session 7

In and out

In session 6 Jack looks in the room but chooses not to enter. In session 7 Nick writes

Jack in and out.

[Session 7: questionnaire]

This becomes a standard comment of his.

Listening and awareness

There are sparse references. In session 6 Jack listens to Steve drumming.

New sounds

It becomes more noticeable that Jack leaves in response to loud or harsh sounds, for example, when Nick plays a cymbal in session 6. Some of the sounds Nick introduces are 'new' in the sense that they have not been heard in the music therapy session before.

Vocal play

By contrast, Jack seems more drawn to Nick's voice. I observe:

Jack nearly leaves but stays when Nick starts to sing.

[Session 7: observation]

In the co-operative inquiry (meeting 3), one participant states:

Jack is often humming around the house.

Instrumental play

In cycle 2, Jack spends more time examining instruments, turning them round and holding them for longer. He turns a drum upside down, holds Nick's trombone, picks up a buffalo drum and moves a keyboard.

Not knowing

Music therapy inquiry participants begin to explore the meaning of Jack's play in detail by watching videos of the sessions, but find it difficult to privilege any particular interpretation:

Cathy: Jack's moving the keyboard.

Nick: Yeah. I don't know why. Whether he wanted it back where

it was or whether he just didn't like it.

Cathy: Or maybe he did like it

[Cycle 2: dialogue with Nick:]

Nick writes that:

Jack showed an interest in the keyboard.

[Session 7: questionnaire]

This non-specific language sidesteps the difficulties of not knowing, and I recognise it as a strategy I often employ in my own clinical work.

Important relationships

The references here are very sparse and inconclusive. In session 6 Steve sits in one corner playing and Jack chooses to sit in another. The following week I write:

Jack comes in. Ralph appears to react and leaves.

[Session 7: observation]

Jack comes in and puts his foot up on a chair so that Nick can tie his shoelace. When watching this on film Nick wryly comments, 'Well I have got a use then!' and laughs. This adds to my impression that Jack connects very little with the people around him. I ask:

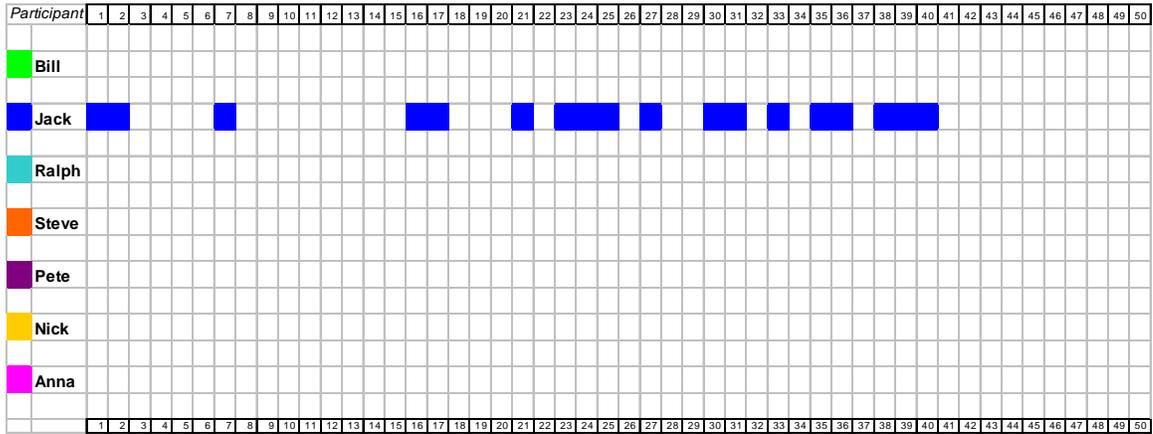
The tying of shoelaces – is this some chance for physical contact?

[Analytic memo, session 7]

10.8 Cycle 3 (sessions 8-13)

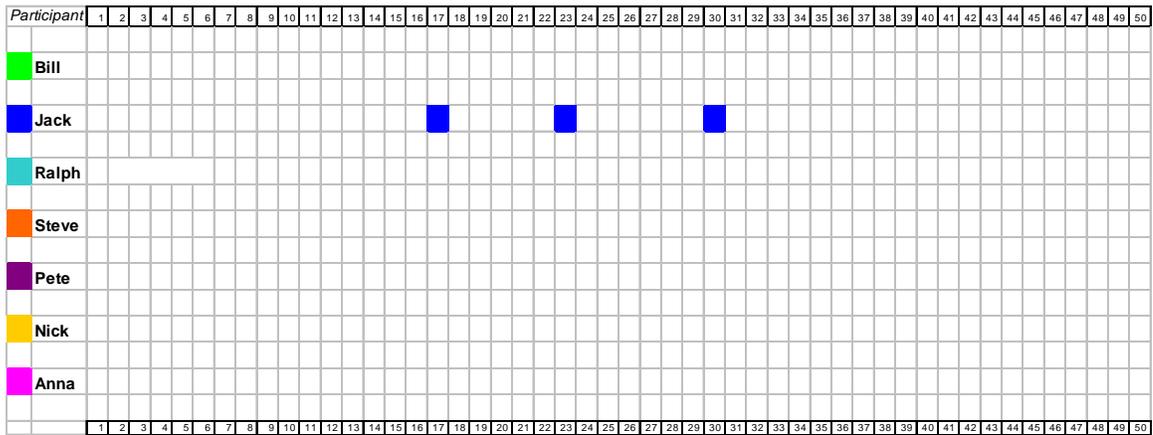
Attendance

At first Jack's attendance was still sporadic and brief but more frequent. Graph 4 (p242) shows session 9.



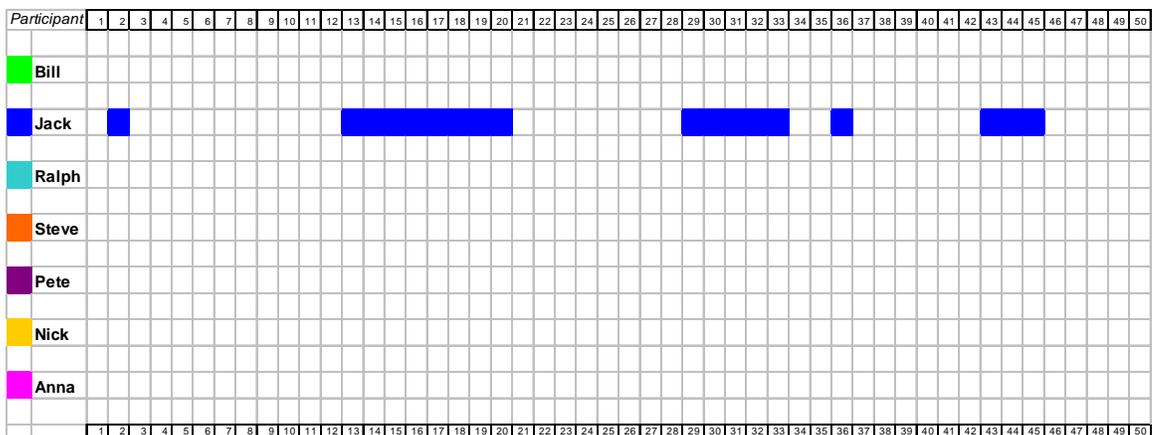
Graph 4 session 9

He attends about ten times per session. His attendance reduces towards the end of this cycle (see graph 5, session 12).



Graph 5 session 12

However, in session 13 he comes in for several minutes at a time (graph 6).



Graph 6 session 13

In session 13 he also spends more time standing outside, apparently listening to Nick's playing.

In and out

In session 9 Nick writes that Jack stays in longer, and sits down more when he is in. I notice that Jack is humming when he is outside the room, and discuss this in the co-operative inquiry. Jack begins to try to take Nick out of the room by holding his hand in session 10. At times in this cycle Jack walks past the door, not coming in; he also tries to take Nick out several times. Nick writes:

Jack in and out

for sessions 9, 12 and 13. Pete keeps Jack out in session 11. By contrast, Steve stands outside watching Jack play with Nick in session 13.

When Steve watches a session video with me, and then puts his own copy in his bedroom, Jack walks into Steve's bedroom and stands there. It seems that he has no sense that this is Steve's private space. I wonder if he has a concept of private space at all.

New sounds

In session 10 Nick hits a drum and Jack, who is sitting, gets up and leaves. In session 13 Nick plays a rattle. Jack leaves with his fingers in his ears. I am reminded of the information that Jack had hearing problems, and wonder if some sounds caused pain.

In contrast, Jack enters when Nick plays the trombone. I write:

Nick has introduced some new instruments and Jack seems interested in these.

[Session 13: analytic memo]

Listening and awareness

I observe in session 8 that Nick does not respond when Jack picks up instruments and then Jack leaves, whereas Jack stays longer later in the session when Nick responds musically by singing when Jack plays a drum. This suggested to me that Jack is sensitive to the amount of awareness and time Nick can give to him.

Vocal play

Nick sings as he ties up Jack's shoes. Apart from this there are no data.

Instrumental play

Jack continues to give and accept, exploring small instruments. Once Ralph stops him from doing this.

While Nick is packing up Jack takes a guiro from the box. Ralph enters, takes the guiro from Jack and puts it back in the box. They both stand looking at instruments in the box. Jack tries to take more out and Ralph pushes him away. Jack then tries to take Nick out by hand.

[Session 8: observation]

Jack plays instruments to make sounds at least three times a session from sessions 9-13. One change we all note is that instead of just leaving when there are loud or harsh sounds, he comes in when certain sounds are created. 'He enters to a metallophone sound that Steve is making' writes Anna in session 10. He also begins to share musical interaction, becoming part of a trio by tapping his foot.

Nick finds different ways of giving and receiving instruments from Jack. He gives beaters to Jack and finds a game to play using a small drum shaped like a

bat and using a ball.

Not knowing

I notice that I think Jack is feeling different emotions. In session 9 I ask 'Is Jack distressed?' because he walks in quickly after Bill has screamed in the corridor. In session 10 I write 'Jack looks in but does not enter – is he afraid?'

Important relationships

There are more data here; mainly descriptions of incidents of where others demonstrate having power over Jack. In session 8 Ralph takes a guiro away from Jack. Pete throws a seedpod and Jack leaves immediately in session 12. In the previous week Pete had actually shut Jack out of the room.

Jack does take his opportunities however: in session 13 he comes in immediately when Pete leaves.

Jack's relationship with Steve hints at a mutual interest, although these are only brief examples: in session 10 Steve rushes out of the room and Jack follows closely; when Steve plays a metallophone Jack enters; when Steve continues Jack comes in and out frequently as if interested in continuing to hear Steve and at the beginning of session 13 Jack is followed in by Steve. Steve comes in again and leaves with Jack several times.

Within the therapeutic relationship, there are small signs of Jack beginning to build a relationship with Nick. I write:

This session was important for Jack because of all the instrumental exchanges with Nick.

[Session 8: analytic memo].

Jack holds Nick's hand in session 10. Nick points to a chair and Jack sits there

briefly. I write:

An important session for Jack who has been building relationship with Nick.

[Session 10: analytic memo]

Nick writes:

Demands from Pete and Steve reduce my time with Jack.

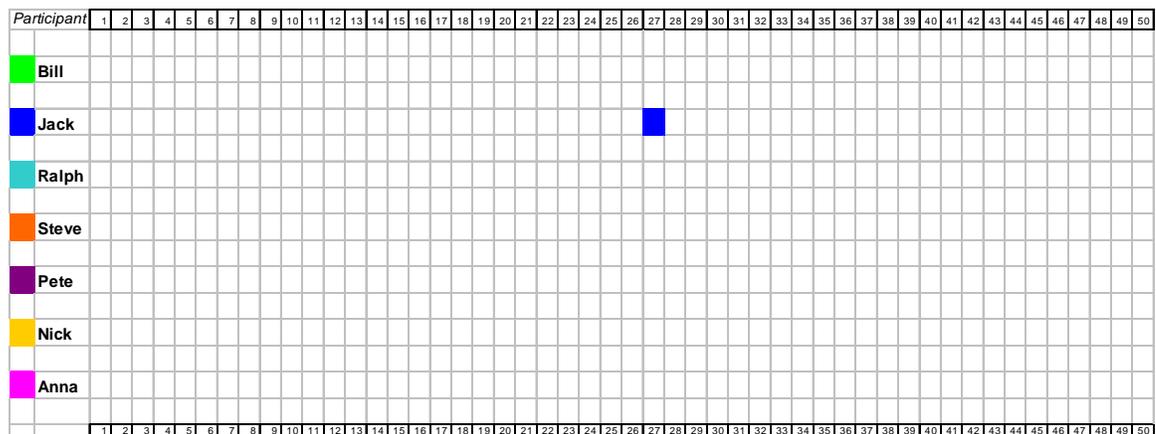
[Session 10: questionnaire]

Jack also shows more trust in Anna and sits next to her several times in session 11.

10.9 Cycle 4 (sessions 14-23)

Attendance

During the period leading up to Bill's death Jack hardly comes in at all, usually less than three times per session. Graph 7 shows session 18.



Graph 7 session 18

In and out

Nick writes 'Jack in and out' in sessions 16 and 22, and 'in and out as usual' in sessions 20, 21, 25 and 26, as if conceding that this is Jack's expected pattern of a

behaviour. Although, his slightly longer appearances register on the attendance graphs, Jack has also used the session as a thoroughfare several times. I note it three times in session 14, and once in session 15. By session 17, Nick has arranged to have the door locked so that Jack cannot do this, although on reflection Nick expresses regret at becoming like other members of staff in taking control of locking doors. Jack tries to go through seven times during that session.

There are more data which suggest why Jack might leave the room: Nick playing his trombone and Bill shouting outside are two examples.

Most of the data which describe Jack standing outside or passing the room are my observations, whereas Nick focuses more on Jack either not coming in, or just using the room to get out to the garden. To Nick this implies either a lack of interest in the session, or a lack of understanding that he might have any impact on the session by walking through. In dialogue and in the co-operative inquiry, there is discussion about this. For example:

Nick: Jack doesn't come in a lot.

Cathy: No but I noticed that he was skipping and laughing a lot outside the room, and was responding to the music.

Nick: It's difficult for me to know that in the session.

Cathy: It seems to me that he's listening a lot outside.

[Dialogue with Nick, cycle 4]

New sounds

There are more examples of Jack choosing to enter the room after Nick has played specific sounds. In session 15 Nick plays the windchimes and Jack comes in. I write:

Nick has used instruments to call people in. Some success in this, it appears.

[Session 15: analytic memo]

Conversely, in session 17 Nick plays a bird whistle to Jack who is standing outside and Jack leaves immediately.

Listening and awareness

In session 16 Nick sees that Jack is listening outside the door. The music is really loud so Jack is more easily able to do this more easily.

Vocal play

In session 20 Nick writes:

Jack was humming pitched notes corresponding to my singing.

[Session 20: questionnaire]

This is the first time Jack has shown any kind of musical connection through using pitch.

Instrumental play

Jack seems to lose contact with many of the changes in cycle 3. He focuses only on the buffalo drum. In session 16 he plays it, holds it while Nick drums, and explores it with his hands. He hits the strings on the back of the drum with a beater. In session 22 he takes the buffalo drum three times, and plays it and holds it while Nick plays it. He also touches the guitar. Nick refers to the buffalo drum as

‘Jack’s lifeline’.

Not knowing

In the co-operative inquiry, participants again acknowledge how difficult they find it to make sense of Jack’s behaviour. This leads to an exploration of how much unpredictability there is in the general environment:

Dave: Jack does it all the time [*referring to his erratic attendance*] – I have no idea why he does it. It’s the sort of stuff they all do in music therapy – I’ve no idea why they do it!

Claire: I think with the unpredictability of the residents, introducing any other unpredictable factor into the scenario is very stressful.

[Co-operative inquiry: meeting 4]

However, Nick finds that watching sessions on videotape are helpful in beginning to deal with his uncertainties. He realises Jack is doing more than he had appreciated during the sessions.

Important relationships

Jack avoids Ralph and Pete. Pete is aggressive to Jack (as explored in chapter nine).

10.10 Cycle 5 (sessions 24-33)

Attendance

At the beginning of the cycle Jack’s presence is still very infrequent. The frequency of Jack’s visits build up but in session 30 he stays for almost the entire session. From then on his periods of visiting the session are longer, but not as long as in

Kate Up and down...

Rose Up and down.

[Co-operative inquiry meeting cycle 5]

In and out

Jack becomes more engaged with the music therapy by being inside the room.

Nick writes:

Jack was in and out *humming*. He seemed to be more present.

[Session 27: questionnaire]

Other staff members notice this too. Craig, who filmed session 32, wrote:

Jack looked through the window at us from the garden and then after a while came to the door. He seemed inquisitive.

[Session 32: questionnaire]

Jack continues to try to take Nick out of the room, even in session 30 where he stays most of the time. Nick resists, trying to stay in the room for the rest of the group members and this time Jack does not leave. In the following two sessions, where Jack does not stay for the entire session, Nick again writes 'Jack came in and out as usual.' However, we can see from the attendance graphs that he came in for longer than usual on both occasions.

In the co-operative inquiry participants discuss why Pete shuts Jack out of the room.

New sounds

In session 24 Jack comes in when Nick plays the trombone but then leaves.

Jack again shows some sensitivity or even pain in response to certain sounds: in session 31 he puts fingers in his ears as Pete moves tables but does not leave. He

then leaves with his fingers in his ears when Steve plays the windchimes. In session 32 he leaves when Nick plays the ocean drum.

Listening and awareness

Anna is absent for a number of sessions which allows other staff members to film and so become participants briefly. One staff member, Angela, finds the following significant:

The responses of the residents and their interests – how they reacted
– either if it's just watching or listening or actually playing.

[Session 24: questionnaire].

Vocal play

Anna writes that Jack hummed when in the room for session 29. She marks this as significant. Jack gets involved in several duets and trios in session 30 by tapping his feet and by humming.

Instrumental play

Jack explores different instruments. Nick tries to show Jack how to play the buffalo drum. This departs from Nick's usual style of therapeutic work, as it is more instructional. Jack's most imaginative play seems to me to be with the buffalo drum. Jack brings it in before the session starts (making sure it is there for him) and accepts it every time Nick offers it to him. Then in session 28 he starts to refuse it, which is new. This indicates to me that:

Jack feels to be more decisive and autonomous with this move

[Session 28: analytic memo].

Participants in the co-operative inquiry discuss Jack's apparent attachment to the buffalo drum, making links to a time when he carried a spoon around. Susie

is considering buying him a similar drum for Christmas.

Susie: You were saying about Jack and the drum. Does he do anything with it?

Nick: Sometimes he plays it, sometimes he gives it to me, and sometimes we pass it back and forth.

Rose: Even if the drum's in a different position in the room, he'll seek that one out will he?

Nick: Yes. I don't know what he gets out of it.

Rose: He went through a stage of carrying a spoon when he first came here. It became very important to him and then all of a sudden he lost interest in it entirely. It was something he could manage in his hand, and some of the movements and the way he held the spoon – you know, I couldn't do that! I tried and I couldn't do it.

[Co-operative inquiry meeting, cycle 5]

In session 30, where Jack stays for a lengthy period, he plays the drum, accepts beaters, throws instruments, plucks the guitar, gives the windchimes to Anna and gives a drum to Nick twice. He also gives a drum to Steve. Perhaps as part of his greater assertiveness, he throws the shaker and moves tables back when Pete moves them. He becomes more musically involved in trios by moving his body to the music and humming. Nick and Anna both comment on Jack's involvement. I reflect that Jack is becoming more visible. Nick writes:

Jack was humming pitched notes to my singing (around D). He picked up the guitar and strummed while he sat next to me. Afterwards he seemed to be watching me and the others out of the corner of his

vision. It really is significant, the length of time he was in the session

[Session 30: questionnaire]

Anna writes:

Steve and Jack seemed sad, then Steve cheered up. Jack moved the tables and instruments around. All three men, Jack, Steve and Pete were in the room together for a long time. Jack sat on the chair for most of the session. Jack tapped his leg to the drum Steve was playing. Jack tried to play the guitar.

[Session 30: questionnaire]

In session 33 Jack begins to sing to glissandi played by Nick on the metallophone.

Important relationships

Most of the data refer to the dynamics between Pete and Jack which I have already discussed in chapter nine. However, given that there are such scarce data about Jack's relationships, his responses to Pete, for example when he pushes tables back that Pete has moved, seem to have considerable importance.

Jack shows a little affection by holding Nick's hand in session 28; on this occasion the purpose is not to lead him out.

10.11 Cycle 6 (sessions 34-38)

Attendance

Jack is in the room more often, for periods which are longer than in cycle 5 and continue to increase in length. Nevertheless, nothing comparable to session 30 is ever repeated. Graph 10 shows session 38, which includes periods of up to five minutes in the room.

leaves.

In session 38 I wonder whether Jack enters because there has been a noticeable increase in music in the room.

Listening and awareness

Anna writes:

Jack was looking at the drum with tiny beads.

[Session 26: questionnaire]

She also feels he has difficulties in musical interaction:

He was humming along a few times. And it always just felt as if he wanted to be involved but couldn't.

[Session 37: questionnaire]

Vocal play

He does not appear much after this. Anna writes:

Jack hummed along to Nick's singing and tapped the drum to the music.

[Session 38: questionnaire]

When involved in humming carols Jack seems to be present in the session in a new way: he sits closer to Nick and responds by tapping his foot to the music of other participants.

Instrumental play

In this cycle Jack shows some quite new reactions to the music. In session 35 Anna reports that Jack throws the shekere aggressively. In session 36 I film because Anna is away. I write:

Jack enters and sits and slaps his face. Nick plays 'This Old Man' in a

rhythmic manner on the keyboard. The music stops. Jack leaves.

Nick says, 'Jack was watching me.' I say, 'I think he put his hand on the keyboard.'

[Session 36: observation]

In the final two sessions Jack begins to play the conga drum during the Christmas carols and in response to other events. Anna notes:

Jack tapped his fingers on the side of the drum. He seemed to like Christmas carols.

[Session 37: questionnaire]

I write:

Nick sings Jack's name to every syllable in the carol as he comes in and sits with Nick. Nick continues to play carols to Jack and Jack vocalises with him. When Nick starts singing 'In the Bleak Midwinter', Jack leans forward to the congas and knocks it rhythmically with his knuckles.

[Session 37: observation]

Anna notices that:

Jack hummed along with Nick and tapped the drum to the tune.

[Session 38: observation]

She explores this in dialogue:

Jack was tapping on the drums last session... I just really felt he wanted to do more but didn't have the skills to do that.

[Cycle 6: dialogue with Anna]

Not knowing

In her final dialogue with me, Anna wrestles with her changed attitudes towards

Jack and tries to make sense of what she feels and thinks.

Cathy: So do you feel he's been really damaged by his
institutional life?

Anna: Yes...but then I didn't know what he was like to start with.

Cathy: None of us do. No one here.

Anna No. I do think they're all a lot more capable than what they
are capable of now

[Dialogue with Anna, cycle 6]

Important relationships

Aidan's relationship with Jack becomes a new but powerful factor. This is shown in session 34 when Aidan simply gestures to the door and Jack leaves.

Nick writes about this incident:

Aidan showed his dislike of Jack.

[Session 34: questionnaire]

Anna adds:

Aidan shut the window when Jack came to it. He looked very
disappointed when Nick called Jack's name.

[Session 34: questionnaire]

Reflecting on this it seemed to me that Aidan was trying to eliminate all trace of Jack from the session. Jack must have aroused a very powerful reaction in him.

This will be explored more fully in chapter fourteen.

I recorded some brief observations relating to Jack's relationship with Steve.

In session 37 Jack leaves as Steve enters and Steve keeps the door open.

However, Steve has already shut the door after Pete. Both Nick and I interpret this

as deliberately keeping Pete out. In this case, Steve's leaving the door open to Jack may imply a kind of tolerance or even an invitation.

Jack knocks the congas with his knuckles when Pete moves the drums. Nick, Anna and I are all unclear about whether it is the noise or the repositioning of the instruments that Jack objects to. This is an isolated example, but suggests to me that Jack is beginning to find ways of letting Pete know that he objects to what he is doing.

In the case of Ralph and Jack, Rose, from the co-operative inquiry reports:

Nick says when Ralph comes in Jack goes out. In fact, if Ralph doesn't come in, Jack stays for longer. Jack is more aggressive but more assertive with it which can't be a bad thing for him.

[Cycle 6: dialogue with Rose]

In Jack's relationship with Nick, Nick feels confident enough to try more direct approaches to Jack. He tries patting Jack's face in session 34, and moves physically closer to him in session 36. In both instances, Jack leaves immediately. Despite this, both Nick and I agree that their relationship is more trusting. I write:

Jack is showing a closer connection with Nick.

[Session 37: analytic memo]

The following figures (figure 12, p260: figure 13, p261) summarise the main trends of the changes Jack makes from the chosen categories. I then identify and discuss some emerging patterns.

| | CYCLES Cycle 1 | Cycle 2 | Cycle 3 |
|--------------------------------|---|---|---|
| CATEGORIES | | | |
| Attendance | Very brief visits Fairly frequent | In for longer periods 3-4 minutes in 9 times/session | In about 10 times per session. His attendance starts to drop. |
| In and out | Nick: Jack needs a clear diagonal space | 'In and out' becomes Nick's standard comment Jack present outside Often looks in room | Often walks past room. Tries to take Nick outside. Seems to have no idea of 'private space' |
| New sounds | Enters to bongo sound. Does he leave to specific sounds? | Leaves to harsh sounds Stays when Nick sings | Enters to trombone Leaves to rattle and loud drums |
| Instrumental play | Gives drums to Nick. Exchanges instruments. Plays drum and metallophone | Examines and explores instruments Tends to move them rather than playing them | More playing to make sounds Shares musical experiences Taps feet to others' music |
| Vocal play | No data | Hums in house Stays when Nick sings to him | Nick continues to sing to Jack |
| Listening and awareness | No data | Listens to Steve drumming | Listens to Steve. Stays longer if Nick responds to him |
| Not knowing | Does Jack know what to do with instruments? | Is Jack interested? Confusion about the meaning of his actions | Inquiry into his motivations What are his feelings? |
| Important relationships | No data | Few references | Ralph and Pete dominate Jack. He develops relationships with Steve, Jack and Anna |

Figure 12 Summary of changes Jack makes in cycles 1-3

| | CYCLES Cycle 4 | Cycle 5 | Cycle 6 |
|--------------------------------|--|---|--|
| CATEGORIES | | | |
| Attendance | Attendance reduces averages 0-3/session | From low to full attendance in session 30 | Increased frequency and length but not as in session 30 |
| In and out | Uses room as thoroughfare Connects with music when outside room | More present in room. Noticed by all participants | Tries to take Nick out Aidan tries to get Jack out |
| New sounds | Enters and leaves to specific sounds | Only leaves to very loud sounds. Copes by putting fingers in ears | Interest in familiar or pre-composed music such as carols and keyboard demos |
| Instrumental play | Only uses buffalo drum ('lifeline') | Plays buffalo drum in new ways. Refuses instruments. Gives Gives instruments to peers | Plays conga and keyboard. Throws instruments Increased musical engagement |
| Vocal play | No data | Humming in trios and duets. Humming pitched notes with Nick | Singing and humming carols |
| Listening and awareness | Listens outside room Nick makes music when alone | Considerably more musical involvement | Looking at instruments in a new way. Uses music to comment on Pete's actions |
| Not knowing | Participants inquire into Jack's actions | Linking his use of instruments to use of spoon | Anna questions her assumptions about Jack |
| Important relationships | Jack avoids Ralph and Pete | Stands up to Pete by moving tables Increased interaction with Nick | Steve and Jack may have positive sharing. Jack bullied by Aiden but protected by Nick |

Figure 13 Summary of changes Jack makes during cycles 4-6

10.12 An overview of Jack's changes

Looking at the year as a whole, the data relating to Jack are few compared with the accumulated data for Pete, Steve and Ralph. However, it is possible to discern some changes that Jack makes during the inquiry, and changes in perceptions about him by participants of the co-operative inquiry. Developments during cycle 5 suggest that Jack's constant wandering is an aspect of his behaviour which can change.

In the first cycle (sessions 1-4) Jack makes brief appearances but there are very few examples. His use of instruments seems to be the richest source of data, but participants are baffled by what he does with them.

In cycle 2 (sessions 5-7) Jack comes in more frequently and for slightly longer periods of time. Although his visits are still part of his wandering, he does also spend some time listening outside the room. In this short cycle Jack's use of instruments begins to develop.

In cycle 3 (sessions 8-13) Jack begins to show signs of being more involved with others through the music. He shows more specific reactions to particular sounds, and the sounds that particular people (Nick and Steve) make. His lack of understanding of private space becomes apparent to some participants. Greater involvement with participants leads to his being bullied.

Jack almost drops out of the music therapy inquiry during the fourth cycle (sessions 14-23). He only plays with one instrument, and generally uses the room as a thoroughfare, as if he has lost touch with any meaning which being in the session had for him. As he is still listening outside at times, I wonder on reflection whether his experiences with Pete and Ralph in the previous cycle have led him to

disconnect with the process. Another possible explanation is the rising tension in the home as Bill becomes increasingly ill and distressed.

After Bill's death, Jack's attendance starts to increase except for the period when he has a brief holiday away. In this fifth cycle (sessions 24-33) he is less likely to leave when there are loud or harsh sounds, so we might conclude that he is more determined to stay. One main development is his humming as part of the music made in the session. He decides to stay for an entire session and this contrasts remarkably with his previous combination of wandering and standing outside. Standing outside may have been a prelude to this. His connection with Nick begins to strengthen through musical play.

The final cycle (sessions 34–38) includes a radical change in Nick's clinical practice: the introduction of pre-composed songs. Although this is partly due to the approach of Christmas, it enables Jack to make much closer musical connections with Nick. Despite strong objections from other participants, Jack stays in the room for increasingly long periods, often sitting close to Nick or Anna. He also begins to express his feelings in music, although this seems to be just the beginning.

Although most of the changes I have described seem quite tiny, the change in the degree and manner of his participation is indicative of his potential for more dramatic change. He reduces his isolation through the music therapy inquiry, and despite the risk of hearing unwanted sounds or being bullied, he chooses a musical relationship with Nick.

Attendance - an overview

This category provides a strong indicator of Jack's involvement. He begins by building up the length and frequency of his visits, but during cycles 3 and 4, he comes in considerably less often. The meanings of his visits during this time

seem to be unconnected with participation in the session. His attendance increases after Bill's death until he stays for a whole session. The contrast between session 30 and a session in cycle 4 could not be more dramatic.

In and out - an overview

This category allows us to look at different aspects of Jack's use of space. For example, he uses a clear space in the room to enter, and this is possibly linked to his poor eyesight. He sometimes uses the room simply to get to the other door, but he sometimes stands at the threshold, listening to the music but not committing himself to entering. He does not appear to understand the privacy of Steve's bedroom space. However he continually tries to take Nick out of the therapy space and lead him to his own bedroom. 'In and out' is a phrase often applied to Jack, and the inquiry seems to provide him with the possibility of exploring what 'inside' and 'outside' mean to him.

New sounds – an overview

Jack's preference for sounds becomes clearer and more specific through the year. Some sounds are either too painful or too difficult for him to bear in the early cycles, but by cycle 5 he uses a strategy of putting his fingers in his ears so that he can stay. Rhythmically and harmonically sophisticated or complex music appears to be the most attractive and motivating to him, although he has clear preferences for some single-melody instruments like the trombone.

Instrumental play - an overview

The sequence of actions is quite puzzling, because Jack begins by playing instruments in cycle 1, but then spends the next three cycles exploring and moving the instruments as objects rather than as sound-producers. The only exception is

his exchange of instruments with Nick. This seems to be a means of making a connection with him, although in a way which is quite emotionally disconnected, and certainly unconnected with music. In cycle 4 the buffalo drum seems to me to become necessary for him to maintain any kind of connection with the session. He had used the spoon in a similar way when environmental changes were perhaps too distressing to allow him to connect with others. However, in cycle 6 he plays the conga in a manner that is quite deliberate and different from before; and this is perhaps the beginning of his expressive musical play, certainly from the point of view of playing instruments.

Vocal play – an overview

As with Pete, Jack's use of voice is the first way of making connections in the music with others. He begins by humming outside, first noticed in cycle 2. He also seems to be drawn to Nick's voice. However, in cycles 5 and 6 he uses his humming to become part of the musical interactions and play. By humming and singing carols with Nick, he is also able to reconnect with his past a little, as he knows the tunes and has clearly learned them previously.

Perceptions of listening and awareness – an overview

There are not many examples here, but notably, Jack is interested in Steve's music. His peer relationship with Steve is in direct contrast to the relationships with Aidan, Pete and Ralph.

Important relationships – an overview

One trend is that the references to Jack's relationships increase through the cycles. Jack does have relationships with each participant, but with Pete, Ralph, and later, Aidan, these are characterised by their domination over Jack. Jack tends

to avoid these three men, and possibly the presence of Pete and Ralph is a factor in Jack's loss of connection with the inquiry in cycle 4. Jack starts to find closer connections with Nick, hinted at in cycle 2, but continuing throughout the year. Towards the end of the year he seems to find a way of both confronting Pete and consolidating a relationship with Steve.

Not knowing – an overview

Participants ask about the meaning of Jack's actions consistently throughout the inquiry. Although everyone knows that he is labelled autistic, he continues to puzzle. However, towards the end, some staff participants are beginning to make links with other patterns of behaviour he has shown in the home. Anna realises that there is potentially much more to Jack than she had assumed.

Further inquiry into 'not knowing'

'Not knowing' or unpredictability was an acknowledged cause of stress for workers at the home. Jack symbolised this for some of the participants. As a result, we decided to explore our inquiry with Jack through a form of presentational knowledge, and produced a collage, part of which is shown in plate 10.

Perspective one

To me this picture is like an arial view of a vortex, as though all the observations will somehow get sucked down into the middle. To me, it's about his autism: I can't always grasp what Jack does and I often forget.

Perspective two

This picture is all about what other people think about Jack. He doesn't feature here much. Well, I suppose some of his actions do, but it's what other people have thought. I don't know what Jack would make of it all.

Perspective three

I agree that we don't know much about Jack or his history, and it's difficult to make sense of what he's done in the music therapy. Or in fact, how he ticks at all. But at least the picture shows that he has affected people and he's made some music too. It was good to make the collage because it really made me think about the different ways we can think about Jack. I think it's amazing that he has changed after all this time.

9.13 Summary

Some of the data lend themselves to the interpretation that Jack is autistic. For example, he related to objects rather than people at first and he did not seem to recognise either the meaning of private space or a group room. He was often remote and disengaged from other people and forged few relationships. The ones he did develop were primarily through musical means. He avoided group contact at

first, and did not seem to show any interest in communication with others for several months. This fits with Lorna Wing's 'triad of impairments' found in autistic individuals (1993): difficulties in communication; participation in and understanding of interactional social cues; and lack of symbolic or imaginative play.

Conversely, some of his behaviour, such as crossing the room with diagonal space clear of instruments, and leaving in response to harsh sounds could be linked to visual and hearing impairments: tunnel vision increases the likelihood of bumping into instruments at close range, and otitis media may increase sensitivity to loud sounds. Jack's lack of affectional bonds and poor communication skills could explain why he was extremely unlikely to trust others, and preferred the safety of isolation. In a sense, as I knew so little about him, I tended to think that the cause or explanation of how he was seemed less important to emphasise than the way in which he was able to change in a number of almost imperceptible moves.

Change was inherent in Jack's use of instruments, particularly in terms of relationship. His giving and exchanging of objects showed small changes throughout the year. Even when Jack seemed to withdraw, he and Nick found a way of re-engaging, for example in the sharing of Christmas carols: recognisable shapes, related to a past and a shared culture. Sometimes Nick was able to tell what Jack was humming, sometimes not.

We talked about Jack very little in the co-operative inquiry. It was all too easy to dismiss him. Three other residents bullied him. He was vulnerable and invisible, yet began to find small ways of being empowered. In session 30 he showed me that he was prepared and able to change in a radical way within the context of the music therapy inquiry, by choosing to stay and become part of a

group. He also taught me that he is the person who can reveal most about his missing history, through song.

Nick said about Jack:

I think Jack has shown me that change can only occur when a person is fully accepted as they are without any pressure or expectation to change. It is then that change becomes possible.

[Personal communication after the formal end of the inquiry]

CHAPTER ELEVEN

Steve

11.1 Vignette

Steve is stocky and grey-haired, with an expressive face which often breaks into a cheerful smile. He greets me as a newcomer by shaking my hand. He is introduced to me as 'Steve'. At first he struggles to speak, holding me with an intense gaze... 'M-m-m-my name is Steve...' I think he might have finished but he carries on. 'M-m-m-my dad is called Steve and my brother is called Frank.' Speaking is clearly a great physical effort. He proudly shows me his bedroom. Then we have a cup of tea in the lounge with Bill, Ralph, Anna and an agency nurse. Steve is friendly and enthusiastic for a while, but he soon starts to slow down. At one point he seems to go into a trance-like state, although when Anna asks him a question he begins to look around again. Eventually he is so tired that he needs help to get up and go to his bed. It is eleven in the morning.

11.2 Background

Steve was in his early forties and had lived in an institution from the age of thirteen. He was still in touch with his family. At the time of the inquiry, his father was very ill. He refused to let Steve visit him or know that he was ill, to avoid Steve becoming upset. However, the lack of communication from his father in itself upset Steve.

Steve came across to me as a friendly, affectionate man who had very sudden, unpredictable mood swings. He seemed frustrated by his difficulties in expressing himself, but did often persevere. He had an infectious enthusiasm for

the instruments offered in the music therapy sessions. Sometimes he would hug Nick or me and try to tell us what he had just been doing. He did not seem to have any strong dislike for any of the other residents, and rarely left the room because someone else had entered.

11.3 Communication

Steve has Kluver Bucy syndrome which results in short term memory difficulties. He also has uncontrolled epilepsy and mental health needs. Because of his dysarthria (oral musculature motor disorder) it is very effortful for him to produce speech but he perseveres and likes to engage with others. The first word always takes time to produce and he also needs time to process information. He does understand quite complex sentence structures. He understands and makes sense of life through routine.

He may point at what he wants and is very interested in pictures. He seems to tire quickly and can go into almost catatonic states where he can't continue with an activity. He understands when he is included or excluded.

[Extract from Steve's communication report, November 2000]

11.4 Issues about participation and assent

Although Steve's family members were able to give assent for Steve to be involved in the inquiry, he also had the potential for understanding some of the process. When I brought a video camera before the music therapy started, Steve was keen to watch. He inserted the video tape in the machine at one point. Once when the

video player was not working he looked disappointed. I said I would return on Monday and we counted to Monday on his fingers. As discussed in chapter five, gaining even partially informed consent is best thought of as a process rather than a discrete event. Steve spent time watching videos and filming himself with the camcorder several times during the year. He watched parts of sessions 1, 2 and 6 on video, but it was only after a private viewing of session 13 that he seemed to grasp the causal chain which linked having a camcorder in the session to viewing himself on television. Later in this chapter will examine in detail the change in his response to the video. From this point, Steve explored with Anna, Nick and me what influence he could have on the filming within the music therapy inquiry sessions.

11.5 Organisation of the data

I have used examples in this chapter from the following categories: all seven categories within the theme 'music' (1.1 to 1.7), important relationships (2.1), new sounds (3.1), responses to newness (3.6), range of emotional expressions (4.1), other forms of emotional expression (4.6), self-awareness (5.4), responses from watching videos (8.1), responses to the use of videos (8.2), benefits of video use (8.4) and aspects of illness (9.1).

From the data there are three main areas that consistently relate to Steve: his creativity in music, his relationships within music, and how his inquiry was enhanced by the use of the video. Creativity and relationship within music are closely related and at some points inseparable. Although presented separately, each section can be read in conjunction with the other. As there are only three themes presented, I do not provide summary charts for Steve.

11.6 Creativity in music

Cycle 1

In the first two sessions Steve immediately became involved with the instruments, trying each one and experimenting with different ways of creating sounds.

For example, while he plays the xylophone in session 1:

He plays a glissando and Nick follows him.

[Session 1: observation]

He is so involved he is not affected by others leaving:

Ralph leaves and Steve continues playing glissandi.

[Session 1: observation]

Steve also tries unusual sounds and tactile experiences such as rubbing the beater on the drum skin, and playing on the edge of the drum. This experimentation is encouraged by Nick's own music: he also tries playing with the drum in unusual ways. When Steve plays very loudly, others come in to listen.

In session 2 Nick describes Steve as:

much more energetic this week. Because of his epilepsy he can be in a different frame of mind and physical state and I think this comes across in the music.

[Dialogue with Nick]

Cycle 2

Steve's exploration of new sounds continues. He tries playing the guitar with a stick, and beats on the edge of the drum rather than the skin. He plays glissandi on the keyboard.

Cycle 3

In session 8 Steve begins to experiment with body movements in conjunction with playing instruments. In session 8 he rubs a drum skin and starts rocking from side to side. Seeing the letter names written on the xylophone bars he sings 'ABCDE' and plays the xylophone one note at a time.

In session 9 Nick writes:

Steve explored new instruments (to him) from the bag I brought in. He played by himself and sometimes interacted with me.

[Post-session questionnaire]

However, by session 12 Steve is sharing the enjoyment of new sounds with Nick most of the time. Nick writes in the questionnaire:

He explored some of the smaller instruments with me, including reed horns and the vibraslap.

In session 13 Nick shows him a new instrument called a mouse which Steve plays with a stick. I write in an analytic memo:

Nick has introduced more new instruments and both Steve and Jack seem interested in these. Nick is producing instruments I have never heard of – Steve is stimulating his therapist's creativity!

Cycle 4

Steve begins to explore unusual combinations of instruments. In session 14 he picks up some maracas using them to play the windchimes.

He begins to dismantle instruments and mend them; for example he unwinds the tangled windchimes and unscrews the cymbal. He also tries new ways of playing familiar instruments. In session 15 he makes the windchimes silent by

holding them. He then briefly releases them and starts exploring the sounds he can make.

Steve's exploration is not confined to instruments. He turns to the environment around him:

Steve stamps with his feet and then hits the wall with his beaters. He then rubs his beaters against the wall. He lines the stick up again. He beats the trolley fairly gently with one stick. Nick plays the trombone with a similar rhythm. Steve then gently hits the glass in the door. His beating speed accelerates, and he starts using two beaters. Steve bends the beaters. He starts opening doors using the beaters which are plastic with wool heads, i.e. they are not really strong enough for this kind of work.

[Session 15: observation]

Nick, too, creates unusual sound combinations. He whistles to Steve's keyboard playing. It is as if, with Nick's encouragement, Steve is expanding the boundaries of what an instrument might be. He seems unconstrained by any expectations of what music could be, so is refreshingly free to make music on the doors and walls.

Cycle 5

Steve returns to his imaginative self in session 24, the week after Bill's funeral. He puts two guitars next to each other and hits their necks together.

The nurse who had been filming noted: 'Steve seemed interested in the different sounds coming from the instruments.' [Post-session questionnaire]

In session 31 Steve plucks loud single notes on the guitar, hums with Nick and together they develop a lengthy improvisation where each person plays only one

sound at a time alternately. I write:

The use of single notes seems significant – there was lots of exploration of single sounds. There was also silence and I wonder if there was very acute listening in this session, and a quality of musical participation which was new.

[Session 31: analytic memo]

In session 33 Nick is still able to find new experiences for Steve. Nick plays the swanee whistle and Steve watches intently. He takes the whistle offered to him by Nick.

Cycle 6

In session 34, after Aidan has musically dominated the early part of the session, Steve reverts to he brought earlier to the inquiry, 'ABC'. Nick responds with one note on the xylophone for each letter. Steve gets through the entire alphabet. Then there is silence.

Nick knows that if he tries a new sound it will revitalise Steve:

Nick stops playing and says 'Steve, you're tired aren't you? What would you like to do?' Steve stays silent. Nick then changes the sound/timbre of the keyboard. Steve begins to sing with this.

[Session 34: observation]

Overview of 'creativity in music'

Steve's fascination with creating new sounds began in his first session and continued throughout the inquiry. It was both a strong motivation for him to come to the session, and a stimulating balance for Nick in contrast to the frustrations of working with Ralph and Jack. Both men enjoyed experimenting together, sharing a delight in the unusual and different sounds they could make. For Nick, the music-

making was unconventional, and Steve was able to challenge both him and me in our conceptions of what forms improvisation might take.

However, I think that Steve's easy musical relationship was the source of some envious attacks from Pete, challenging Steve in turn. I will now explore how this was expressed within the music therapy inquiry primarily through music.

11.7 Musical relationship

Cycles 1 and 2

In cycle 1 Steve is already playing duets with Nick, making variations in the way he interacts: following, leading, and exchanging ideas. At first Nick talks about Steve being more focussed on the instruments than in playing together with him.

What's happening here is that Steve wants nothing to do with me and

I haven't realised it yet. I'm thinking 'how can I connect to him?'

Actually I think he's just interested in playing the instrument.

[Dialogue with Nick: watching session 6 on video]

Steve's communication struggles caused complications:

He started talking to me and I could not understand him. This caused

him to be angry with me and he showed me a fist.

[Session 6: Nick's questionnaire]

By session 7 they were able to develop some more extensive musical dialogue:

We had an interesting exchange when answering each other on

drums, and then when he played metallophone, and I played

trombone.

[Session 7: Nick's questionnaire]

Cycle 3

By this time there is more information about Steve's relationships with other participants. Nick writes in session 8:

He seems to keep his distance from the other men.

Steve is sensitive to Bill's distress as early as session 8:

Steve spends several minutes just arranging instruments. However, when he hears Bill vocalising outside, he immediately starts to play the drums, as if he is galvanised into expression.

[Session 8: observation]

Jack may also have responded to Steve's low moods. In session 10 Steve is distressed throughout the session and comes in and out. He is closely followed by Jack on all these occasions. Whenever Steve plays a drum, Jack leaves.

Cycle 4

Most of the data at first is about the developing therapeutic relationship between Steve and Nick.

In session 15 Steve gets 'stuck' trying to organise the windchimes, and Nick helps him to a chair. Nick realises that when Steve becomes physically immobilised music can start to get him going again. When Steve plays the trolley and wall simultaneously, Nick provides some heavy accompaniment on the keyboard. Steve stops and starts and from this each man negotiates control of the music with the other.

After this session Steve watches the video of session 13 with me. Then in session 16 he enters in a different way. He embraces Nick, talks to him, smiles at the camera and then starts to play. This develops into an improvisation where Steve rocks backwards and forwards on his feet between drums, playing three consecutively, and Nick stands opposite him playing in a similar way. At one

point Steve becomes 'stuck' and just plays repetitively on one drum: Nick varies his pattern and rhythm and this seems to help Steve vary his playing again. This interaction continues for about ten minutes. Then Steve runs out, returning about fifteen minutes later to have another duet with Nick, again looking at the camera first.

Nick writes:

There was close interaction between me and Steve and we played the conga and tympanum together with smiling and eye contact. It was full of fun. Pete seemed involved in this too – there is a growing relationship between the three of us.

[Session 16: questionnaire]

In the following week we have the first example of Pete and Steve vocalising together.

In session 19 there is a spontaneous trio between Steve, Ralph and Nick.

Nick writes:

Ralph played the conga with a beater then threw it down. Steve played the windchimes and conga with a beater – with me, as Ralph listened.

[Session 19 questionnaire]

Session 23 is described in more detail in Bill's chapter, as it is the day that Bill dies. Steve is aware that Bill is dying and he is quite different in this session. He sits with Nick, each man playing a guitar. At first Steve is playful, introducing a game of kicking his heels, amusing Jack. The game gets slower and slower. Steve finally falls asleep holding Nick's hand and then goes into a seizure, at which point Nick stops the session.

Cycle 5

Steve is consistently pleased to see Nick, playing excitedly at the beginning of each session.

Steve's changing relationship with Pete is primarily expressed in his music. At first in session 24, Pete tries to stop Steve's music by knocking instruments over, and this does stop him. By session 26, Steve seems determined to keep his music going despite any physical attempts to stop him.

Pete tries to throw Steve's beater. Steve carries on beating the drum and his music sounds more heated – faster and louder. Pete pushes Steve's drum, but Steve plays another. Steve's music sounds faster. Nick says 'angry'. Pete moves a chair, and Steve stops. Nick begins to sing and Steve resumes playing in time with Nick.

[Session 26: observation]

In this situation, Nick supports Steve to continue when he is about to give up, and the music survives.

In session 28 (the week before Aidan arrives) all four residents are in the room. Steve and Nick play a duet and the others listen. Pete seems to become very envious and takes Steve's beater, breaking it in half. Steve then stops his music and instead arranges beaters on the xylophone as if to regain some order.

Then:

Ralph shouts out. Pete throws a drum across the room. Nick sings louder and Ralph leaves, vocalising. Steve sits immobile, frozen. Nick sits with him and talks to him. Steve still has the xylophone although he had wanted to change instruments. He walks to the door, undecided about whether to leave. He then takes Nick's hand to lead

him out.

[Session 28, observation]

The following week, rather than being forced out, Steve retaliates:

Steve hit his drum beater on Pete's head when he tried to throw stuff.

[Anna, post-session questionnaire, session 29]

Despite Steve's frustrations with Pete, he is able to acknowledge Pete's contributions to the musical sound:

Steve drums very loudly and energetically. Pete knocks the gong.

Nick then plays the gong with a beater. Pete and Steve listen. Steve points to Pete and says 'yes'.

[My session observation 29]

In session 30 Steve makes efforts to include Pete:

Steve has been playing the drums for several minutes with Nick. Pete pushes the table Steve is sitting on. The music stops. Pete throws a drum. Nick guards the other drums from Pete. Steve reaches over to Pete. Pete stays apart. Steve holds out his hand to Pete. Then he begins to play the guitar and Pete vocalises, seemingly in response.

[Session 30: observation]

Despite this, Steve still leaves when Pete becomes too disruptive. Nick writes:

He seemed both disturbed by Pete and amused by him.'

[Session 30: questionnaire]

In session 31 Steve again hits Pete with a beater. The member of staff filming chastises him. Steve seems very self-conscious and does not play for some time. By session 33 Pete has begun to listen to Steve's music more, especially when he sings his alphabet song.

Cycle 6

Anna writes:

Nick played 'Over the Rainbow'. Steve looked away, seemed quite affected by it, then bashed the keys quite aggressively to his own tune. Nick and Steve played a loud, busy tune for some time. The tune got lighter and more simple and Steve's mood changed as he went along.

[Session 35: questionnaire]

Both Anna and Nick were puzzled by this incident. This was the first time Nick had introduced any pre-composed songs into the music therapy inquiry. Perhaps Steve became aware of Nick's developed musical skills (he is an accomplished keyboard player with the ability to add rich harmonisations) and suddenly felt musically distanced from him. As soon as they reconnected in the music, Steve's aggression dissipated.

During the following week, Steve had been particularly concerned about why his father was not in contact. In session 36 the staff member filming wrote:

Steve sat with Nick in this quiet session. He soon seemed quiet and drowsy. Nick started to play a lot of music for him on the keyboard, including 'Somewhere over the Rainbow', which seemed to match the feelings that Steve had. I thought that Steve needed Nick to be a sort of nurturing father-figure.

[Post-session questionnaire 36]

Nick writes:

An intimate moment between Steve and me...he wanted to share his feelings. I played a different type of music.

[Post-session questionnaire]

Anna reflected in depth on the meaning the music therapy might have had for Steve during her final dialogue:

His moods changed very rapidly anyway but you could really see the change in his mood in the music. At one time I particularly remember that on drums he looked so satisfied. He was just so angry before. It was satisfying to see him get it all out of himself. Obviously making the noise itself was very, very important. It was almost like a kind of spiritual thing when he was on the drums.

As for his relationship with Pete, Steve has the last word on this. In session 37

Anna writes:

Steve locked Pete out of the room. He said that he wanted Pete to stay out. He left the room soon after Pete came in.

[Session 37 questionnaire]

My version is this:

Pete takes the windchimes out. Nick stops him doing this. Steve goes over to the door and feels the windchimes. Then he locks the door.

Nick asks 'why have you locked Pete out?' and Steve says, very fluently, 'because I have!' He then plays the windchimes.

[Session 37:observation]

Overview of Steve's relationships in music

Throughout the inquiry, Steve has used the music as a way of developing his

relationships with Nick, and also with Pete. The mutual exploration between Steve and Nick, particularly through making music on unusual surfaces led to a trusting relationship. Steve was then able to express some of his feelings of loss and Nick in turn could offer emotional support through the music. Steve had lost his old home, contact with his father and a man he had lived with for fourteen years within the space of a year. On reflection it seemed to me particularly important that Steve was able to receive this support from a man, because his father was unavailable to him.

11.8 Steve's relationship with the camera

In cycles 1 and 2, Steve shows no interest in the camera despite the preparation work before the music therapy began.

The main shift in Steve's awareness comes in cycle 3 after watching a video of session 13 with me in a different location, described in chapter five.

When he next comes in to the music therapy room, he goes straight to the camera.

This is actually session 16. I write:

Pete and Nick watch Steve playing. He plays fast and looks back at the camera (showing awareness that he is being filmed).

[Session 16, observation]

As I have described earlier, Steve's music was bolder and more confident from this moment on.

Two sessions later, Steve puts his legs round the African drum, and hits hard. He seems to be frustrated about something. Then he stares at the camera and stops playing. When he continues he plays with a fixed beat. At this point I wonder:

Is his creativity stifled by what he feels about being filmed?

[Session 18: analytic memo]

He seems to be taken by surprise by the camera in session 24, so perhaps has forgotten about it.

He hits the camera with a guitar neck, apparently by mistake, and then stares into the camera for some time.

[Session 24: observation]

His interest in the camera is rekindled by session 27. He plays fast, drumming loudly and starts smiling at the camera. Anna writes:

Then he starts playing every instrument he can.

[Session 27: questionnaire]

Nick notes:

He tries a new beater and smiles when he achieves a louder sound.

[Session 27: questionnaire]

In an analytic memo I reflect:

This is a good example of Steve performing for the camera.

[Session 27: analytic memo]

Before session 28 begins, Steve is using the camera and filming himself. I observe:

He seems very delighted

[session 28: observation]

Nick writes: Steve performed to the cameras by jumping around. I joined in by playing congas – a musical performance developed between us.

[Session 28: questionnaire]

The following week Steve comes in holding Nick's hand. He waves at the

camera, plays a gong and it falls over. Steve laughs. When Nick and Pete fight over drums, Steve looks at the camera, again suggesting some heightened consciousness of the filming process.

In session 30 Anna continues the camera work I started with Steve in the previous session. Anna writes:

Steve hit the camera with a beater and then saw himself on the screen.

[Session 30: questionnaire]

Finally, in session 37, Steve moved the camera around. This was the same session in which he locked Pete out. In the final two cycles, Steve's confidence and self-esteem seems to have been directly affected by his awareness that he was being filmed. He learned that he could control the filming by choosing what to do, that awkward incidents such as fights might be filmed, and finally that he could control the camera himself. Perhaps the parallel discoveries that he could change the filming, and that he could lock Pete out, were part of a greater discovery: that of his growing sense of autonomy.

Overview of the Steve's use of the camera

As I will show in the following chapter, for Ralph, use of a camera was an unwanted intrusion. By contrast, the presence of the camera helped Steve develop a greater sense of self-awareness, self-worth and empowerment. By filming his music and his musical relationship with Nick, Steve was able to re-experience his creativity, and also show others what he had done. He was proud of his achievements. His epilepsy and short-term memory problems may have made it quite difficult for him to remember what he had achieved from day to day, so being filmed may have offered a way to revisit lost memories. As Anna concludes:

I think Steve really enjoyed being in front of the camera.

[Anna, final dialogue]

11.9 Summary

Nick said of Steve:

He is someone who is really able to use music therapy well.

[Cycle 6: dialogue with Nick].

Steve's inquiry indicates how important it is if the therapist is open to very different ways of making music. If Nick insisted on responding to Steve only when he played instruments conventionally, both the improvisations and the therapeutic relationship would have taken a more restricted form. Nick entered the project having spent five years as a therapist reflecting on such issues, and this influenced not only his relationships with residents through the music, but his relationship with Anna and other staff members who became participants in the music therapy part of the inquiry. The music that Steve and Nick played together seemed to be experienced as quite acceptable by untrained members of staff. One staff member commented that Nick followed Steve's lead much more than 'we' did in the home, and that she would learn from this.

Steve's inquiry also tells us that by working carefully towards a process of informed consent, he was able to make his own meaning of his experience of participation with a camera. He transformed what seemed to be a shock (discovering that he and Nick could be put on television) into a way of affirming his musical creativity, of which he increasingly took control. Seeing himself on film seemed to strengthen his sense of identity, particularly because the digital camera allowed immediate playback through the screen attached to the camera. This was

a learning opportunity for Steve that he has continued to develop through the support of his keyworkers: by making films and showing them to others.

Steve was also a key figure in the musical dynamics of the music therapy group. Pete, Ralph and Jack often listened to his music, and if any trios or quartets formed in the music, Steve was always a participant. Steve was also the only resident who made obvious musical connections with the new group member, Aidan. Steve's music also acted as a commentator at times, increasing in intensity when another participant expressed distress, or when there was tension between two people. His ability to provide regular drumming for minutes on end provided what I see as a containing function in some way. I would argue that he was also able to shoulder some of the therapeutic responsibility with Nick in his dealings with Pete and Aidan, in terms of tolerating them and including them in the improvisation experience. This last perspective comes from my own belief from group analytic theory that each group member can become a therapist for others within the group experience.

CHAPTER TWELVE

Ralph

12.1 Vignette

Ralph walks into the lounge, keeping an eye on everyone there. He sits down heavily, folds his arms across his chest and looks down at the ground. He seems to me to have a rather grumpy expression. He also seems to be pretending to ignore other people. When Bill comes in and tries to sit in Ralph's chair, Ralph makes a low-pitched sound rather like 'hmmmp' and pushes him away in a sudden and slightly ineffectual gesture. When Sally, an agency worker, comes in, he stands up with a smile, and reaches out swiftly to pat her head. She says affectionately, 'Hello Ralph.' Ralph then starts to pick up some pens that Steve has been using to draw with. He puts them all on a bookcase. Sally says, 'You love to tidy up Ralph.' They both go out to the kitchen so that Sally can make him a cup of tea. Ralph comes back and drinks his tea. Then he drinks Steve's tea, Jack's tea and half of Bill's tea before anyone stops him.

12.2 Background

Ralph had been born abroad. When he was two, his family moved to England. He was sent to live in a hospital from the age of four, but I have no information about the circumstances. At the start of the inquiry he was fifty-six, taller than his companions and thin, with a pronounced stoop. He appeared shy, or perhaps diffident. He shouted out quite a lot, although with no discernable words. Until a recent stroke, he had been able to speak, mainly in single words, but he had now

lost this ability (see communication report below). Although staff members were aware of this, I did not hear anyone consider how this experience might have affected Ralph. Ralph often hit objects or people, although not particularly hard. At times he sat in a chair in the lounge apparently ignoring everyone.

12.3 Communication

He has had a recent cerebro-vascular accident (CVA) which may have affected his ability to understand and express language. He responds to subtle body language and this is his main means of communication. Before the CVA he used single words such as 'yes' and 'no'. Now he mainly uses body language and smiling. He has no interest in pictures or symbols. Objects of reference would be helpful. He needs people who know him well, increased opportunities for choice and needs a timetable with objects of reference.

[Communication report, November 2000]

12.4 Issues surrounding participation and consent

Ralph had no known next-of-kin and so, as in the case of Jack, the home manager gave assent for Ralph to be involved in the music therapy inquiry. She felt that he was much more likely than Jack to be able to make some sense of the process and express his dissent if he wanted to. However, on the basis of the data I will explore the scenario that Ralph did indeed consistently express dissent alternating with ambivalence about being filmed, but it was a long time before I and the other participants were able to acknowledge this.

12.5 Organisation of the data

Instrumental play (1.2)

No data

Vocal play (1.3)

No data

Range of emotional expressions (4.1)

Anna says in her first dialogue:

If you try to get Ralph to do some painting, he'll just look at the paintbrush, scream and run out. Maybe give you a little punch on the way.

Later she says:

Anna: I think that perhaps in a different environment he'd be capable of doing a lot, lot more.

Cathy: Is that a kind of frustration for you?

Anna: Yes, because I know he can do things. If he doesn't want to do things he'll shout quite loudly.

In session 4 Ralph gives the trombone to Nick. When Nick plays it Ralph vocalises and laughs. Nick writes, 'Ralph played the zither quite assertively.'

Attachment issues

Ralph leaves twice in session 1 when Nick makes some musical connections with Pete then with Steve. I write:

Is this jealousy? It seems unbearable for Nick to show an interest in anyone else.

[Session 1: analytic memo].

Anna makes a link with Ralph's possible history of neglect and poor attachment

experiences when she says:

All the years he's spent in institutions have made him...He's been left to his own devices – he'll do less when staff are around. As if he's been rejected or something and now he won't take that step to do anything.

[Cycle 1: dialogue with Anna]

Jealousy and rivalry

In session 1 there is a hint that there is rivalry between Ralph and Pete. Pete vocalises and Nick responds by developing this vocal shape. Ralph gets up, looks at Nick, waits (as if hoping that Nick will vocalise with him instead of Pete) and then leaves. There is also some evidence of Ralph's jealousy of Steve. In session 2, when Nick gives the keyboard to Steve, Ralph gets up and leaves, as if he cannot bear Nick to be spending any time with or attention on anyone else.

Identity and roles

The home manager says, 'Ralph sees most of his relationships that he's built have been with carers rather than peers,' and later, 'Ralph can be disruptive but he sees himself in a different light to the other men.' I ask, 'In what way?' and she replies, 'He aligns himself with the staff. He thinks he ought to be organising it when he gets there.'

Anna explains:

There are a lot of things he's capable of doing but he's conscious of perhaps the staff, not necessarily the residents but the staff and what he should be doing. Because of the way I think he was in the institutions and the way things were then. He's helpful: he'll tidy up: vacuum. He's quite defensive over the staff. If one of the residents

lashed out, he'll be the first one holding them back. He's capable of quite a lot. But he's never been pushed.

[Cycle 1: dialogue with Anna]

In session 1, a home care worker said:

Ralph put beaters on the drum. That's because he likes tidying up.

[Session 1: questionnaire]

Exercising power through action

Anna thinks she has a responsibility to exercise some power over the men for their good through the notion of 'pushing': 'It's just getting to know the men, seeing what they can do, pushing them.' I ask her if this is a way of expressing that she has higher expectations of them.

Exercising power through non-action

Cathy: Ralph is just sitting there.

Nick: He did a lot of that, looking like he wasn't very interested in anything but in session 5 he was very engaged.

[Session 1 video: dialogue with Nick]

Responses to the use of video

After watching the video of session 2 with Ralph and Bill I wrote:

When Bill heard himself vocalising he closed his eyes. Ralph looked carefully at this point.

[Field notes, February]

This was one of the most controversial points in the inquiry as one staff member who witnessed this felt that Bill might have been caused unnecessary distress by seeing himself on video. It is interesting that Ralph seemed alert, perhaps similarly

and maracas. Nick writes, 'He played very expressively on the cymbal for a short time.' In session 7 he prefers to play small instruments.

Vocal play

No data

Range of emotional expressions

Nick, encouraged in session 5, has feelings of disappointment about Ralph in the next session:

Ralph started coming in and playing in a completely different way – initiating music. That was great. I was carrying that optimism into session 6, and it doesn't fulfil the hopes I had. But I know that what happens in one session can't reflect the overall pattern.

[Dialogue with Nick]

Attachment issues

Nick: Why is Ralph keeping his back to me?

Cathy: Is he frustrated about not being able to communicate?
And because of this he needs to cut you out?'

Nick: I think maybe that happens sometimes. But I think he's really has got difficulty engaging, and I don't think it's just from being autistic, if he really is. I think he expects very little, but is angry about that.

[Cycle 2: dialogue with Nick]

Nick also says in dialogue that he can get 'a bit despondent' during the sessions and 'there's no need to, although I get most like that with Ralph'.

Jealousy and rivalry

Nick writes:

I felt Ralph was put off by Pete being in the room. He seemed angry and aggressive.

[Session 7]

Nick also wrote:

Ralph and Pete: the way they relate to or avoid each other. Do they compete for my attention?

Identity and roles

In the co-operative meeting Nick presents Ralph helping with the instruments as his initiative as early as session 7:

Nick: I asked someone if he wanted to come out and help me bring some of the stuff in. That was a new thing, a new

Range of emotional expressions

When a staff member comes in and (very unusually) plays instruments in session 8, Ralph plays the metallophone emphatically and leaves. Anna, returning from a break, writes:

Ralph's confidence seems to have doubled.

Attachment issues

No data

Jealousy and rivalry

Steve plays the xylophone, singing 'ABC'. Nick matches this on the metallophone, also singing. Ralph tries to take the xylophone away from Steve.

[Session 8: observation]

In the same session, Ralph pushes Jack away from Nick when only the three men are in the room. Conversely, Pete shows rivalry in session 11 by moving Ralph's sticks off the drum after he has played. Ralph leaves. Nick writes:

Pete became difficult as I was interacting with Ralph, so Ralph left.

In session 13, Pete hardly comes in and Ralph is more present. I ask whether this is because Pete is absent.

Identity and roles

Nick writes in session 11 that Ralph helped bring in the instruments. Ralph also brings in a number of instruments in session 13.

Exercising power through action

In session 8 Ralph takes a guiro from Jack and replaces it in the box. Jack tries to take the instruments out again and Ralph pushes him away. In session 11

Ralph tries to hold Nick's trombone as he is playing it. He also tries to take windchimes out of the room. I write:

There are some examples of Ralph controlling the other men.

[Session 11: analytic memo]

Exercising power through non-action

No data

Responses to the use of video

In session 11 I write:

Ralph enters, goes to the camera and rubs the lens.

He does the same two sessions later. Nick and I discuss how much Ralph might have understood when I played him some video footage of session 1:

Cathy: Ralph was ambivalent, showing interest and then looking down. But he was very keen to put the tape into the machine.

Nick: He carries the video camera in to the sessions.

Cathy: Ralph was clearly responding to the sound and vision too. I don't know how well he could see it. I think he may have some sense that the sessions are being recorded – well, I don't know.

And afterwards Ralph took the tape from me, walked to the door and then gave it back to me as I followed.

Nick: He thinks it's yours.

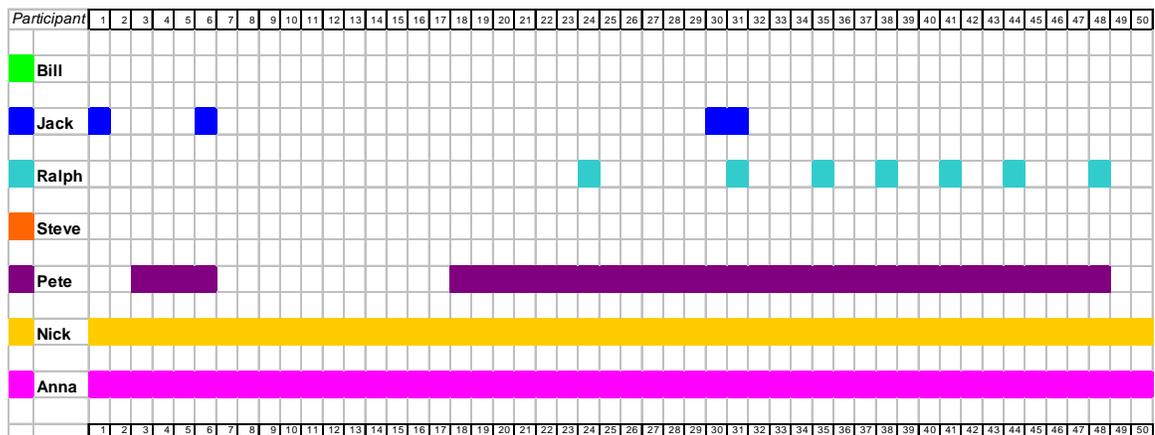
Cathy: He has his own copy now.

[Dialogue with Nick]

12.9 Cycle 4 (sessions 14 – 23)

Attendance

In most of these sessions, Ralph came in for slightly longer periods than before. He came in, on average, six times a session, for up to five minutes at a time, although some appearances were noticeably more brief. He was on holiday for session 17. He did not come into session 18, which was dominated by Pete and Steve. Ralph did come in on some occasions where Pete was present, so although he may have avoided Pete sometimes, there was no straightforward connection. Ralph avoided music therapy in session 23 although he helped bring instruments in. Graph 15 shows session 21, where Pete and Ralph were often in together, and Steve was on holiday.



Graph 15 Session 21

Instrumental play

This cycle is characterised by Ralph's very brief but positive bursts of playing. Ralph continues to explore a variety of instruments. For example, in session 16 Ralph goes straight to the conga drums when he enters. Nick says that

they're almost irresistible to play.

I write:

Ralph makes very tentative drumming sounds and vocalises.

As Ralph leaves immediately after he has played, Nick takes the congas into the corridor. Ralph walks away from them. When watching this on video Nick says:

I never know what he means when he vocalises.

It seems that Nick feels very much at a loss at this point, and that Ralph, by rejecting the congas when Nick has carried them out (they are heavy), is putting himself in quite a powerful position. In contrast, two sessions earlier Ralph had shared a drum with Nick and they played together for several minutes.

Several times in this cycle, Ralph shows interest in the music, standing and listening, without actively taking part. At other times he arranges instruments. He participates in trios and quartets with Steve, Pete and Nick. Nick, who is exasperated by Ralph, says he has talked about him in supervision several times. Nick tries to transform some of this exasperation into creative play. For example, in session 19 Ralph carries in a tray and gives it to Nick, who plays it like a gong. I note that the tray is one of the few objects around the house that is available to play with.

Vocal play

There are only two references. I write:

Ralph makes a roaring sound outside

[session 15: observation]

and in session 20:

Ralph vocalises, picks up a beater and turns to face Nick's drumming.

These examples, and those in cycle 3 seem to show Ralph emphasising a gesture

by making a vocal sound.

Range of emotional expressions

In session 14 Ralph leaves. Nick, alone, hits the cymbal very emphatically. In session 19, Ralph picks up a bag of instruments right at the beginning of the session, and then shouts out very loudly when he leaves. I find it difficult to understand the reason.

When Nick looks at the video of session 16 he becomes enthusiastic:

It's almost amazing to have these three together! [Ralph, Steve and Pete] They're all focusing on the drum at the same moment. Four of us in fact.

[Cycle 3: dialogue with Nick]

Attachment issues

Nick starts to talk more directly about how he sees the difficulties with Ralph.

He writes after session 22:

It is as if Ralph *cannot engage* in an activity.

On reflection he expands on this:

It is as if he cannot engage *unless* there's an activity going on: he can't really engage with me either way. [Co-operative inquiry meeting: cycle 4]

Jealousy and rivalry

Pete shuts the door aggressively on Ralph in session 20. However, Nick writes:

Ralph was less avoidant of Pete today.

In session 21 Ralph leaves as soon as Nick sings 'Pete'. He leaves later when Pete returns to the room, and leaves a third time when Pete pushes a drum Ralph

has just played across the floor. Nick, however, writes:

Ralph was in more and seemed less put off by Pete.

In the co-operative inquiry meeting in this cycle, Nick discusses Ralph's relationship with Pete:

Ralph and Pete relate to each other, avoid each other and compete for my attention. So there are three different types of interaction going on between them.

Identity and roles

In session 14 Ralph closes doors and windows in the room. At the end of session 19 he carries out a bag of instruments. Nick writes:

He helped me pack up.

Exercising power through action

In session 14 Ralph plays Nick's drum. This has parallels with the action of trying to take his trombone. Are there issues of ownership and dominance here? Ralph also picks up a seed shaker on the floor and puts it on the drum. He shuts a window and the door Jack has just gone through. In session 15 he returns a drum that Pete had taken out. In session 16 he takes the bars of a xylophone, although Nick intervenes to stop him, resulting in Ralph leaving the room. In session 19 Nick goes out to encourage Ralph in, and he roars apparently in refusal. In session 21 he stands at the door holding a drum and gives it to Nick, then leaves. He then comes in and takes the keyboard, standing it by the wall.

Cathy: Ralph's in the session quite a lot.

Nick: I think I just need to let him come in and out for now. And

not be too impatient about getting engagement.

[Dialogue with Nick]

Exercising power through non-action

Ralph ignores Nick as he goes past the room, despite Nick calling to him by name (Session 17: observation). In session 19 it seems to me that Ralph avoids any overtures from Nick by distraction: he moves a rainstick from a wall, wobbles Nick's trombone case and then leaves.

Responses to the use of video

In session 15 Ralph grabs the camera, which seems a more aggressive move towards it than before. However, in session 16 he goes to the camera and simply smiles, but kicks instruments on the floor. In session 20 he looks directly at the camera.

12.10 Cycle 5 (sessions 24–33)

Attendance

From session 25 to session 29, Ralph was present for more of the time. Session 28 shows periods of up to 4 minutes at a time and regular entrances (graph 16, p308). This increase is reflected by all four remaining residents and perhaps represents a time when they felt more united as a group through bereavement.

Then I reflect in an analytic memo that

Ralph participates in quite a quirky way. It is as if he wants to assert his presence without having to come in and be a participant like everyone else. It is a different side of his ambivalence.

In sessions 28 and 29 he plays different instruments and shares drumming again with Nick. Then he does not appear in session 30 or 31. Nick is frustrated by this and in supervision makes a determined plan to challenge Ralph in the next session.

He encourages Ralph in at the beginning of session 32 and does not allow him to leave: a departure from his normal practice. Nick continually sings to Ralph as he does this. I write that:

Ralph is clearly unhappy.

He leaves and Nick says in the session:

I don't want him to feel trapped.

Then Ralph returns, plays one note and leaves. Nick shouts:

That was good!

after him. Ralph returns, and stays for longer arranging xylophone bars, until Nick puts his hand on his shoulder, at which point he leaves. Ralph spends most of the rest of the session standing outside in the corridor.

Nick writes:

As Steve and Pete did not come in it gave me space to work with Ralph. I spent time encouraging him to come in to the room. I engaged and challenged him to stay.

Nick does not say how he felt when Ralph left each time, but uncharacteristically Nick ends the session early.

Vocal play

No data

Range of emotional expressions

In session 28 Steve's drumming gets louder in intensity as Ralph moves towards the camera, and Ralph, perhaps picking up this feeling, leaves. I write in session 29:

Ralph's contributions were brief but forceful.

In session 32, when Nick tries to keep Ralph in, I observe that:

Ralph is clearly unhappy.

Attachment issues

No data.

Jealousy and rivalry

In session 28, Pete makes Ralph leave by walking up to him. When Pete throws a drum Ralph leaves again, this time vocalising.

Identity and roles

In session 28 Anna writes:

Ralph stopped Pete throwing the xylophone.

The staff member who filmed instead of Anna in session 32 wrote:

He seemed interested in putting parts of the xylophone back in the box. (Maybe this is because he likes to put things away.)

After a conversation I had with the home manager I wrote:

She thinks Pete and Ralph are vying for the dominant role now Bill is no longer here. She talked again about Ralph aligning himself with the staff. This seems to be a universal interpretation in the home. I wonder if

this perception helps to maintain a strong power differential between the residents and staff.

[Field notes, October 2001]

Exercising power through action

Ralph comes in (session 26), opens the window, plays one note on the glockenspiel and leaves. I write:

This seems assertive: as if Ralph wanted to show that he was there.

In chapter 9 I have already described how Ralph begins to hold Pete back when he thinks he is about to throw a large instrument. Anna writes:

Ralph stopped Pete throwing the xylophone.

I ask:

Is the action of Ralph trying to stop Pete interfering with Nick showing that he is taking a position of responsibility or authority(?)

[analytic memo, session 28]

Exercising power through non-action

In session 32, after Nick has actively tried to keep Ralph in, he leaves, returns to the door outside and walks past ignoring Nick, although Nick sings his name which he usually likes.

Responses to the use of video

Cathy: There was a week when Nick forgot the camera, session 25.

Anna: Yes, Ralph was in [*the session*]. Which has made me start thinking perhaps he does understand a lot more than what we thought. And perhaps he has strong opinions.

[Dialogue with Anna]

Nick wrote:

Ralph played of his own accord. He spent longer in this session than all the sessions put together. This may have been because there was NO CAMERA..

[Session 25: questionnaire]

Anna wrote:

Not having the camera was significant! Ralph seemed much more interested in the session. Is this due to not being filmed?

[Session 25: questionnaire]

In session 28 Ralph moves to touch the camera. Later he enters the room again and raps his knuckles on the camera before leaving. I interpret this as:

Ralph shows his annoyance with the camera.

[Session 28: analytic memo].

12.11 Cycle 6 (sessions 34 - 38)

Attendance

Graph 17 shows session 34, where Ralph stays for up to 5 minutes at a time.

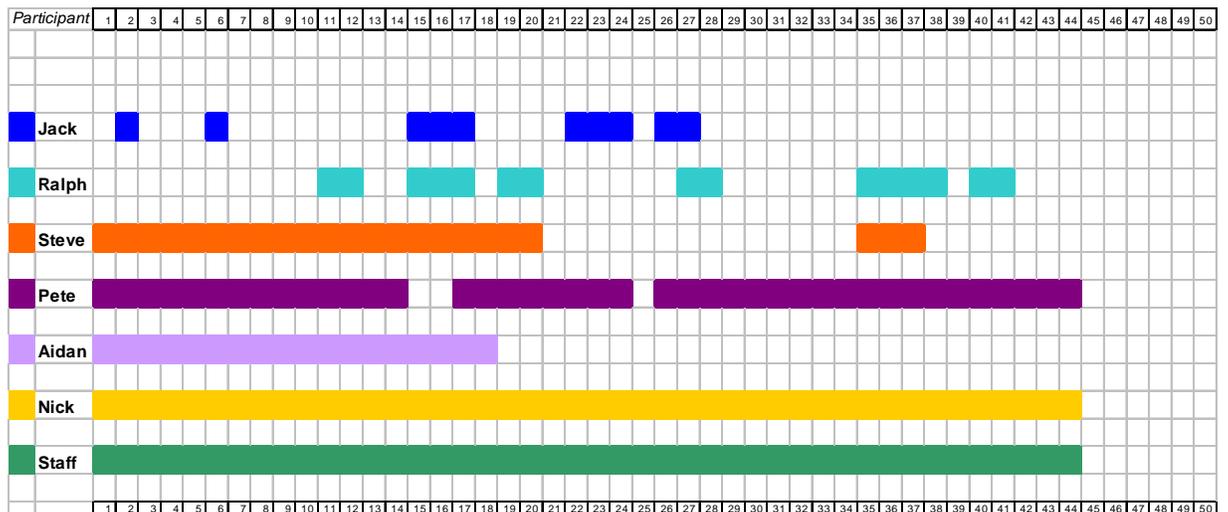


Chart 17 Session 34

As noted in chapter seven, Ralph's attendance increased after session 38 when the camera was withdrawn.

Instrumental play

In session 34 Ralph, Steve and Pete are all standing listening to Nick's music.

Then:

Ralph takes a drumstick and plays very rapidly. Nick joins him in this new energetic feeling. Then Ralph suddenly stops and leaves.

[Session 34: observation]

I write:

It is as if Ralph cannot enjoy joining with Nick in music for too long: as if he cannot bear it.

[Session 34: analytic memo]

However Anna notices that:

Ralph turns to face Nick when he sings to him. I think this is new.

[Session 34: questionnaire]

Vocal play

No data

Range of emotional expressions

Anna reflects on Ralph's mood shown in the music therapy inquiry:

When he was in he'd pick up the beaters and you could tell his mood from that. I think that the fact he even picked it up to bash shows he was in a positively aggressive mood.

[Dialogue with Anna]

Attachment issues /Jealousy and rivalry

No data

Identity and roles

Anna sees Ralph as a group leader. She described him during a walk in the country:

He'll want to move one of them along if they're dragging behind. He'll get very upset. He obviously likes to be part of the group, but then, I think he might be a bit in charge of the group, particularly since Bill...*[sentence trails off]*.

[Dialogue with Anna]

Exercising power through action

Ralph hits the back of a chair when Pete moves the keyboard. Pete stops. [Session 34: observation]

Exercising power through non-action

No data

Responses to the use of video

In session 34 Ralph moves the camera. This results in the video being unclear.

Here Ralph has taken effective action to disrupt the research findings, whether this was his intention or not.

Anna is quite affected by Ralph's responses to the video and it has led her to reflect deeply about her own perceptions of Ralph:

Anna: Every time he's come in, nearly every time he's gone for the camera...to push it away, whatever, and he's gone out soon afterwards. Which has made me start thinking

perhaps he does know what the camera means. Perhaps
 he doesn't want to be filmed.

[Dialogue with Anna]

Summaries of the changes Ralph makes

Figures 14 (p315) and 15 (p316) show the changes made in all categories by
 Ralph. The charts are presented as they were for Pete and Jack.

| CYCLES | Cycle 1 | Cycle 2 | Cycle 3 |
|------------------------------|--|--|---|
| CATEGORIES | | | |
| Attendance | Full attendance in lounge | Much less in dining room | Brief at first, increasing Does Pete influence Ralph's attendance? |
| Instrumental play | No data | Takes turns with Nick Plays expressively for brief periods, and explores a variety of instruments | Often ambivalent about playing and stops Pete and Steve from playing Expressive cymbal playing |
| Vocal play | No data | No data | Shouts when he plays |
| Emotional expressions | Ralph's aggression, frustration and assertiveness are described | Nick feels disappointment that Ralph does less | Plays emphatically 'Confidence doubled' |
| Attachment | Anna considers Ralph's possible history of neglect | Ralph turns his back on Nick Nick reflects on feeling despondent | None - Nick focuses more on Pete |
| Jealousy and rivalry | Possibly jealous when Nick attends to Pete and Steve | Nick: Ralph and Pete compete for my attention | Pete and Ralph stop each other taking part. |
| Identity and roles | Seen as identifying with staff 'Likes tidying up' | Nick asks Ralph to help with instruments | Ralph continues to help with instruments |
| Exercising power | Anna: Ralph should be pushed'. Ralph sits/pretends to be asleep | No data | Ralph controls Jack and stops his music |
| Response to video | Moves the camera in session Intensely engaged in watching video of session 2 | No data | Ralph rubs camera lens twice |

Figure 14 Summary of the changes Ralph makes in cycles 1-3

| CYCLES CATEGORIES | Cycle 4 | Cycle 5 | Cycle 6 |
|------------------------------------|--|---|---|
| Attendance | Brief and infrequent although some longer periods | Increase in attendance Still sporadic | Sporadic attendance |
| Instrumental play | Brief intense bursts of making music Participates in trios and quartets | More spontaneous play Less involved later in cycle | Spontaneous and interactive play which Ralph cuts short Rapid, energetic playing |
| Vocal play | Very little | No data | No data |
| Emotional expressions | Nick: enthusiastic about trios Ralph shouts out | Ralph's music shows intensity | Anna: His mood is reflected in his playing |
| Attachment | Nick: Ralph <i>cannot</i> engage | No written data, but engages in music | No data |
| Jealousy and rivalry | Ralph less jealous of Pete | Pete still aggressive to Ralph | No data |
| Identity and roles | Ralph continues to help carry in instruments | Ralph controls Pete to help Nick. Does he compete with Pete for dominance in the home? | Anna: Ralph is group leader |
| Exercising power | Much of Ralph's actions control others He also ignores Nick pointedly | Ralph seems to take a position of authority over his peers. Continues to ignore Nick | Nick reflects on Ralph hitting him. Ralph hits chair rather than Pete |
| Response to video | Grabs camera, looks at it, explores the tripod. | Ralph is more involved with music when there is no camera | Ralph disrupts the filming Anna's perceptions of Ralph are changed |

Figure 15 Summary of the changes Ralph makes during cycles 4-6

12.12 Overview of Ralph's changes

In the first period (sessions 1– 4) we see a man who spends most of his time in the room, but does not engage with the music. Instead he escapes by pretending to sleep. He seems jealous and aggressive, but takes some pride in taking a tidying or ordering role. He seems suspicious of being filmed. The history of his disrupted early life is raised as an explanation for how he is.

When the inquiry moves from the lounge to the dining room in session 5, Ralph comes in much less frequently. However, he begins to create some

interactive music. Nick becomes hopeful, then disappointed as Ralph withdraws again.

In the third cycle, Ralph's music can be intense and expressive, but his attendance and participation is ambiguous. He starts controlling other people in the session and shows a rivalrous relationship with Pete. He continues to tidy and help move instruments in.

By cycle 4 Ralph seems more confident and is occasionally participating in group music. His attendance is still sporadic and he seems to use his presence and absence as a way of controlling Nick. He is more relaxed with Pete but often ignores Nick. Nick becomes exasperated and wonders if Ralph is incapable of making relationships. Ralph perseveres with moving instruments through to the session, even though he often does not play. He hits or moves the camera during every session he attends.

After Bill's death (sessions 24 – 33) Ralph is more involved, coming in more often and playing expressively and interactively. He tolerates Pete more and seems to take more of a position of authority with his peers when he can.

In cycle 6 (sessions 34 – 38) Ralph is involved only briefly, but with intensity. Others reflect on what they have learned from him and there is general agreement that Ralph has been objecting to being filmed throughout the year, and this has affected his involvement. Nick and Anna decide to continue working with the group without using a camera.

On reflection, I have asked myself why I did not respond to Ralph's communications about the video earlier. Generally, Ralph's participation was so confusing it was difficult to know what he was communicating. Anna and Nick wondered in the middle of the year if Ralph had very little understanding. The

gradual realisation that he probably knew very well what the filming meant took some time to accept. Moreover, it would have been awkward to film others but not Ralph, posing a threat to a major part of the inquiry. The video was proving to be a valuable learning tool to a number of participants, particularly Steve, Nick and myself. Ralph was keeping away and that was his choice. However I did also feel that Ralph was compromised during the year, and my practice was essentially quite unethical in relation to him.

Attendance – an overview

Ralph raises the question of the difference between physically being in the room, and 'engaging' as Nick describes. Although Ralph was present in the first four sessions, he made very little music. It seems reasonable to assume that he was in the lounge mainly because he liked sitting there.

I am curious about the way Ralph seemed to avoid Pete in cycle 3, but through cycle 4 chose to be in the room whether he was there or not. However, Ralph is part of the general pattern of more frequent attendance in cycle five after Bill's death, which also applies to Jack, Pete and Steve.

However, it is the impression of ambivalence which Ralph creates, with his choice of being in or out, that is most striking. He spends some time being outside, or even walking past the door so Nick can see him, as if he uses non-attendance as a weapon. Although Ralph's attendance is higher on average than that of Jack, Nick is much more puzzled and preoccupied by Ralph's non-attendance. Ralph somehow manages to convey subtle meanings in his choice of whether or when to come in that are not inferable from Jack, who simply seems not to understand the social meaning of inclusion in the same way.

Instrumental play – an overview

Ralph's instrumental play compounds Nick's frustration, as it conveys that Ralph is capable of more, as Anna suspects. Ralph shows from cycle 1 that he can take turns, which for Pete or Jack would be a sophisticated accomplishment. His playing is nearly always in the form of a brief burst, which by all accounts is full of intensity and communication. However, the shape of this is nearly always difficult to connect with: even in cycle 6 Ralph plays interactively with Nick but then stops the music abruptly. It seems not to be a simple disengagement, as it is with Jack, who gets 'lost', but an angry rejection of Nick's music, and by implication, of being engaged with him. Ralph can play with his peers, and listen to them but on the whole tends not to. The data on his peer relationships are quite meagre considering his ability to interact. For example, there are no instances of Ralph playing with Steve, except when taking part in the group music. Ralph seems to spend more time stopping Pete and Jack playing, or organising the instruments if they have been moved.

Vocal play – an overview

Here again, what is striking here is the paucity of data. Ralph does shout when he plays, which seems to reinforce the intensity of the feeling behind his expression. However, he does not at any point appear to respond to Nick's vocal play, except to leave.

I make sense of this by suspecting that Ralph is angrily refusing connection with others, rather than acknowledging a need. This may be due to his poor attachment experiences in his early life, rather than his autistic tendencies, or a combination of both factors.

Range of emotional expressions – an overview

Ralph aroused strong feelings and hours of reflection for the participants in the music therapy inquiry who had verbal skills. In the first cycle, we describe the emotions that recur with Ralph: aggression, anger and frustration. In cycle 2 Nick is already beginning to feel frustrated because Ralph is showing the capacity to express and participate, and yet he seems to be withholding this. Nick oscillates between hopefulness and despair, a pattern commented on in chapter seven, but which is epitomised by his experience with Ralph. Examples from the later cycles mainly include emotional descriptions of Ralph's music, and Anna summarises this by saying that she could tell his mood just by the way he picked up a beater. His participation and confidence in doing so does increase through the year: His emotional expression through music is not ambivalent, unlike his connection with others.

Attachment issues – an overview

The data in this category are diverse and patchy. They are encapsulated by Anna in raising the issue of Ralph's attachment experiences in the course of her own inquiry, and by Nick in reflecting on the question of whether Ralph cannot or will not engage, which by implication may be linked to his attachment experiences.

Jealousy and rivalry – an overview

Most of the data relate to the apparently competitive relationship between Ralph and Pete. Nick comments on this throughout the inquiry. At first Ralph shows his most sensitive reactions when Nick tries to connect with others. The rivalry between Pete and Ralph comes to a head in cycle 3, when each man tries to stop the other from playing. By cycle 4 Ralph seems to do this less often, and on the

surface appears more willing to tolerate Pete. However, when considering Ralph's reduced attendance in this cycle, I think it is likely that Ralph withdraws, while Pete's relationship with Nick becomes deeper and more attached.

Identity and roles

In cycle 1, participants who are familiar with Ralph describe how he likes to take a helpful role and also likes to tidy, or put objects in order. After some thought, Nick decides to involve Ralph by asking him to help bring instruments in to the session, which is an onerous task for one person. This has implications for Ralph's role, as he effectively moves from being a 'client' to a 'music therapy assistant' in a conventional view of music therapy. Nevertheless, this is the one example of Ralph consistently carrying through a role and developing it. By cycle 5 he is also restraining Pete when Nick is trying to repair an instrument. Is this an issue of identity and role, or simply something that Ralph likes to do, perhaps to feel in control?

The co-operative inquiry revealed that some participants thought of him as aligning himself with the staff, and a number of examples show him organising instruments and preventing participants playing during the music therapy inquiry, as if he were taking a staff role. (Ironically, Nick and Anna rarely took a directive role during the inquiry, except in relation to Pete throwing large instruments, and later, when participants locked others out of the room). Being in a music therapy group where each person has an equal opportunity and right to participate might have been unacceptable to Ralph. By bringing instruments in, Ralph was able to take a role that made him different from other residents, and by avoiding regular participation in the music therapy, that role was sustained to an extent.

Exercising power through action – an overview

Ralph does not show much of this until cycle 3, and in the music therapy room he tends to exercise power over Jack and Pete. He is quite gentle and there are no examples of him hurting or even really intimidating anyone, which I feels suggests some sensitivity and restraint. Pete, by contrast, is less likely to control his actions, which often get physically out of hand.

Exercising power through non-action – an overview

The inhibition of an action is difficult to recognise and describe. My overview is that Ralph employs the tactics of refusing and ignoring very effectively, probably more often than he takes direct action. It is his lack of attendance, lack of engagement and walking past the room without looking in that affects Nick so strongly. Ralph seems to know that Nick has an investment in Ralph coming in, and is determined to do this only on his own terms.

Responses to the use of video – an overview

This is a very interesting but puzzling collection of data. Ralph is alert, interested and involved in the preparations before the inquiry starts in terms of the camera. He seems to understand and want to be involved in the causal sequence of putting the videotape in the television, watching it and putting it back. Whether he connects this with the use of the camera is unclear. He often approaches the camera in the inquiry, and all participants who comment on it agree that he is conscious of the presence of the camera and at least ambivalent about it. He starts by moving the camera, then rubbing the lens, then examining the tripod and finally, in cycle 6, moving it so that it does not record anything useful to the inquiry. It is difficult to decide whether he is suspicious of this strange object which

requires a person to sit behind it, or whether he knows it is a camera recording his every move. However, it is clear that he does object to it on some level, as he comes in more when it is not there. Perhaps he is picking up on the way that some staff members avoid the room because of the camera inside.

12.13 Summary

At first glance, Ralph was involved in the music therapy in quite a small way. In my previous practice, because of his brief attendances and refusal to engage, I as a music therapist might have been reluctant to continue working with him, as I had the pressure of a long waiting list. Ralph stands aloof in the inquiry: he truly challenges us and asserts his right to be himself. He is the detached observer much of the time, but he successfully involves Nick in detailed inquiry. How much of his lack of engagement is due to early attachment experiences? How much is due to living in an institution where residents have had to compete for the attention of carers?

Another factor might be that Ralph had a stroke the previous year, and lost his speech. How did his experience of this loss affect how he chose to participate in the inquiry?

The questions Ralph raised in relation to video consent, questioning the role of the client, and the power of an ambivalent stance are important, fascinating and warrant further exploration in chapter fifteen.

CHAPTER THIRTEEN

Bill

13.1 Eulogy

Bill came to live with us fifteen months ago along with four other friends whom he had lived with for several years.

Bill was one of the main players at the home, keeping us all on our toes. Every time we thought we had things covered Bill would step up the ante¹⁰ and challenge us again.

Bill had a stubborn streak, which, after speaking to his brothers, apparently this runs in the family. He could object strongly to our efforts to care for him but endeared himself to all those who have supported him over the years.

Even towards the end he had a few choice words for the Doctor who was supporting him.

Bill's demands for walks became legendary regardless of the weather. Although Bill was well equipped for adverse weather conditions, staff often came back soaking wet because Bill had insisted on taking his usual route without taking a short cut. Even on returning home he insisted on his circuit around the garden or through it!

Something the team has found particularly pleasing was the re-establishing of contact with Bill's brothers and family, sharing stories and pictures with Bill about his early childhood.

[Speech made by the home manager at Bill's funeral, August 2001]

¹⁰ 'Upping the ante': from a term in poker where the stakes are raised before the next hand is dealt.

This eulogy paints a picture of a man who has a strong will and a sharp mind. The author conveys a strong feeling of fondness for Bill. The references to fighting and resisting care give us some flavour of how he dealt with his illness and impending death. His insistence on walking the same route in the country may represent an autistic resistance to change, but also shows him as a person who felt he was able to assert his wishes.

13.2 Background

Bill was the third of five brothers, so living in a home with four other men had close parallels with his family background. In a photograph taken with his other brothers when he was six, he looks no different from them, except for a more solemn expression. As an adult he was not tall but was squarely built. He was moved into a residential setting as a child and was considered subnormal and autistic. As with Jack and Ralph, his written history was patchy. The family members were estranged from one another. Bill's keyworker, with help from the police, managed to make contact with them again before he died. Bill had lived most of his adult life in a hospital ward with twenty other residents with severe learning difficulties, without family contact or support.

Care staff discovered that Bill, aged fifty-three, had lung cancer less than a year before the move. The prognosis was that he had less than a year to live. At the time of the inquiry he had already surpassed this expectation.

13.3 Personal impression

Bill was very thin with a pasty complexion. At my first meeting with him, before therapy started, it was clear that he was quite ill and had considerable difficulties in

breathing.

13.4 Information from staff members

Rose, the home manager, and Bill's keyworkers thought hard about whether they wanted him to have access to music therapy. They said that because his illness was terminal, they were committed to promoting his quality of life rather than his longevity: he might enjoy music therapy so why not 'give it a go'?

Bill did not have an up-to-date communication assessment. Rose told me that he had some comprehension of speech but might choose not to speak. He found it difficult to wait in many situations. He could make some clear choices. Despite having cataracts he liked having the television on.

One of his keyworkers hoped he would respond to music therapy. She said:

I've had Bill up and dancing. If the music is blaring he will do it. Bill will turn the music up himself.

[Field notes, cycle 1]

13.5 Involvement in the research process

Bill pushed away any attempts of mine to show him the photographs explaining the research process. In any case, it is not clear whether he would have been able to see them. He did not reject contact with me, but wanted me to take him for a walk outside. Several times he led me to his boots at the door. Although the television was constantly on in the lounge, I did not see Bill show any interest in it.

Rose, when giving assent, said:

I'm hoping that he will pick up instruments and communicate.

Because it will give us another facet to communicate with him. We've found little pockets he is happy for us to talk about [Dialogue, cycle 1].

13.6 Bill's contribution to the inquiry

Rather than working through the series of cycles as I have done in the chapters for Pete, Jack and Ralph, I will consider three main periods during which Bill affected the inquiry. The first was in cycle 1, culminating in the co-operative inquiry decision to change to a different room for the therapy. Bill's actions in session 2 became the catalyst for this decision. The second period was from sessions 16 to 21 when Bill did not come into the room, but related to Nick through the door. At this point he was very vocal outside, and so affected the people inside the room, who could hear him. Finally, Bill's death in August and the subsequent loss felt by all the surviving participants had a profound effect on the inquiry.

Much that happened in relation to Bill outside the inquiry is not documented here. However, the music therapy inquiry was a situation in which the residents were able to meet as a group, independent of their carers. Some of the feelings and actions expressed, therefore, give an opportunity to explore, sensitively I hope, a number of aspects of this particular bereavement.

13.7 Period one: in the lounge

At the beginning of the music therapy inquiry, Bill stayed for most of each session. He tended to sit on a sofa quietly. Here are some descriptions from session 1. Nick took a gentle approach:

Bill was asleep most of the time, but he seemed to tolerate it all and was relaxed. I played some music just for him and sang. I was happy that he was in there. I kept the music calm and soft.

[Session 1: Nick's questionnaire]

I'm trying to make a connection with Bill and offer him something of

me...a gentle piece of music he can connect with...did you notice that I was playing a long way from him? And earlier on I felt I was a bit too close.

[Dialogue with Nick: watching session 1]

Anna wrote:

Even Bill who appeared to be asleep for much of the session responded, when Nick sang his name, by sticking his tongue out each time. I've never seen him do that and I'm sure it was a genuine response. Bill usually stops things and he didn't; he could easily have got up and gone out if he'd wanted to.

[Session 1: questionnaire]

In session 2, Nick decided to bring a chair in from the dining room. Before the session Nick had tried to move an armchair around so that he could face the other participants, but Bill objected to this. Nick explained in a subsequent dialogue that he wanted to sit down rather than tower over the other participants. Bill, however, immediately asked Nick to take it back. This extract is from my observation watching the video:

Bill stands up and says 'back' and approaches the chair. He vocalises in an agitated way, points to the chair and leaves the room. He comes back almost immediately and tries to move the chair. A staff member who is in the room says 'Don't move the chair.' Nick says 'It's all right.' Bill then raises his hand. Nick says 'No, I'm not going to take it back. I'm going to sit on it. Will you let me sit on it?' Bill gets up and runs towards the chair. Nick sits on it. Bill vocalises at a higher pitch and takes Nick's drum away. Bill tries to get the chair. Nick blocks him. Bill shouts 'Never!' and 't-t-t'.

Then Bill goes to Ralph and takes his drum away. Bill sits down and vocalises in a very high-pitched voice.

Nick moves the chair slightly, Bill gets up and grabs it and vocalises. Then he sits down.

When he next vocalises, Nick starts singing in a similar manner. Bill breathes very heavily.

Bill goes out. Nick asks Anna whether she thinks he should take the chair out. Anna says 'It's tricky. Sometimes he does this and ruins it for everybody.'

[Session 2: observation]

When reflecting afterwards, I had a number of questions. What did it mean for Bill to have a piece of furniture moved from one room to another? Was having therapy in his own house too intrusive when he was under strain from a serious illness? He tried to communicate the same message in six different ways, using a range of strategies.

I am aware of another construction of the events, prompted by Anna's comments. Bill is autistic and finds change difficult to tolerate. If he is consenting to take part in the therapy, it is Nick's clinical responsibility to work with his resistance to change, particularly if, as Anna says, Bill's behaviour has consequences for everyone else who lives in the house. This is something that Nick explores during further inquiry.

[Bill vocalises on the tape] He's really pushing me now, trying to push me off the chair and I'm thinking 'Ah, yes, this is good.' He's strong. And he says 'Bye.' And I thought 'Yeah, fine.' And now I think we've had enough focusing on this chair so I decide to take it out. No harm

done I thought, I still think.

I thought 'No, I'm not going to take the chair out immediately' because I felt that would have established a pattern. I wanted to explore what this meant for him. Was it a way in which we could connect? It may be that in having this experience of interacting with me, he might discover a new or different way of expressing his wishes

[Dialogue with Nick, watching session 2]

Nick explained that he felt it was worth challenging Bill, saying:

His opinion is valued by me but because he is terminally ill does not mean I can't challenge him.

[Dialogue with Nick, watching session 2]

My initial reaction was that Bill was not being heard, despite his wide range of communications. However, I also became aware of my own agendas at this point: I was *not* the therapist here, but had suddenly stepped into the position of wishing that I had been, because I would have done things differently. How much of this should I reveal to Nick so early in the inquiry, when positions of trust were not yet established? Perhaps I would have acted in the same way as Nick if I had been in the room.

I felt that the best thing to do was to seek Bill's views on how he felt about the experience, and took the video to the home the next week. We had arranged that no staff members would be present, so that the men were free to react in any way they chose. There were a number of technical difficulties with the home television, and I had to return later with a working one from the university.

Here is a description of what happened:

I showed Ralph and Bill sessions 1 and 2, which they both watched.

There were continual staff interruptions so that I kept turning the television off. I explained to the staff member in charge that it was not viewing for staff. Despite this she came in and sat down. When the second session started on the video, Bill started moving his head from side to side to Nick's guitar playing. Five minutes later the incident with the chair appeared. I watched Bill very carefully. Ralph also watched the video intently at this point. When Bill heard his voice going into high pitch, he closed his eyes. I immediately turned it off and apologised to him, as I took this as a sign that he didn't want to watch it. At the same time, Ralph got up and walked out. I felt very uncomfortable about this, and wondered about the wisdom of showing Bill the tape in the first place.

[Field notes, February 2001]

The staff member, who was not part of the co-operative inquiry, was concerned that Bill might have watched something that would have caused him distress, and expressed this in her next supervision. Another staff member had also suggested that by having the session in the lounge, Bill might not have had a choice about being in the inquiry or therapy.

Bill spends most of his time in the lounge. It *is* the most comfortable place to sit. Sometimes he can get up and leave, but sometimes I don't think he feels well enough. I think the therapy should take place somewhere where all the men can choose whether to come or not.

[Written communication, later discussed in co-operative meeting 2].

As there were two issues which needed immediate discussion in the inquiry group, both the members of staff who had raised them were invited to the next meeting. This time the meeting was not cancelled, but brought forward. Until this

point, it seemed that the communications of greatest importance within the inquiry were all being made, through a third party. I thought it was essential that we met in a group to set a practice of inquiring directly, together in the open.

Ironically the power failed during the recording of the second co-operative inquiry meeting, so that it was impossible to transcribe. The process of this meeting has already been described in chapter seven.

One consequence of the meeting was that the therapy room was changed. Nick was reluctant to change the venue but did agree. Normally it would be unusual for a music therapist to change venue on the recommendation of a non-therapy staff member, as continuity and consistency of the therapy are generally held to be of great importance. The inquiry design meant that the therapeutic framework itself was under question.

Nick felt that he had been undermined, and had less control than he was used to as a therapist. He said:

I wonder if I'm giving too much power away. Or maybe I have too much power.

[Dialogue with Nick, cycle 2]

As part of Nick's individual inquiry process, he was forced to question the assumption that the therapist alone should have the power to determine venue. In some cases, the therapist might be wrong. Nick later said that this episode had been so challenging that he had privately considered withdrawing from the inquiry at this point. However, this was balanced by the great support he felt he was offered by the inquiry structure.

The issues Bill's part in the inquiry raised during the second cycle helped shift the culture of the co-operative inquiry. In cycle 2 participants seemed to have been

galvanised into a greater level of commitment. The deputy home manager, acting as a link between Nick and home staff members, helped organise and agree a series of practical measures which would support the therapy. It was as if Nick's agreement with the change the venue had indicated to the home team that he was flexible and could be trusted.

In cycle 2 (sessions 5 – 7), Bill hardly came in. Some of the participants in the co-operative inquiry thought this meant that the room change was a good decision. However, Nick became concerned that Bill was being kept away from the session and wondered if some staff members were over-protective.

He said:

Until Bill's experienced the therapy he doesn't have anything to go on whether he chooses to come in or not.

I hadn't had long enough trying to show Bill what it was about before he was taken away from me. That's how I feel. There's something stopping Bill from coming in, I feel. I was happy with the music therapy being in the lounge. So people could see what it was.

[Dialogue with Nick: cycle 3]

I was able to show Nick from my field notes that Bill had been sitting alone on a sofa while staff members were performing other tasks. They were not engaging him in any way as an alternative. However, I believe that what happened was that by shifting the therapy to the next-door room, Bill experienced some sense of exclusion, partly as he may not have had the energy to get up and walk to the room.

The incident also encouraged participants to reflect on how they might exercise control over Bill. For example, the deputy home manager says:

Claire I wonder if the men don't recognise the authority figures in the home. They do. Bill will be running around screaming and the staff will be unable to stop him but I'll say 'Bill will you sit down please!' And he will.

Dave They're scared of you.

Claire [Joking] Yeah! But he won't do something he doesn't like.

[Co-operative inquiry meeting, cycle 3]

13.8 Period two: engagement outside

Bill spent a total of three minutes in the music therapy inquiry from sessions 5 to 16. At times he would become very angry or distressed and could be heard screaming outside. Nick was concerned about the effect this would have on the rest of the residents. Some of the residents did seem to act differently when Bill was distressed. For example, in session 9, Bill screams outside: Jack walks in very fast then out again.

Three sessions later, Bill is heard shouting outside. Steve immediately kicks the seedpod, which is unusual for him, and begins drumming rapidly.

From session 17 Bill appears to begin to engage in the therapy in his own way, from outside.

Bill is vocalising outside. Nick responds with the trombone. Jack comes in and tries to get through the outside door. All the residents leave the room.

Analytic memo: are they trying to escape the sound of Bill's voice?

Bill shouts again and Jack walks in. Care staff are very noisy outside.

Bill is heard outside, vocal and angry. Anna says 'All morning he hasn't done it'. Nick goes outside, and then walks past the door with Bill who

is saying 'Key, key, key.'

Analytic memo: Bill is saying 'key' because he wants someone to unlock the door for him.

[Session 17: observation]

Nick writes:

Bill has dominated the dynamic today despite not coming into the room.

[Session 17: questionnaire].

Anna writes:

Bill has been very vocal and upset in the corridor today, which seemed to change the moods of the other men. Bill carried on for most of the session, unsettling the others.

[Session 17: questionnaire]

In session 19 Bill is outside in the corridor vocalising at the start of the session. Nick vocalises in response. Ralph and Steve come in and start playing together. Bill appears at the door later and throws in a shaker that has been left outside. Bill and Nick throw the bean shaker in and out of the room. Ralph stands outside, watching. Steve, inside, starts to play the drum very loudly. Bill starts throwing the bean shaker in very hard indeed. Ralph refuses to come in when Nick asks, but stays to watch. Bill keeps vocalising when he throws the bean shaker in. Nick, although playing with Steve, responds with his voice, and later on, with a keyboard improvisation. Nick writes:

Bill engaged with me by throwing the vine leaf shaker in and out of the room. He did not come in but stood outside the door. He threw with considerable force. Steve watched Bill do this as he played the

congas. I tried to engage with Bill outside the room. Bill vocalised and I answered with trombone.

[Session 19: questionnaire]

Then a member of staff talks to Bill and he vocalises again, rather like a wail. Nick responds to this on the trombone and Bill stops immediately. A couple of minutes later, when Nick plays the trombone again, Bill begins vocalising. Ralph is still outside, witnessing all this but not participating actively. Nick plays the trombone again in response to Bill's vocalising. All the residents leave. Nick waits. Three minutes later Bill returns to his position outside the door, making a vocal sound again. Nick replies on the trombone.

Nick says retrospectively:

This was the most engagement and contact I ever had with Bill. [Final dialogue, cycle 6]

Anna is more restrained and writes:

What was significant was that even Bill showed an appearance. He came to the dining room and stood outside.

[Session 19: questionnaire]

To me it was if Bill had begun to realise that Nick was hearing him. He began by returning an instrument to the room, territory he had chosen to avoid. Both men were able to use the fact that they could hear each other through the door. Bill did not have to concede anything by going in, but he and Nick manage to communicate. The other residents left them alone, and Bill returned several times. Ralph seemed keen to be a witness.

The final time Bill's voice creates a presence in the therapy room is in session 20. Bill vocalises, further away than in session 19, and Nick imitates him.

Pete laughs at this. Ten minutes later, as Pete starts to play vocally with Nick, and explore his sounds, Bill vocalises again from far away, and Pete stops abruptly.

Nick continues singing gently. Nick writes:

Bill was vocally audible in the music therapy room. I felt that Pete may be stopping him coming in.

[Session 20: questionnaire]

13.9 Bill's death

Session 23 contains some information that to some extent compromises the dignity of the participants. Extracts from my description are included because I think it is important to show just how different this session was from any other, and how Pete and Steve may have shown their individual sense of distress or bewilderment.

Anna was away and all the other staff members were involved in work surrounding Bill. Nick and I decided that I would need to film the session.

I write:

On our arrival, Steve, Pete, Jack and Ralph are all standing at the front door waiting for us. Freda, a member of agency staff explains to us that Bill is dying and that she has explained this to Steve. As I bring the instruments in with Ralph, Nick goes to see Bill. I am left with the knowledge that I did not say goodbye to Bill who dies that evening.

[Field notes, 9th August]

In the session, only Steve and Jack enter. Steve plays a guitar duet with Nick, who has brought two guitars. Jack listens, standing by the window. He seems to stay in marginally longer than usual (although perhaps my sense of time is affected by the feeling in the house). By the sixth minute I write:

Steve slows and appears to go to sleep. Nick sits patiently beside him. Steve wakes briefly and begins to play the guitar again. Then he falls asleep again.

After a minute Nick moves his chair closer and gently tries to take the guitar from Steve's hands. He holds Steve's hand and sings gently to him for several minutes. Suddenly Steve goes into a major seizure and filming immediately stops, as Nick needs help to stop Steve falling to the ground. His body is completely rigid. I leave the session to summon help from staff who are familiar with his epilepsy.

As I step outside the door, I am overwhelmed by a powerful smell. I see that there are faeces on the floor, and furthermore someone is throwing large amounts of it softly against the windows. Nick stops the session there. Nick and Freda carry Steve to his bedroom through the other door, while others of us clean up the mess.

[Session 23: observation]

Nick writes:

Jack stayed in the beginning for a longer time and in a different way (he leaned against the window.) There was a close connection between Steve and me – we played guitars together. The music had a sombre quality. I held Steve's hand for comfort and support. He fell asleep and then had a seizure. The events in and around the session were significant. Bill was very near death.

[Session 23: questionnaire]

In field notes I write:

The music therapy has given Steve a chance to express his sorrow and be supported by Nick. I felt that I should not be filming, as this was too intrusive. Pete did not manage to come in but expressed his

distress in a different way. I note that he kept his smearing outside. I was impressed at how carefully house staff had supported Steve and informed him about what was happening. For the other residents this was more difficult and I was not sure about how much had been attempted. However, residents were free to visit Bill in his bedroom if Bill agreed to this.

[Field notes, August 2001]

The following week, Nick and I were invited to the funeral and wake, where we met some of Bill's family. It was a way of being included in the life of the community home at an important time. For some of the younger care staff this had been the first time they had experienced death at such close quarters. Some of them talked about feeling that people in the community home were like a second family. However, none of the residents were involved either in the funeral or the wake, even Steve. It was striking that the people who had been with Bill the longest did not have a ritual opportunity to say goodbye.

13.10 Cycle 5: reactions to bereavement

General attendance was quite high after Bill's death (see Appendix 8, session 24-38). Only those who were specifically informed about Bill's death seemed to show discernable grief reactions in the session. The appearance of Aidan as a new group member only six weeks after Bill died provoked considerably more reaction, examined in the next chapter.

However, there were some specific references to the effect of Bill's death, which are included here. In session 25 Nick writes:

Steve was very sad to leave at the end [Session 25: questionnaire].

Sadness at the end of a session can be associated with bereavement. During session 27, when Nick and Anna are alone in the room, Nick plays the keyboard.

Anna says, 'It was the tune – kind of sad'. Nick said he was thinking about Bill and all the changes as he played.

[Session 27: observation]

In the co-operative inquiry meeting at the end of cycle five, participants addressed the question of the impact of Bill's death on the residents.

Rose: I certainly felt that the behaviour of the men changed when Bill died. There was definitely a period when all their behaviours escalated. And it was like a jostling for position. I think music therapy is a place they can definitely express their feeling.

Dave: Yeah, the atmosphere within the house for about six weeks was fairly sombre to say the least. The men had been together for a long time. He'd been a constant and suddenly that person had gone.

Selena: He'd been the top dog. It had a major impact.

[Co-operative inquiry: meeting 6]

There was also some reflection about the difficulties originally experienced within the inquiries in cycle one.

Rose: Well obviously the staff were quite protective of what was happening to him. They didn't see it as Nick saw it. He was concentrating on the session. The staff were probably [thinking] 'well he's upsetting him.'

Cathy: Do you think it should have gone ahead, given that Bill

was quite ill?

Rose: I've got no regrets over that, because it may have been that he would have participated and benefited. Once we'd got past the issues about the room it had no impact on him, which has got to be positive.

Nick: Well he did start to get involved in the therapy.

Anna: Yeah, definitely.

[Co-operative inquiry meeting, cycle six]

Then, surprisingly, Rose, who had been most vocal about the importance of not filming Bill when he was distressed asked:

Can you make up a video for us of Bill from the music therapy? I don't mind what's on it, as long as it's him.

[Dialogue with Rose, cycle 6]

Instead she was happy to accept photographs which I took when developing Bill's photographic 'resource book'.

13.11 Summary

The complex relationship between Bill and Nick, compromised by circumstances and competing agendas, did achieve some development. Notably, this was through the use of voice, echoing some of the experiences of Pete and Jack. Nick was prepared to work outside the boundaries of the session quite deliberately, again moving away from his normal music therapy practice.

In addition issues raised by Bill's part in the inquiry served as a focal point and catalyst for changes in policy and culture within the co-operative inquiry team. It started with a combined focus and commitment in cycle 2, and developed to the

point at which the outside researchers became more fully included in the home community at Bill's funeral.

The implications for music therapy practice, individual and collective learning and the question of the need for people with learning difficulties to be involved in funeral rites will be discussed in chapter fifteen.

I will end this chapter with an extract from the Bible reading that was selected for Bill's funeral. It seems to embody some of the humility and reflection that the participants in the co-operative inquiry displayed at this time.

Rejoice with those who rejoice, weep with those who weep. Live in harmony with one another; do not be haughty, but associate with the lowly; do not claim to be wiser than you are. Do not repay anyone evil for evil, but take thought for what is noble in the sight of all.

[Romans 12.14-18]

CHAPTER FOURTEEN

Aidan

14.1 Vignette

Aidan is sitting on the arm of a sofa in the lounge, talking and signing with vigour in a conversation with his keyworker. He is charming and flirtatious, and as he is in his early thirties, much younger than the other residents. Jack comes in and sits in a chair in the opposite corner. Aidan scowls at him and then walks over. He leans over Jack putting his face very close, staring. Jack looks down and as soon as Aidan backs away, he gets up and leaves quickly. Aidan makes a dismissive gesture with his hands, screws up his face and slams the door shut. He resumes talking to his keyworker as if nothing has happened. She asks him why he slammed the door on Jack, and he becomes quite angry with her, then goes to sit on the sofa with his arms crossed across his chest.

14.2 Background

Aidan was moved into the community home because his father was no longer prepared to let him live at home. He was moved into the house, and also into the bedroom that had been Bill's, with only one day's advance warning, as an emergency. None of the residents had any idea that someone was going to move in. There were no visits to prepare Aidan. Trust officials acknowledged that this was an inappropriate placement because Aidan was considerably more able and

younger than the other men: but there was no other option. From the point of view of this inquiry, I can only comment on what emerged in the music therapy, but it was clear that it was an extremely difficult transition for Aidan, but also for Pete, Jack and Ralph. The sense that the other residents were conscious of a group identity came to be expressed in the therapy, and raised many issues about inclusion and exclusion.

14.3 Issues with participation and consent

Aidan gave his own consent to be filmed, although it is unlikely he was able to understand what the full implications of being involved in a research project might be. He did, however, show that he understood how a camcorder worked. Although he had some interest in seeing himself on film, he soon seemed to become bored with this and walked away when we watched ourselves on video together.

14.4 Attendance

Aidan's involvement is limited to three sessions only: session 29 in cycle 5, and sessions 34 and 38 in cycle 6. He moved into the home during the week of the 29th session and came briefly to the session. From then on, he was normally out at a day care centre during Thursday mornings, when the music therapy inquiry ran. However, he had no day care during session 34 and in session 38 he had deliberately missed the opportunity of going by locking himself in his room.

The limited data which applies to Aidan covers three aspects of the music therapy inquiry. The first is what the music tells us about relationships between Aidan and others, the second is what Aidan's arrival tells us about the group, and the third is specifically about exclusion and inclusion.

14.5 Music and Aidan's relationships

At first Aidan's appearance is something new and stimulating for the musical life of the group:

Aidan, a new resident, came in and played spontaneously a wide range of instruments – we made contact in the music we played together.

[Session 29: Nick's questionnaire]

However, Pete seems to react badly to any attention Nick gives to Aidan:

Pete sees Nick signal to Aidan, approaches the table and pulls off Nick's trombone.

[Session 29: observation]

In session 34, Aidan stays in for longer, and his attendance this time is anticipated. He seems to want to make musical connections with Steve.

Aidan and Steve have a duet. Steve is singing. Nick joins them and Pete moves a chair. In response, possibly, Aidan puts on the demonstration again. This time Nick ignores this and continues a musical dialogue with Steve. Aidan turns off the demo and starts playing single notes, which matches rhythmically quite closely with Nick and Steve's improvisation.

[Session 34: observation]

In an analytic memo I write:

A new person and some very new music seemed to have an energising effect on the session, but possibly Steve was displaced a little.

[Session 34: analytic memo]

Nick writes more about how he sees the relationships:

Steve played but was not too lively and became tired. I think he was dominated by Aidan a bit too much. Pete became challenging at times, when jealous of my attention to others.

[Session 34: questionnaire]

The staff nurse, Madge, who filmed the session was influenced by how Aidan had seemed before the session. She wrote:

Aidan visibly cheered up in the session, especially with the stimulation of the keyboard.

[Session 34: questionnaire]

The connection between Aidan and Steve survives some of the more difficult group dynamics which will be described in the next section. For example, in session 38

Nick writes:

Steve played energetically on the timpani drum. Aidan joined in on the djembe so there was a brief connection.

[Session 38: questionnaire]

I write:

Steve appears very cheerful. He hits the drum with one hand. Aidan claps rapidly as if answering. He then drums very fast and Nick joins in.

[Session 38: observation]

However, Anna reports on the ways Aidan tries to be covertly aggressive to Jack and Pete:

It's been very different since Aidan joined the group. He's just...really nasty. He's always pushing them over, and giving them a sly punch

and things like that. He likes Steve because he can talk to him, but he doesn't like Jack and Ralph at all.

[Dialogue with Anna, cycle 6]

Aidan's participation in the group is met by ambivalence as well as fascination by the other participants as we will see in the next section.

14.6 Aidan's arrival and the group

Nick did not know about Aidan's arrival until a few minutes before the session. Nick invited Aidan into the inquiry. Here he explains his decision to include him:

Nick: Aidan was in today.

Rose: Did he participate?

Nick: He did. I thought he got something out of music therapy today. It was a bit of an unusual dynamic, and in a way, disruptive, but...on the other hand he...

Rose: ...brought a different dimension to it?

Nick: Yes, and he is part of the group and the home so I wouldn't have considered not having him in. It's just that if he does come he's going to cause a hiccup... a difference.

[Co-operative inquiry: meeting 6]

In session 34 there is some disagreement between Aidan and Nick about what music is acceptable in the session, and who is going to control it. The following extracts are from my session observations.

Aidan starts singing and puts on the rhythm section on the keyboard.

Nick turns it off [Session 34: observation].

Some of the other participants become interested and involved:

Aidan puts the demo on again. Jack enters rapidly and stays. Pete jigs his leg. All three seem to be involved in the rapid, complex rhythm 'n' blues style.

When Nick joins with Aidan musically, the others become disconnected from the music, and stand together in a group:

Nick plays arpeggios on the keyboard to match the demo. Aidan moves as if dancing to the arpeggios, nodding his head. Ralph enters and stands still with Steve and Pete, just watching Aidan dance.

Then the 'old' group members act in such a way that the continuity of the session changes.

Ralph leaves, Pete then starts to dismantle a xylophone and Steve starts to sing 'ABC' in a completely different key, a tritone¹¹ apart from the demo.

As the next quotation shows, Nick's music starts to relate to Steve's singing and as a result, Aidan decides to leave. Steve, by singing 'ABC', holds the continuity musically.

Jack sits in the corner. Steve keeps singing, and Nick joins with him. Aidan starts another demo then leaves. Steve carries on until he reaches 'z'. Then he stops and there is silence.

¹¹ A tritone is a musical interval: the equivalent of 6 semitones, or an augmented fourth. For example, a tritone away from C is F#. This discordant interval was referred to as *diabolus in musica* (the devil in music) during medieval times. The implication here is that from my Western musical perspective, Steve's choice of key could not be further away or less related harmonically or acoustically.

It is worth noting that although Steve sang 'ABC' several times during the year of the inquiry, this was the only time he went past 'P'.

Nick writes immediately after the session:

Aidan was present for 20 minutes. He made a difference (disruption) to the dynamics.

[Session 34: questionnaire]

Reflection

This perspective of Aidan as a disruptive force explains Nick's musical choice to support Steve's music rather than Aidan's. Keyboard demonstrations can also cause musical dilemmas because they are often powerful, pre-programmed music in a specific idiom. By their very nature they are rigid and inflexible. Pushing a button, a very simple action, creates complex music that can give the button-presser an experience of great power. Nick's first response is to turn off the demonstration, depriving Aidan of power within the music. However, Aidan, in turn, is depriving the other participants of power as they would struggle to produce music of a similar complexity and force. Nick does quickly reflect on this, however, because later on he creates music that is concordant with the demonstration music. This gives some musical legitimacy to Aidan, who duly responds by dancing. However, this is countered by Steve, Ralph and Pete creating music that bears no relation to Aidan.

It seems to me that Nick's allegiance is crucial. The group which consists of Ralph, Steve and Pete is effectively asking him whether he is going to entertain Aidan as a member of the group or not. Nick, sensitive to the men he has spent nearly a year making music with, chooses to support

them. This might be unbearable for Aidan who responds by leaving. This only works because all these men want to be with Nick.

In the following co-operative inquiry discussion, which takes place soon after the session, the participants of the inquiry reflect on the arrival of Aidan.

Rose: It's negative for the other men. Their behaviours are more challenging because of Aidan. And they feel, you know, quite intimidated by him.

Nick: He's doing his best to communicate with people but it so happens this is the way he's learned to do it.

Rose: Yeah, I'd agree with that.

Nick: So it isn't really negative.

Rose: It's negative for the other four men.

Cathy: It seems to be quite a major change to have a new person in the group so soon.

Selena: To lose a member and then gain another member in such a short space of time is quite an issue for them and for us.

Nick: It was a group today. I kept thinking and feeling 'group'.

[Co-operative inquiry: meeting 6]

Nick, who had been torn about who to support in the session is able to take the role of advocate for Aidan in this meeting.

14.7 Exclusion and inclusion

By session 38 the question of how Aidan can be part of the group has become a central focus.

Nick writes:

Most of the session was focussed on a new group member, who has hardly ever attended...he tried to stop other men coming in. Aidan kept locking the door – he wanted the session on his own. He told Jack to leave.

[Session 38: questionnaire]

In my account:

Aidan gestures to the door and Jack. Jack walks out. Nick says strongly to Aidan 'if you do that, you leave!' Aidan, Steve and Nick all drum. Nick invites Jack back in. As Jack comes in, Aidan leaves.

Aidan returns quite soon, and makes an obscene gesture to Nick. He throws a cup, unhappy that he is not allowed to lock the door. Anna explains that he is here because he missed day care by deliberately locking himself into his room. She says 'he is very fed up'.

[Session 38, observation]

Reflection

Here Nick is asserting a ground rule for the new group member: every participant has equal access to the session. Aidan seems to find it unthinkable to share with Jack. Perhaps sharing a house as an equal with Jack implies to Aidan that he is like Jack. Perhaps Jack's difficulties are a threat to Aidan's identity. I am reminded of some research on self-advocacy Sticking Up For Yourself where Simons writes:

The self-advocates expressed complex attitudes towards their fellow adults with learning difficulties. Some reacted to pressures on them by distancing themselves from their less able peers. (Simons 1992)

Anna writes:

Aidan played all three drums and tried to explain why he wanted the door locked and why he told Jack to leave. The other men didn't come back into the room when Aidan was in. Aidan played the drum to Nick's keyboard for a long time. Aidan kept locking the door and became very angry when we wouldn't let him. He shut the window and stopped playing when Jack came to the window from outside. He looked very disappointed when Nick called Jack's name.

[Session 38: questionnaire]

Reflection

Anna is picking up on Aidan's attempts at connecting with Nick both musically and verbally. She vividly describes his feelings and how he is left alone by the other residents. Aidan's anger at not being allowed to lock Jack out can be seen in the context of a locking culture within the house. He is locked into the house, but he is not allowed to lock others out. Perhaps this distinction feels unfair. Certain people in the house (nursing staff and home care workers) are allowed to own keys and lock doors, but Aidan is not. Nick has refused to be a keyholder during the year as he does not want to be associated with this division, but now he becomes part of what Aidan perceives as unfair.

Nick begins to work with Aidan on his difficult feelings.

Aidan arranges several drums around him in a kind of barricade. Nick asks 'Are you hiding?' Aidan gets up and shouts at him. Then they play drums together and Aidan moves to the bells and other instruments. Other men come and go. At the end Aidan does not want

to leave.

[Session 38: observation]

Reflection

What does the barricade symbolise? Does Aidan react strongly to Nick because it is painful to admit he is hiding? Aidan has recreated the same situation with drums as he did by locking himself in his room. It is as if he needs to protect himself. Perhaps Aidan needs protection from the envious feelings of some of the other residents, and from the feeling of being an outsider. He has been put in the position of being an unwelcome replacement for someone who is mourned. He is in a vulnerable position and seems to be responding by being aggressive to even more vulnerable participants like Jack. Nick is trying to balance his needs with the needs of the group, and this time is more sympathetic to Aidan, although it means that some of the other men do not want to come in, and miss out, especially Pete.

14.8 Future involvement in music therapy

The issues of exclusion and inclusion were most clearly articulated in the final session of the music therapy inquiry. During the final dialogue with Rose, which took place after the sessions were filmed, I heard that Nick had decided that Aidan should not be included in the music therapy group, for the benefit of the other participants.

Rose: Aidan doesn't come in now. Nick said that he could be quite threatening within the therapy session, which is not what it's all about. We agreed that the group had been

working towards some quite positive outcomes, so to have somebody come in a bit threatening and negative defeated what they were all trying to achieve.

Cathy: And he was coming into a group that had already formed.

Rose: Yes, and had been brought closer by their bereavement.

[Dialogue with Rose: after cycle 6]

Reflection

Nick offered individual sessions to Aidan instead, so that he was able to continue the connections they had begun within the music. However, I feel that working with Aidan within the group might have enabled movement towards a more accepting state of affairs within the home, and broken the pattern of regarding the outsider with suspicion. This suspicion had been a phenomenon which Nick, Anna and I had also encountered in different ways. Nick recently explained that because Aidan was moved across to the other house, this was the reason for offering him individual therapy instead.

14.9 Summary

Aidan's arrival in the music therapy inquiry revealed that a sense of group identity already existed among the residents. Some of the early remarks made by participants of the co-operative inquiry suggested that there was no spontaneous interaction whatsoever between the residents. For example, Claire says early on:

To be honest, apart from when we structure an activity, like kicking a ball backward and forth, *I never see any interaction at all.* [My italics]

[Co-operative inquiry: meeting 1]

What seemed to be most difficult for the residents was to allow the group to change by incorporating a new member. I maintain that there are several reasons for this: the lack of preparation for Aidan's arrival; the poor timing; Aidan's recent traumatic history; the tenuous nature of the group identity and Aidan's differences in the way he used music. Steve's openness to making connections with Aidan could be explained by his nature and communicative potential within music. However, it is also the case that Steve was the only resident who had tangible support in bereavement work when Bill died. Perhaps, for Ralph, Pete and Jack, the disappearance of Bill may have been both a relief and a terrible worry. These feelings could have been confused and exacerbated by the sudden appearance of 'nasty' Aidan only a few weeks later.

For Aidan himself, the music therapy inquiry gave him a space to inquire into his pressing questions about his own feelings about exclusion and inclusion. He raised the question of the essential unfairness of the 'locking' culture, despite being the most excluding of all the participants. He found a way of expressing his difference in his music, and began a dialogue with Nick, essentially in the music, which could be developed into his personal inquiry.

PART FIVE

CONCLUSIONS

CHAPTER FIFTEEN

Findings, discussions and conclusions

15.1 Summary of the study

As the first inquiry using action research in music therapy at doctorate level, this project explored ways of inquiring into the impact of a music therapy intervention through collective reflexive processes. These processes occurred non-verbally through musical improvisation and verbally through discussion. People who did not use verbal communication as a primary communication were able to participate in the inquiry process using sounds and actions. The significant advantage of this approach has been to involve the views of socially marginalized people who are usually only researched *upon* as 'subjects'. Differences between these methods of inquiry did result in some inequalities between the verbal and non-verbal participants. Much rested on how verbal participants were able to interpret and reflect on the contributions of the participants who did not use words. This in itself has imposed some limitations on the written findings of the research. However, despite initial scepticism from both research and clinical colleagues, this inquiry shows that group music may be used as a valid inquiry medium and that participants with widely varied communicative styles and cultural backgrounds

were able to learn from co-inquiry.

Findings in relation to the research question

In response to the original research question: 'what benefits did group music therapy make to people with severe learning difficulties and severe challenging behaviour?' there were a number of important findings. Participants, both 'clients' and 'therapists' were able to explore their awareness of others, improve and change established relationship patterns, encounter new ways of dealing with conflict, develop awareness of their own accountability to others and explore the limits of their tolerance of others. With a clearer expression of group identity came the experiences of transformation of feelings, making sense of a significant bereavement, and the experience of helping others change their minds.

These findings reinforce the tacit collective knowledge within some clinical writing about music therapy reviewed in the second chapter, but here it is established through the detailed analysis of minute-to-minute observational data over a process of thirty-eight sessions. They contribute particularly to the limited research and clinical writing focussing on the impact of group music therapy on clients and therapists.

From the co-operative inquiry part of the research, we found that introducing a music therapy intervention as an inquiry also brought benefits to staff members, most clearly to the day care worker who assisted in the sessions, but also to staff who were not part of the therapy.

General findings that were shared from the music therapy inquiry enabled staff members to change their perceptions about the residents, and about their own relationships with residents. The predictable nature of the session timings allowed staff to reflect on the benefits of more structure within the weekly timetable.

They were able to take pride in the way they supported sessions by allowing residents more autonomy. The literature reviews did not seek research that addressed the impact of therapy on staff members who were not directly involved. However, it seems likely that there is little such research. Furthermore these findings might well be of interest to therapists, community home workers and commissioners of services.

Principal themes from the music therapy inquiry

The shared creativity in musical play, particularly through voice sounds and encounter with instruments allowed the exploration of the recurrent themes of inclusion/exclusion, choice/control, public/private, and rivalry/mutuality.

Non-verbal participants communicated a number of opinions that challenged the thinking of other participants. Not every resident wanted to participate as a client, or be filmed. Some did not like the way a therapeutic intervention interfered with being at home. Those who did participate consistently throughout the inquiry showed they had a need for creative play in their lives. This challenged both the home workers and the host institution to find more ways of providing objects in the home for both functional use and/or creative play.

Principal findings from the co-operative inquiry

Staff participants found that much of their work stress was due to specific conflicts in their own conceptualisation of their own responsibilities, and perceptions of the residents. Recurring themes in relation to working in the home were empowerment/risk, unpredictability/certainty and despair/hope. Members of the co-operative inquiry group realised that we often did not acknowledge clear communications from the residents, and that our ability to listen was often linked to

and limited by our personal agendas. Through the inquiry we began to construct new possibilities of listening to and understanding the communications of the residents.

Other findings included those about the relationships between residents: that they were constantly changing, and were significant to the residents even if they appeared to show little outwards signs of this. Also, some residents had their freedom significantly curtailed as a result of the needs of the others.

Findings in relation to action research

The research builds on the practice and understanding of action research in that it extends inquiry into the mode of music and that it involves non-verbal people. It reinforces the claim that critically reflexive action research is fundamentally concerned about the ethical nature of the inquiry and examines ways in which ethical thinking can both shape an inquiry and change throughout the process.

15.2 Introduction to discussion of findings

In the following discussion about the implications of these findings, the focus will be on the key areas of ethics in context, power, participation, support within community care and boundaries in practice. Each discussion addresses the complex connections between music therapy in practice, community care and action research within the inquiry.

15.3 Ethics in context

Ethical thinking as a priority

A notable feature of the co-operative inquiry was that participants put

questions relating to the ethical nature and design of the project firmly in the centre. There were a number of reasons for this: a commitment to caring for vulnerable people; in some cases, an identification with those who have low or vulnerable status in society; professional cultures which placed a strong emphasis on duty and accountability, and personal fears about falling short or lacking competence.

The themes of insider/outsider and inclusion/exclusion emerged in a number of guises. For example, the therapist and researcher were seen initially as outsiders who might not be trusted to respect the privacy and dignity of residents who were seen as highly vulnerable. Also agency workers, those who were not part of the 'family' within the home might take parts of the research with them. There was a tension between what could be revealed into the public domain, what should be kept confidential, and who should be privileged with such information. With such difficulties and professional pressures it is not surprising that the inquiry members relied on conventional therapeutic standards and procedures at first.

Ethical thinking was dominated by the tension between autonomy and risk, where the music therapists tended to focus on empowerment as a priority, and the nursing staff managed the anxieties about risk to participants, finding common ethical ground was only possible by participants recognising their differences and challenging their own suppositions. Early on in the project it was clear that lack of common agreement about ethical values led to the possibility of the project collapsing.

From this local experience it seems that participant agreement on what constitutes the main ethical values and priorities in the project is fundamental and crucial. Where there are strong disagreements, there are two crucial elements:

sensitive, clear facilitation of the inquiry process, and the existence of participants who are able to move between the two camps and reduce a sense of polarisation. Our findings, therefore, support the argument in critically reflexive action research that ethical considerations form the core of such inquiry.

Subjectivity and consistency in ethical thinking

As ethical thinking continued to evolve during the project, the subjective nature of many ethical decisions was apparent. The inquiry found that ethical decisions were often not formed by what they saw as natural moral laws, but rather were informed by their own agendas. For example, understandable fears protecting an ill man from possible or imagined risk in the music therapy sessions were sometimes more important than allowing him the autonomy to decide for himself whether to attend. One bereaved staff member completely reversed her views on video confidentiality because her need to 'see' Bill after he had died was a more powerful need for her.

Furthermore, using an idea of ethical practice as if it were a moral imperative such as 'we must protect him' or 'we must allow him freedom' became, in some instances, a way of exercising power. All participants were concerned to appear to practise ethically, and were easily undermined by the accusation of being unethical. This taps into the wider debate in Britain concerning 'political correctness'. Declaring one's concerns for others can become a way of elevating status, even if emanating from altruistic motives. Similarly, a person may be accused of choosing an ethical high ground when in fact they believe firmly in what they have done. This highlights the strength of a research design where decisions are made collaboratively, and there are a number of participants who are able to

hold differing views. To an extent this compensates for individuals who are particularly subject to different personal agendas.

Various participants remarked that the most fascinating part of being involved in the project was the exploration of ethical thinking in dialogue with others, and having the flexibility of changing practice throughout the cycles. The beginning of the project had felt stressful because of the need to make a number of decisions about the design, but the cyclical nature of the inquiry allowed for some decisions to be reversed or modified.

Despite the changing nature of some ethical thinking, there were a number of decisions that endured. The residents were filmed throughout. Videos were made available to the residents and support was available for them to reflect on this material. The details of the interactions and statements within the music therapy inquiry were kept confidential within that inquiry group although general statements were shared with the co-operative inquiry group. The residents were not intentionally coerced to attend or participate in any particular way, and the door was always open for them to come in and out.

These decisions were debated throughout the cyclical research process, but there was a collective desire to keep them consistent. All these decisions can function as recommendations for practice within similar contexts. I would also recommend that therapists and support workers consider the ways in which their personal and professional agendas affect the way that they construct what they consider 'ethical'.

Informed consent

Some of the most innovative work in the project occurred in relation to informed consent. From the early inquiry work, we discovered that informed

consent was better thought of as a creative process rather than something that is achieved at a specific moment. The idea that anyone was fully informed was an unreachable ideal. It was imperative to work on the mode, method and timing of communication about issues deserving of consent, because each participant had complex communication needs. The use of different media was especially important in this.

I believe that the main contribution of the inquiry towards a notion of informed consent was an exploration of how limited levels of understanding were worth pursuing. This exploration led to some significant change in choice, control and dignity for some of the residents. For example, various ways were devised to work towards informing residents of the fact that they were being filmed, what that might mean, and of allowing their responses to change practice. One participant (Steve) changed his attitude to the inquiry as a result of understanding that he was being filmed, which he appeared to experience as positive affirmation of his participation. Ralph eventually managed to influence practice in relation to the use of the video camera.

The research literature showed that involving people with severe or profound learning disabilities in informed consent procedures is relatively rare, despite some very creative and persistent exceptions. Therefore some of the findings of this inquiry could be used to inform good research practice involving vulnerable people with complex communication needs. It also seems important to take into account how emotional and empowerment issues may also affect communication and ability to understand the opportunities and threats available to participants in research.

Complexities and limitations

There were a few complex ethical challenges that were not resolved. The difficulty of a resident owning a video tape which had images of other group members meant that the resident also needed to manage confidentiality, and this did not always happen. This raises a dilemma that applies to the filming of all group work. If one group member objects to the filming, what is the best moral action to take? Should all filming be stopped or the group member omitted from the filming (or even the group)?

More seriously, there were limitations to the effect that views of the participants had on ethical decisions. For example, Ralph's reaction to the presence of the camera was not accepted as an objection until he had hit the camera on a number of occasions. Good ethical practice would have meant that on his first objection, it would have been removed, or at least switched off when he was in the room. However, there were other research agendas impeding this. Removing the camera would have meant a catastrophic reduction in the amount of data available to be analysed in order to understand residents' more complex communications, so removal of the camera altogether meant an overall reduction in the ability of the residents to influence the inquiry. The alternative would have been much more detailed note writing immediately after the session, and this increase in work and time was simply not available for participants. The effect of Ralph's protest was only clear to him and others after the formal end of the inquiry when the therapy continued with no camera.

None of the residents in this inquiry appeared to make any objections to recording aspects of sound. This may have been due partly to the difficulty in grasping the more abstract concept of audio recording. Ralph's objection to the

camera could simply have been to the presence of a foreign object in the room, although his early observed reactions support the theory that he did understand some of the implications of filming.

Both Nick and I have altered our own practice of filming non-verbal people since undertaking the research, relying most heavily on detailed observation and recall after the session, and using audio rather than video recordings. My conclusion is that filming is only justified if the benefits to the participants or a client population as a whole are significantly greater than the need for tight confidential practice. A client needs to trust the therapist, and sometimes compromises that seem slight to the therapist may prevent a client from ever feeling that he or she can use the therapy safely.

Summary

The inquiry, whilst establishing the fundamental place of ethical debate within the process of action research, found participants struggling with the complex nature of the ethical questions raised. The research was particularly practically demanding first because of the ambitious involvement of people with enormous differences in powerlessness, communication styles and background, and second, because of some of events occurring within the inquiry year. The collective and cyclical nature of the research process was invaluable in maintaining such challenging ethical questions in the forefront of inquiry resulting in a number of changes, and recommendations for practice.

Questions of empowerment and disempowerment were crucially related to many of the ethical notions developed and reinforced. Therefore, it seems natural to move on to the next main area for discussion: power.

15.4 Power

As explored in chapter four, one defining feature of action research methodology is that it offers the opportunity to restructure power relationships. The way that different types of action research manage power relationships between participants helps define the type. For example, participatory action research actively promotes the perspective of particularly vulnerable participants with the intention of the process empowering them. The process of examining the issues raised within this complex inquiry is particularly revealing because of the complex inequalities in the power relationships between participants themselves, and also participants and the wider community.

Power and hierarchy within the inquiry process

The introduction of critically reflexive action research into a staffing system with a clear hierarchy meant that the rigidities of the system were highlighted and challenged. As all the members of the co-operative inquiry had equal rights, at least by definition, certain group members stood to lose power. At times, group members could not reconcile the tensions of being in the group with their professional roles outside, and made unilateral decisions, such as the insistence of moving the therapy session to the dining room.

Although the logic of this decision was compatible with the values agreed by the co-operative inquiry group (such as allowing any resident the option of choosing whether or not to attend the music therapy inquiry) it was enforced rather than reached by consensus. The therapeutic judgement of the music therapist and the duty of care of the nursing staff both held authority within the group and there were predictably a number of conflicts between staff.

Group dynamics within the co-operative inquiry

The cyclical nature of the research design meant that these decisions could be revisited reflectively in later stages of the project, when more was known and the practical issues were less pressing. Both the music therapist and home manager used the inquiry to reflect on personal use of power and decision-making. These two people began by feeling that they held the most practical and emotional accountability within the project, although I was deemed to hold overall accountability for the success. As the process moved forward, all three of us began to rely more on other members of the inquiry to support the inquiry process, despite our clearly defined roles in terms of practicality.

In order for this reflexive process to develop throughout the project, there were three principal supporting factors. The first was my opportunity to reflect critically on my role of facilitator through challenge by the supervisory group and peers. I adopted a style whereby I attempted to contain the inquiry process, but did not make unilateral and key research decisions. Although I believed my role was to articulate some of the decisions made by inquiry members and the differences between them, decisions were grounded in what other participants felt. I did not, however, total relinquish power in terms of decision-making, choosing sometimes to state my own opinion as a participant.

A second factor was the availability of a series of dialogues in which Nick, Rose and Anna were able to inquire in more depth away from the gaze of other group members. Rather than this having the effect of ameliorating the full force of collective decision-making, it allowed participants, by articulating and exploring thoughts and feelings that they found too intimidating in the group, to find it more possible to share their concerns collectively in the following inquiry meeting.

Therefore the opportunities for reflexive dialogue outside the group actually strengthened the collective reflexive process.

The third factor was the presence in the inquiry of certain participants who held less power in the staff hierarchy but were able to cross over from one subgroup to another. Anna, the day care worker continually negotiated between Nick and the home staff within the music therapy inquiry, and Clare, the deputy manager was the 'go-between' for Nick and Rose in the first two cycles. Anna and Clare were also able to contribute more unusual perspectives within group discussion partly because there were fewer consequences for them. They were able to think freely and take positions of risk, whereas Nick and Rose took positions of accountability. In this way the group was able to negotiate some of the more difficult decisions without taking defensive positions, especially following meeting two.

Power in the music therapy inquiry

Unlike the co-operative inquiry, the music therapy inquiry offered an opportunity to inquire together weekly. Participants found ways of exercising power in a variety of ways, some more effective than others. Although I have mentioned the vulnerability of the residents, they were sometimes extremely powerful, such as Pete using his strength to move instruments around.

From the detailed analysis of power relationships in part three of the thesis, a number of findings arise. Participants chose to express their feelings about power relationships within the music therapy sessions, often through competing relationships with Nick. Envy reminiscent of sibling rivalry, where siblings compete for the attentions of a parental figure, was the most common form of expression. Less powerful residents, such as Jack, began to discover that they were able to

influence others rather than avoid situations by leaving. Experiencing musical relationships through play and listening allowed participants to re-experience ways of being powerful, in sound, in the use of space and territory in the room, and by winning attention from Nick.

Nick himself moved between periods of feeling totally disempowered, such as when the therapy room was empty, to feeling powerful as a therapist because participants competed for his musical attention. From my own therapeutic experience, disempowerment is something I have frequently experienced when working with groups of people who have had an institutionalised past (and often, present). A temptation to escape these feelings can easily lead the therapist to find ways of persuading clients to attend therapy or remain in the room.

At times the collective demands of the residents made Nick's job extremely physically and emotionally challenging, and he was not always able to notice or respond to every individual participant's competing needs. It raised the question of whether this therapeutic work was too demanding for just one therapist, and whether two therapists should be working with a group of this size and need. The answer to this, I think, is that more useful therapeutic work could be done with two experienced therapists working together with a commitment to reflexive practice, although clearly much was achieved with just one therapist.

Following the formal end of the inquiry, Anna joined Nick in a co-therapist role. This was a good outcome, as there were no available resources for a trained therapist to join Nick, and also because Anna's learning through the inquiry had made her aware of her own power and potential. She did not think of herself as a therapist, but was able to share the burden of acting with the group of residents. She had always shared the thinking about participants with Nick throughout the

inquiry.

Although power issues were significant in both arms of the inquiry, power issues were inquired into much more directly within the music therapy arm. I think that there were various factors enabling this: music, which can be used to express or symbolise aspects of power and strength safely and directly; malleable space, which allowed the exploration of territory; and the frequency of the sessions.

Although power has not been a recurrent theme in the work of music therapy practice or research, I believe there is a strong argument that music therapy offers much to allow change and transformation of power in relationships.

Deliberate limitations of power: 'not doing'

The success of the inquiry hinged in many ways on the ability of others to curb or curtail their power. The Trust management team deliberately kept out of the inquiry once they had approved it, allowing it to happen at what one manager termed a 'grass-roots level'.

Home staff members curbed their curiosity to know what was going on in the music therapy inquiry, and respected the confidentiality of the participants in this part of the inquiry. Their thoughts and struggles with this became evident within the co-operative inquiry, particularly because for some it raised strong feelings of being excluded.

The therapist learned that it was important for him to pay attention to this excluding effect. Once staff participants understood why they were not involved in the music therapy inquiry, and were convinced that this was helpful to the residents, they were more accepting of their 'non doing' role, and became actively helpful in giving practical support. The process of explanation and challenge that took place through the inquiry meetings was essential to this. Without this

transparency, staff members could have continued their earlier examples of intrusions, loud noise outside, unhelpful comments to residents and attempts to cancel the group at short notice.

All participants needed respect from other participants, and it was important that Nick and I articulated how helpful the 'non-doing' was to the participants concerned. Inquiry into the meaning of these findings and application to other aspects of life in the home formed part of the co-operative inquiry.

Power issues within the thesis: the imbalance in representation and gaze

One criticism of this inquiry is that the research gaze is most clearly on the non-verbal residents rather than the verbal participants in the co-operative inquiry, and as such may even imply a shift towards researching *about* rather than *with* people.

I have partly tried to address the power imbalance within the thesis by attempting a respectful way of writing about others, often using a description of an action as if it were the words of a participant, and also by including using multiple interpretations or perspectives of that action. Many times I found it difficult to decide how to interpret an action of another participant, and how important that action was in relation to all the others.

The choice of the Framework analysis system allowed me to suspend judgement about the relative importance of various observations until wider patterns had been established. The detail has meant a more laborious read but I have risked this in order to honour the communications, and to allow the reader to interpret more freely.

Although the findings of both inquiries are reported and discussed here, the detail given to the music and actions of the participants in the music therapy

inquiry can be seen as a form of positive discrimination. Just as the co-operative inquiry members escape the detailed gaze of their own inquiry struggles, so their reflexive thinking and action are not documented in as much detail. My personal motivations are important here. Perhaps I should have been prepared to strike a balance for all participants, but I was more concerned to focus on the stories of the residents, because their voices are so rarely represented in any area of life. Also I was more interested in the music therapy inquiry because it involved musical processes and formed a vital and dynamic part of the inquiry. The story, for example, of the inquiry relationship between Nick and myself will have to form part of another, jointly authored form of dissemination.

15.5 Participation

Participation and validity

The longitudinal form of the study allowed aspects of the nature of participation in the inquiry to become a major focus, explored reflexively by most participants in both arms of the inquiry. In co-operative inquiry the commitment of participants to the project is seen to be crucial to its validity. However in the case of the music therapy inquiry, some participants, Jack, Bill and Ralph, spent far more time outside the therapy room than inside. The expectation of very high attendance and focus during the times participants spend together during the inquiry is clearly unrealistic for people who do not often see the point of prolonged contact with others, or who have great difficulties with it. I do not believe that this makes the research less valid. The validity in this inquiry comes more from the evidence of changes in participation, and evidence that participation was lived and thought about throughout the project. If there are to be more participatory inquiries

involving people with genuine and severe difficulties in social interaction, there is a need to the concepts of participation and commitment to be critically reviewed, with a more radical flexibility in approach.

Attendance and quality of interaction

How did we construct participation in the co-operative inquiry? Attendance was viewed as the primary factor in the first three cycles, evidenced by collating graphs and making detailed records of who was in the room and when from the video data. By cycle four the emphasis shifted to the nature of the interaction and therefore the quality of the reflexive processes between participants within the room. Participation then came to be seen by members of the co-operative inquiry as relating to how much participants were willing to express themselves to others, notice others and adapt their behaviour accordingly.

Jack, Ralph, Pete and Steve all moved towards a fuller realisation of participation as the inquiry developed. The patterns varied: Jack's attendance, for example, was sporadic until cycle five, whereas Pete had poor attendance in cycle one, but from thereafter increased his commitment markedly. In contrast Bill connected with the inquiry entirely through musical relating, but not through attendance.

Cultural background and participation

Many of the difficulties in participation the residents experienced in the project were related to their history of institutionalisation. Factors such as low self-esteem, low expectations of personal accountability and lack of experience in social interaction underpinned a reluctance to attend or commit to the inquiry process. However, the inquiry is full of examples of where, through the experience

of making music together, the residents changed the way they relate to one another, particularly in the way they noticed and listened to other people's music. This in turn affected their power relationships and the decisions they made in relation to other.

The participants with a nursing background had expectations of a research involvement along the lines of more traditional research, and this meant their participation was initially uneasy, formed by expectations of being told what to do, and having fears about being passive subjects. By cycle three they were more relaxed, and this made reflexive collective thinking and experiencing more natural. In this way, the quality of their participation could be said to have improved. As stated earlier, we need to develop a concept of the validity of participation that accommodates people who experience particular difficulties with regard to commitment and social interaction. In respect to participatory research involving people with severe communication difficulties, and also people with severe challenging behaviour, their inclusion is an important achievement. I contend, that participation from the residents was meaningful in many instances, although the meaning itself was not always clear.

Other participants in the co-operative inquiry also came to similar conclusions. This in turn brought about change through what may be described as reflexive processes. The changes, although small, impacted on the context of the men's daily lives, resulting in more co-operation between the men, increases in confidence and self-esteem, awareness of own and others' needs and success in working through conflicts.

Learning about participation

Staff members and therapists were able to realise through the findings that the bereavement process could have been managed better: for example either by involving residents in the funeral, or providing alternative rituals to help them mourn Bill. The perception that the death had affected the residents powerfully was an important realisation for home staff members, as was the evidence that the residents did relate to each other. This shows that the inquiry did bring about future changes in the kind of community participation the residents gained access to, through changed perceptions of their carers.

Home staff participants developed clear views that participation in music therapy was something that they wished to see maintained. It allowed all of us in the co-operative inquiry to learn about how to notice and respect different types of non-verbal participation.

Community music therapy and participation

Clearly an inquiry that was not divided into two halves should have allowed greater integration between both sets of participants. However, because of the two available modes of communication, music and words, there was a risk that an integrated inquiry using both modes of communication might have meant less power and influence for the non-verbal. If this had been an integrated study, the inquiry would have been best served by using music as the primary medium as this would allow more equality of participation.

The recent practice developments in community music therapy where projects often use music to bring together 'therapist' and 'client', breaking down the distinction between them shows that a skilful practitioner can facilitate large groups

with great social and cultural difference between participants. As yet, the community music therapy literature deals primarily with projects in which the participants were primarily verbal, or had some way in which to negotiate their positions verbally.

The application of critically reflexive participatory methodology to community music therapy research seems extremely relevant: community music therapy raises fundamental questions about power and participation, and participatory research offers the tools by which to address these questions in a congruent way. I would like to see participatory research practice applied to community music therapy projects, and in particular, this inquiry may be used to develop projects where many of the participants are non-verbal, or have other difficulties that prevent straightforward social interaction. If this is to happen, verbal participants must not see themselves as interpreters for the non-verbal. They should be encouraged to think of themselves as participants who also use non-verbal communication.

Just as examples of skilful community music therapy practice can be used to highlight the participatory limitations of this inquiry, so this inquiry can also be used to inform the practice of community music therapy. How far does the involvement of participants with different power relationships favour the more powerful? How might the project design and facilitation be improved? How clearly are the group processes understood and deconstructed during the course of community music therapy? How are the agendas of the weaker participants served? What is the role of therapist in this? What is the role of music?

Different levels of musical participation

The inquiry has shown is that we should be prepared to broaden our notion of what making music (musicking) involves. In particular, the notion of the

acceptability of the music created became an issue of the inquiry. If I want to be a reflexive music therapist, I need to examine my own aesthetic constructs and prejudices.

In the music therapy inquiry, the major change in musicking practice was towards making music together in larger groups. This represented at first an important relational change from dyadic to triangular relating, which then extended to groups of four people sharing a musical experience together. Often in the quartets, one or more participant was not making sounds, but still seemed involved, either through their stillness, postures of listening, body movements, or all three. This suggests an active but silent involvement, so a concept of active musical involvement without making musical sounds was necessary here.

However, there were many instances of people making sounds upon exit, therefore not allowing themselves to experience the way in which their communications were received (often in the case of Ralph). In this way, some participation involved receiving without actively contributing and *vice versa*. In therapeutic terms, contributing but not receiving implies acting out rather than being involved in a reflexive exchange. Therefore, with Ralph we saw a change from non-reflexive participation to reflexive when he began to stay to receive the reactions of others.

The nature of the sounds made was notably varied, including sounds resulting from hitting beaters on trays or walls. Some vocalisations seemed to be more like shouting than singing, and a question is raised about what we actually hear as noise rather than sound, and what we hear as singing rather than shouting. The wider the range that is constructed as sound, the more inclusive a person is in their concept of what making music may be.

This does highlight the issue of the aesthetic values participants adopt, and the need for them to reflect critically upon these choices. For example, Steve explored the limits of the sounds he could make, and appeared to have an inquiring and very flexible experience of sound. Jack, on the other hand, often withdrew his participation by leaving the room because of finding certain sounds difficult to tolerate. These differences made it difficult for the two men to participate in the music, although by cycle five they seemed to be able to do this.

Similarly, participants in the co-operative inquiry talked about the 'noises' of the men, and how they might appear strange, identifying the need for workers at the home to have a tolerance and appreciation of the meaning of sounds. An important point of inquiry was the requirement to address the sound world in which we live in reflexive music inquiry, and to be particularly mindful of what we might construct as 'acceptable' communication.

Music therapists need to ask these questions early on in training and beyond. What this inquiry shows is that for all those involved in music therapy, even purely in a supporting role, these questions are relevant.

The inquiry also raises the question of whether music therapists should exclude clients from therapy because their attendance is low, or their progress very slow to gauge. There is a strong argument for detailed recording of changes in musical participation. The quality of musical participation in terms of how people participated and with how many others provided richer data than the attendance data, but sometimes the detailed attendance record did allow explanations and interpretations to be more fully formed. The emergent patterns of interaction, and a comparison of how they changed was a useful way of gauging progress in a number of areas.

From this data I feel convinced that it is important to think hard before removing people who are 'poor attenders' from a music therapy caseload. Careful recording is much more likely to convince a therapist, supervisor or other clinician that the therapy is worthwhile, and this inquiry shows that in some cases, extremely low attendance did still allow for important changes to take place.

Working within a community care setting

The findings show that the support received from carers was crucial to the success of therapy, and in this case, the inquiry. At times the inquiry could have collapsed had the difficulties in communication between people from different healthcare backgrounds not been tackled in a sensitive manner. The music therapist needs to be aware of the potential for using their professional responsibilities to exclude other workers, and the care worker may use their grasp of practical realities to undermine sessions in a number of ways.

Tension is very likely to exist between different professionals, so respect, understanding and communication is vital from both sides. The concepts of confidentiality, informed consent, and duty of care can be used as justifications of exclusive practice instead of the protective and caring practices that were intended.

As we have seen from chapter three, workers employed in challenging behaviour units are often underpaid, undervalued and at risk of being injured. Any visitors to the unit must be sensitive to the pressures that they are under.

At the same time, music therapists are from a tiny profession where the main agenda is survival. If the profession develops, more vulnerable people who need the benefits of non-verbal communication through music will be able to access music therapy. Professionals working in host institutions need to appreciate the task of the music therapist. The practical difficulties of running a session at

all in a challenging behaviour unit, managing the instruments and receiving a variety of difficult communications involves a large amount of energy, so any practical support given to the music therapist will increase the likelihood of the therapy being successful, and ongoing.

15.6 Bounded and unbounded practice

Conventional and unconventional practice

In terms of conventional practice, the group therapy sessions took place weekly at the same time and place for thirty-eight sessions. The music therapist and the residents built relationships through musical interaction.

More radical practice involved the following: using the home as therapeutic venue, a change of room space after four sessions, the use of an open door to the therapy room and using communication between participants through doors, walls and into the corridor; i.e. an extension and development of the therapeutic space. Each diversion or transgression from regular practice occurred as a result of the inquiry process. From the perspective of British music therapy practice, these diversions would normally be regarded as non-optimal, and potentially compromising for the client.

Therapy at home

The decision to situate the music therapy in the home was the only practical option because of the limited staffing and transport resources. It was possible to transport the instruments to the home each week, but not possible to transport the group of residents at once to a music therapy room in the community.

Normally music therapy will take place away from the client's home. This provides a space away from a client's everyday world where they can be

challenged, but leaving a home space to which they can return after the therapy to provide comfort and familiarity. Therapy within one's own home gives the client a different experience and creates a different function to the space in which it takes place, including peripheral space.

In this inquiry, some areas of the home were not taken up by the therapy, but sounds did travel from room to room. Sounds of the television in the lounge carried (or intruded) into the therapy room, and sounds from the therapy room carried elsewhere, sometimes compromising confidentiality and reducing privacy. In earlier sessions, there were many staff interruptions to the therapeutic space. The inquiry managed to work with the staff to help manage the problems of the space, so that noise and interruptions were kept to a minimum. In the last session, where, unusually, all staff members on duty were agency workers, it was clear that they did not understand this culture and there were more interruptions.

Would these factors necessarily cause a difficulty to the residents? After all, some people feel more secure if there is background noise rather than a deafening silence. Ordinary comings and goings might allow residents to be more relaxed. However, Nick and I felt the nature and timing of the staff interruptions were often in response to something happening in the therapy, as was the turned-up sound of the television. Due to the nature of the inquiry, the complexities of the situation could be explored away from the time and place of the music therapy inquiry, and thus mutual decisions such as developing a quiet uninterrupted atmosphere was something all participants aspired to.

During the inquiry, residents did make protests about some aspects of the therapy. Bill and Jack, for example, did not like furniture being moved. Ralph may have objected to the presence of the video camera because it was an unfamiliar

object in a familiar space. Pete spent much of his time rearranging instruments, and this could be explained in terms of an expression of uneasiness with different objects being brought into a room which he associated with eating.

By contrast, there may have been some benefits to the situation. The residents were reliant on others to gain access to the community outside their home. One advantage of having the therapy in the home was that they were able to feel that all surrounding space was safe, and therefore their choices to come in and out were not governed by fear of surrounding unfamiliar space. One may speculate how often therapy clients do not feel they can leave the therapy room if they wish to because the environment around also holds some unease.

The residents were also in the process of making sense of having their own private space within a house, and perhaps for some, discovering what living in a house might mean. Towards the end of the year, both Pete and Jack showed Nick their own bedrooms, a space that truly was private for them. They may have wished to have contact with Nick away from others, but this also shows a recognition that the space belonged to them.

Change of room

There was a contrast between the meanings of the shared space in therapy room, lounge and the bedroom. The lounge space had a complex meaning. The television was often on although none of the residents appeared to watch it. In this way, the room appeared to be claimed more by the home staff than the residents, and became an arena for competing sound. It was a space for Bill to relax quietly in company during the last stages of his debilitating illness. It was a space to avoid if a resident did not want to be reminded of Bill's suffering.

The dining room, in contrast, was a more neutral space, but much less comfortable. Tables needed to be moved back in order to allow participants access to the instruments. Staff in the co-operative inquiry felt that the initial choice of venue was a mistake. Changing this, to allow Bill more of a space for convalescence, became a priority over disruption of the therapy. This was a strong indication of how the needs of someone who is terminally ill may impact strongly on the life of others sharing the space. Moving to the dining room allowed a new space for residents affected by Bill's illness were able to gain support and reflect away from Bill.

Open doors

In the music therapy inquiry, Nick spent a considerable amount of time thinking about how the other participants used space in relation to each other including him, and tried to use this to inform his own actions. The home was in fact a locked house, in order to prevent Jack and Bill 'absconding', as there was a risk they would run into a road. In addition, the kitchen was locked, because of the risk of Pete breaking crockery. The residents had to negotiate a complexity of meanings about the space in which they inhabited.

This realisation led Nick to decide to leave the therapy door open as a strong non-verbal invitation to the residents. He also decided to use spaces outside the therapy/dining room to engage people who thought they might not be allowed in, or who were afraid to come in. One complication to the dining room was that it had two doors. One led to the garden. At times participants came in only to get to the garden. Nick had to decide whether to lock this door to prevent the room being used like this (there were alternative routes to the garden), but decided against this 'mixed message' having one door locked and the other open.

Nick felt so strongly about challenging the locking culture of the house that he wanted to take the door off its hinges thus creating a more open and continuous space. This moved us to think more critically about the interior design of the house. The spaces within the house could have been more thoughtfully constructed to allow more fluidity of shared space, a limitation of locking, and clearer messages to residents and staff about what was private rather than forbidden.

The extension and development of therapeutic space

Bill challenged us all in the way he responded to the sound but did not enter the territory of the therapy room/dining room. Nick at first wondered if home staff had a hand in Bill's decision not to attend. However, from my observations I was able to confirm that staff did not appear to be applying either obvious or covert pressure on Bill to make a decision either way, so not attending the therapy was a decision that he made.

When Nick began to play his trombone outside the therapy room, Jack did at times appear in the room immediately afterwards. Bill, however, appeared usually when he was vocal and he heard Nick respond to this through the walls. Therefore, the extension of therapeutic space actively initiated by Nick made a difference to Jack's attendance, and Nick's awareness of Bill's vocal sounds outside allowed some therapeutic work to take place, initiated by Bill. This allowed Bill to retain direct control over any amount of interaction he had with Nick.

The extension of therapeutic space is a concept that is developed to a much greater extent in the practices of community music therapy. The findings from this inquiry suggest that different clients respond differently to the use of space with multiple meanings for them. A community music therapist may work with space boundaries with considerably more flexibility than in conventional therapy

where only one clearly designated space is used. The decisions made about the use of therapeutic space may well affect whether potential participants agree to take part, how they take part, and what meaning they assign to this experience.

Extending the boundaries a little resulted in more inclusive practice in this inquiry, but there are possibilities where residents need the safety of tight boundaries, and might protect or exclude themselves from the therapeutic experience. This is an area that needs more research in conventional therapeutic practice, but particularly so where the use of therapeutic space is extended.

Time boundaries

One may construe the changes described above as transgressions in practice. I believe that these changes often occur in practice, and that the above decisions constituted good practice. Rather than transgressions, they were the application of reflexive thinking and feeling in response to a situation where inclusion and exclusion were particularly sensitive issues. As Nick was the therapist most directly living the experience of the inquiry, his practice was directly challenged in the process. I, too, found myself needing to question my own assumptions about 'good music therapy practice' through observing him and also by supporting by bringing instruments into the home. Instead of the normal experience of clients encountering a therapy room set up ready for music therapy, they saw the instruments being moved in through two sets of locked doors. They often entered the spaces with the instruments, and wanted to be involved in this transfer.

This was an opportunity to negotiate roles that traditionally would not be taken by a client. One participant, Ralph, clearly found this more engaging and useful than the therapy itself. This suggests that there may be value in

involving clients in a setting-up process of the therapy in terms of raising self-esteem, for example, and this lends weight to arguments supporting community music therapy approaches.

The disadvantage was that it was unclear exactly when the start of the session began. I found this quite difficult and asked Nick several times when the boundary of the session beginning was. He concluded that it was when the first resident engaged with him. As this engagement often happened outside the room, this was a move away from the clear boundaries of standard therapeutic practice. The alternative, Nick argued, was that he would not engage with the resident until the entire load of instruments was in the room, and that would be artificial, inauthentic and excluding. It was likely to result in poor participation from that resident for the remainder of the session.

The residents often anticipated the time when Nick and I arrived with the instruments, so it was perhaps this moment rather than the start of the session that had most meaning as the 'beginning' of the encounter.

My main conclusion here is that decisions taken in this inquiry to relax boundaries needed to be context-specific. They were not the result of a lack of reflexivity or poor training. They involved an informed judgement about what might be most useful for the clients, with an awareness of how this may conflict with professional agendas. This realisation made the decisions more difficult to make. The inquiry involved people committed to the National Health Service and working in an area where there was a considerable amount of doubt and uncertainty about what the residents were communicating. In addition the expectations from society about how community homes for people with challenging behaviour should operate were often unrealistic. Using participatory action research enabled context-specific

decisions to be valued and made within the support of a wider circle of fellow researchers.

Implications for practice

In terms of the implications of this inquiry for community music therapy and conventional therapy, it shows not only the benefits obtained from relaxing some therapeutic boundaries, but also the importance of the boundaries that were maintained. The predictability of the sessions, and the increasingly successful attempts of ensuring confidentiality and privacy were important for developing trusting relationships between participants, resulting in deeper reflexive processes and bolder therapeutic work. When these boundaries were transgressed because of lack of communication and collective reflection, the therapeutic and inquiry work was undermined.

Before an intervention begins the setting-up period is crucial and should not be rushed. It is clearly worth having some therapeutic interventions in a home setting, but only if the space and privacy issues are addressed within the inquiry. For those who find it too difficult, there should be no coercion or expectation to be involved in either a therapy or an inquiry of this nature.

In conclusion, it is necessary to know why the boundaries are there, and to be prepared to critically reflect on them rather than unthinkingly applying a learned formula. Balancing this, an appreciation of the importance of containment, respect and privacy for important change also seems important. This process often involves a weighing up of priorities rather than there being an elegant solution. If this is the case, then I as a music therapist, working within a therapeutic process, need to be clear about my values in order to make such decisions.

Implications for therapeutic inquiry

I learned through from the inquiry that for a therapeutic inquiry of this nature it is important to make clear decisions collectively. These decisions include how the intervention is to be set up and which boundaries are essential in the early stages of the inquiry, *before* the therapy takes place. The inquiry process must drive any subsequent changes so that decisions are transparent and clearly necessary to improve practice. It is the responsibility of the team to critically challenge the therapists to help them think about why they are making these decisions.

15.7 Conclusions about engagement with the literature

How useful was the literature reviewed in the early chapters to the implementation and understanding of the inquiry?

As the first piece of action research in music therapy at doctorate level, there was a need to build up a broad picture of the context of music therapy research and practice to position the inquiry. Recent examples of new paradigm research, and the practice contribution of community music therapy were the most important areas of influence, and a clearer focus on these areas with a reduction in the amount of traditional learning disability research may have allowed a more balanced literature review in chapter two. I deliberately avoided the area of developmental psychology of music because I felt the focus of the inquiry would be on social issues addressed by music therapy rather than musical development, or music and autism. The review of music therapy group research would have been more important if it had been more developed, hence the need for a reliance on some group analytic theory instead. I feel strongly the need for further research into group music therapy, leading to the development of group music therapy

theory. The literature about early infant interaction gave emphasis to the non-verbal aspects of the inquiry and the clinical writing about people with a history of institutionalisation convinced me that the inquiry was possible even with people with profound disabilities and anti-social behaviour.

Because of the intersection between the three areas of community care, social action research and community care, positioning the inquiry was a complex process. The most useful literature concerned intersection or overlap between at least two of these areas. In particular, the writing concerning the social construction of disability was a major inspiration and a crucial challenge to my thinking about the thesis as a whole. As there has been so little clear influence from disabled writers on the field of music therapy, this is an omission that needs to change.

The examples of participatory research with people with learning difficulties, in particular a number of articles from the *British Journal of Learning Disability* were important in giving creative ideas and a focus for the research design. Other ethnographic studies with unusual or disturbing voices again served to inspire confidence in the prospect of researching with people who communicated in unusual ways.

Much of the music therapy research on people with learning difficulties focused on behaviour as a way of indicating positive or negative change. Rather than having spent so much time exploring this literature, my focus would have been better spent engaging in more depth with the sociological literature concerning the influence of constructivism and new paradigm thinking. From those influences I gained the confidence to use multiple perspectives to gain critical insights into how we construct behaviours and the meanings of behaviours.

However, the use of music therapy as a mode of inquiry in itself does seem

to be a new way of thinking about music therapy: it is not something I found in the research literature. Through the idea of communication in and around music as a method of critical self-inquiry for both people with and without verbal communication, participants were able to inquire into how they made meaning of their own actions, and those of other participants, within a constantly repeating process, that of the music therapy session. This idea came more from clinical writing about music therapy, my own practice experiences and the extended epistemology of Rowan and Reason. Engagement with participatory research models helped reinforce a belief that my tacit and practical knowledge as a music therapist was a vital research tool.

As a result of my early encounter with new paradigm research without understanding its wider context in the history of action research, it did seem necessary to provide a brief history. However, I feel that the study would have been further enriched by a study in greater depth of the recent work in critically reflexive action research, where many of the conclusions I reached about the limitations of co-operative inquiry have already been articulated. Instead, some of the participatory research concerning disability informed me with warnings about how research agendas may bring about project collapse. Perhaps as a result of this I approached the inquiry with more caution than enthusiasm.

There is a danger that relevant literature comes into print too recently to include. In the case of critically reflexive action research and community music therapy, I did not become familiar with the literature until I was approaching the end of the writing-up period. I do not feel that in these two areas I have adequately grasped what they could offer, but hope to do so in future publications.

Despite this limitation, new thinking in community music therapy reinforced

my conviction that political and social perspectives must also be taken into account when researching music therapy processes and outcomes, and also provided many more radical alternatives for working with the group and community than were embraced in this inquiry. Perspectives from group theory did inform the facilitation of the inquiries, and will be more likely to influence the research design in future. Participatory research values group process, but making meaning of these process may vary enormously depending on the theoretical approach. So much theory has been based on verbal interactions above non-verbal ones, and there is still relatively little theoretical writing on how the processes of group music therapy may work, and the relationship between music and words.

For the design and implementation of the study it was helpful to know what research using other media could contribute to our research design. However, the tiny number of studies that began to address how people with severe or profound communication difficulties could be participants in a research project made this task difficult. Even more notable was one single participatory study with people with challenging behaviour.

In both the community care and action research literature I was struck by how little research related to people with severe learning difficulties. I hope that some of the findings and approaches in this study will inspire others to involve people like the residents in inquiry.

15.8 Future directions

There are a number of future directions indicated by this inquiry. The first area, and probably most important to me, is participatory research that involves more people like the residents. Combining the findings of this inquiry with

knowledge built up by other recent work with people with learning difficulties may result in more radical inquiries, where participants exercise more control over the content and design of the inquiry. The inquiry also gives examples of the way in which people may be involved using different media, and individualised approaches for their communication needs through the creative use of different media. The use of multiple perspectives to construct meaning within a critically reflexive framework should help address some of the most pressing issues of interpretation. In this type of inquiry, a critically reflexive perspective on ethical issues such as informed consent would form an important part of the work.

The second direction is the development of research where music is the main means of communication and method of inquiry. I would like to explore ways in which the actions and opinions of the participants are used to inform the early design and constitution of the inquiry group. Research needs to address conflicting professional agendas. I can see an application of critically reflexive music therapy inquiry with, for example, people with severe mental health needs, pre-school children, people with autism, brain injury or degenerative neurological conditions. It is a highly appropriate model for any music therapy intervention that is extended to embrace a wider community or population. The use of critically reflexive or participatory action research would help those extending practice within community music therapy, allowing more transparency as to the quality of the therapeutic work. This might help alleviate a fear that community music therapy represents unsafe practice and would help inform the way it is addressed in training.

The third direction would be the application of critically reflexive music therapy research in more conventional settings where the support of the institution is important in establishing and maintaining healthy therapeutic practices. For

example, the use of untrained music therapy assistants occurs in practice, but the problems and benefits have not been researched in much detail. This inquiry provided plenty of detail about how an untrained assistant became more reflexive and a very useful connection between the two cultures. She was able to comprehend how participants made connections through music, with the guidance and modelling of a trained music therapist. Research is certainly needed in this area.

Another research option is the use of music as inquiry within organisational change. As music therapy practices diversify, and some music therapy practitioners become skilled at facilitating large groups using music, there is the opportunity to use music reflexively as part of an inquiry process.

Research of a cyclical nature assists practice. In many ways, a therapist developing their own increasingly reflective practice may follow a similar cyclical development. Using this metaphor it may be helpful to make comparisons between collective reflexive inquiry and group therapeutic process. Some of the theoretical influences on music therapy could also be of interest to participatory researchers in order to make sense of the dynamics of collective inquiry. Music helps us to explore relationship, whoever we are, and as such is one of the most inclusive forms of human social activity.

My current music therapy practice involves working with people who have severe mental health needs. The personal inquiry path that I have followed since the inception of the inquiry has radically changed the way I think about music, power, inclusion, bounded practice and ethics and this is most evident to me in this work. The issues of power and communication that Andrew and Christa raised in the first chapter initiated this process, and I hope that as a result, future users of

music therapy may have those questions answered in a more satisfactory and empowering way.

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Appendix 1

Definitions of music therapy

Music therapy is a process and form which combines the healing aspects of music with the issues of human need for the benefit of the individual and hence society. The music therapist serves as a resource person and guide, providing musical experiences which direct clients towards health and well being (Kenny 1982:7).

Music provides communication by activating different kinds of psychic phenomena and by bringing new material into the communication process...the individual is able to express and feel experiences which are non-verbal and non-discursive, such as bodily rhythms and unconscious and traumatic experiences which are anchored in the early childhood of the individual (Lehtonen 1993: 212).

Music therapy is the scientific application of music or music activities to attain therapeutic goals. Music therapy can also be defined as the structured use of music to bring about desired changes in behaviour (Carter 1982:5).

All three quotations are examples from a comprehensive collection of definitions of music therapy compiled by Kenneth Bruscia (1998: 265-277). I have chosen them to illustrate first the different ways in which music therapists have constructed their meaning, and secondly, how diverse the field of practice may be. Carter and Kenny are both writing in North America in the same year, but

there are many points of contrast between their definitions. Kenny's portrayal of the person in therapy is of one who receives guidance and wisdom, but in Carter's definition we might be forgiven for assuming that music therapy does not involve people at all. Implicit in the language are the values and theoretical positions which influence each writer. Lehtonen, representing Finnish music therapy, suggests the influence of Sigmund Freud and Melanie Klein with the mention of unconscious traumatic experiences stemming from early childhood. He manages to embrace a range of processes and experiences, and focuses on the experience of the individual in therapy. Carter's language hints at a struggle to legitimise music therapy in the contemporary terms which carry most power: the scientific method, behaviourism, and achievement of aims. Kenny addresses the impact of music therapy at a societal level rather than focusing on the individual, unlike Lehtonen.

So music therapy includes a variety of practices, influenced by different traditions and constrained by different value systems. There is no single definition, and even what I consider to be the most commonly agreed central feature, that of a relationship between people within music, seems to be missing in one of the definitions here. Recently, Kenny has attempted to move towards a unified theory of music therapy (Kenny 2003) but, as Stige points out (2002: 183) any such attempt is likely to be a focus for strong dissent (although not therefore a reason to refrain from the attempt). Dissent arises because the various discourses on music therapy, and indeed, on therapy itself, contain such wide divergences in values and worldview. From my point of view, this diversity is an argument for keeping music therapy research context-specific, self-reflexive and culturally informed. However, it is not just a matter of this. There are still deeper questions about how we deal with

difference, conflict and the deep feelings that disagreements between strongly held beliefs and values might arouse. It is not enough simply to acknowledge my own location, but I must also acknowledge my responsibilities in managing the conflicts that arise, bearing in mind that certain ways of thinking have more power and status than others.

Attachment theory

John Bowlby wrote extensively about the devastating effects an infant or young child of early separation on from his or her primary attachment figures, usually mother and father (1979, 1988). He identified three phases which the child goes through in reaction: *protest*, *despair* and *detachment*. In this last phase the child 'disinvests' in the lost person and attaches to another figure. Bowlby writes:

When the child finds himself in institutionalised places, where there is no specific alternative figure to which he can attach himself, the consequences are even more grave (Bowlby 1988).

If the child comes to believe that his communications are of no use, he develops 'defensive exclusion' and acts as though contact with humans has no significance for him. Bowlby believes that the aim of therapy in this case is to reconstruct the person's working models of himself and his attachment figures. The therapist provides a 'secure base' (Bowlby 1988) analogous to that provided by an ordinary mother.

Group research in the arts therapies

There is so little research material available in this area in music therapy that I found it helpful to look at examples from the other arts therapies. Two of these

inquiries have influenced aspects of the community home inquiry. One of the main themes of the analysis relates to the use of space, as with Rees's work (Rees 1995). When I made minute-to-minute observations of music therapy sessions using a videotape, I often slowed the tape to inquire into the detail of the action as Koch suggested (Koch 1996). Mair Rees followed an art therapy group for women with severe learning difficulties in a locked ward over two years (Rees 1995:117-137). Like Bunt and Oldfield she used ethological descriptive analysis, this time to observe the use of space and 'its potential symbolic significance'. Rees talks about the ward as a complex social system, and explores ideas about territories and dominance. In making sense of the meaning of her findings she is influenced by Gardner's theories of intelligence (Gardner 1985), which include musical and spatial notions of intelligence. Koch used microanalysis of videotape to inquire into the development of interaction in dance/movement therapy groups (Koch 1996). The findings were interesting: microanalysis opened up different layers of meaning. For example, in real time where the interpretation was that a disruptive member of the group left the group circle, a micro-analysis revealed that that the other members had used body postures to push him out.

Schmais and Diaz-Salazar tried a method of analysis which incorporated aspects of group behaviour, emotion, roles and norms, firmly situating their dance-movement research within a framework of cultural awareness¹² (Schmais and Diaz-Salazar 1998).

¹² It was difficult to access the unpublished details of this research, but this system of analysis warrants further investigation.

Appendix 2

Euphemisms for 'learning difficulties'

Gender, sexuality, mortality, religion, mental illness, handicap and race are the areas around which euphemisms have always clustered. These are the areas where wishes cannot change or put right differences (Sinason 1992: 42).

I note with interest the different euphemisms for 'learning difficulties' used over time and across societies: from *mental retardation* (which was still used by Nick Bouras in Britain in 1994), to *mental handicap*, *developmental disability* in North America and *learning disabilities*, the current official term in Britain. *Learning difficulties* is the term preferred by members of People First, the international self-advocacy organisation for people with learning difficulties. As I mentioned in the introduction, I have chosen to use this euphemism in the title as a way of emphasising that this inquiry attempts to place the views of the service user in the foreground. Valerie Sinason, previously an adult psychotherapist at the Tavistock Clinic in London, has devoted an entire chapter in *Mental Handicap and the Human Condition* (1992:39-54) to a fascinating exploration of how and why euphemisms of mental handicap and their meanings have changed over history. She and her colleagues continued to use the term mental handicap for a number of years after it fell out of professional usage.

The work of researchers at the Norah Fry Research Centre

These include the work of non-disabled researchers Linda Ward and Ken Simons (1998) who discuss strategies for involving people with learning difficulties, and Val

Williams (1999) and Jackie Rodgers (1999) who both facilitated inquiries which enabled people with learning difficulties to identify their own research questions and carry out the research tasks. Their work is characterised by a noticeable degree of reflexivity, and a high level of involvement of people with learning difficulties throughout the research process. The work also includes a review of examples of emancipatory work (Simons *et al* 1989).

Since the middle of the 1990s there has been a development in the range of participatory and emancipatory studies, most often reported in the *British Journal of Learning Disabilities*, such as Minkes *et al* (1995), March *et al* (1997), Rodgers (1999) and Williams (1999). Some studies are based on more traditional paradigms, but have still sought to include the views of service users (Rikburg-Smyly and Elsworth, 1997: 64- 67, Saunders *et al*, 1992).

Challenging behaviour

The provision of services for people with challenging behaviour

Valuing People identifies a number of aspects of service provision which need to be changed for people with behaviour which challenges. It was informed by the Mansell Report (HMSO 1993) which found that:

Even moderate levels of challenging behaviour are not being appropriately managed in mainstream learning disability services, and specialist services (including some of dubious quality) face apparently unlimited demand (Mansell Report 1993: 3).

The report identifies a number of circumstantial factors which influence challenging behaviour, such as a history of neglect and/or abuse, a reputation a person holds for past challenges, a restrictive home environment, carers not understanding the

meaning of the behaviour, over-emphasis on risk reduction, low expectations from carers, and the absence of verbal language. This range of factors reinforces the argument for an ecological approach. Other factors cited, such as epilepsy, sensory impairment, and physical illness acknowledge the part that physiology plays in this phenomenon. Those praised for good practice:

try to use information about *individual experience* as a primary organising force in their work (my italics).

The report was sympathetic to the difficulties carers faced, acknowledging that more progressive services could place higher demands on an already very difficult job. It proposed a charter for people with challenging behaviour or mental health needs which included the following clause:

Services will be delivered in the least restrictive manner capable of responding to individual needs.

One study evaluated the effects of relocation on people with severe learning disabilities and challenging behaviour and found that over three years, both communicative and challenging behaviours increased (McLeod *et al* 2002). The researchers explained this by saying that the people with learning difficulties were now being encouraged to increase their self-expression, activity levels and communications.

Ways of thinking about challenging behaviour

Emerson talked primarily about theories of behaviour and neurobiological models to explain how and why challenging behaviour began and continued to flourish. He recognised that children with normal development showed similar behaviours, such as head banging, at certain developmental stages (Emerson 1995:60). Murphy

(1994) isolated biological, behavioural and ecological factors as the three main aspects of challenging behaviour. Kushlik asked why carers had not been encouraged to use cognitive-behavioural approaches with people with good verbal skills (Kushlik *et al* 1997), advocating the *constructional* approach (Goldiamond 1974).

The constructional approach

An example of this is a carer responding to a communication of 'no' from a resident: 'Thank you for saying 'no' and I'll come back soon and ask again.' This is supposed to protect the carer from feeling rejected, yet it seems to me that there is a danger of encouraging the carer not to hear or accept the genuine communication, or, in fact, be genuine himself or herself. This is one fundamental criticism I have of behaviourism: it seeks to cure the symptom rather than the cause. *Valuing People* mentions only 'modern behavioural approaches' (2001: 103) as offering an effective option other than medication for helping people manage their challenging behaviour. However, it does acknowledge that 'challenging behaviours are best thought of as being a way in which people respond and try to gain control over difficult situations' (page 103).

An alternative approach is to tackle challenging behaviour in terms of understanding it as communication. One book with a fundamentally humanistic approach looks at communication-based approaches in order to help people develop their communicative range. The emphasis is on high staff input and 'rapport-building' (Carr *et al* 1994). Another communication-based approach developed at Harperbury Hospital was *intensive interaction* (Hewitt and Nind 1996) where workers use behaviour similar to that of the person with learning difficulties in an attempt to build up mutual communication, and pay careful attention to

the timing and intensity of their responses. This approach has been informed by and has had an influence on some music therapy practice, as the authors worked with the music therapist Tony Wigram.

If challenging behaviour is thought of as a form of communication, then there are instances where the message is disturbing. In *Learning to Listen* (Lovett 1996) a man with severe learning difficulties continually broke his own legs by throwing himself on the floor. Because he had been institutionalised from infancy the suggestion was that he experienced physical care and intimacy from his carers only when this happened. The man's legs were eventually amputated purely to prevent the behaviour. Lovett uses this as an example of a situation in which the underlying cause of the behaviour is ignored. Even without extreme examples such as these, it is not surprising that institutionalised people have low expectations of others. In *Slings and Arrows*, another man who had survived institutional life, and was now living independently, wrote about his history, saying:

It's lovely that people show an interest in my life (Baron 1989: 25).

It seems this was not something that he expected.

Appendix 3

The paradigmatic frame of action research approaches

The paradigmatic frame of a research approach is determined by the underpinning philosophy of the theories of being or reality (ontology) and the theories of knowledge (epistemology). The ontology of all action research, according to Reason is essentially that of relativism (Reason 1994: 332). This is similar to the ontological basis of constructivism, where Guba defines relativist ontology thus:

Realities which exist in the form of multiple mental constructions, socially and experimentally based, local and specific, dependent for their form and content on the persons who hold them (Guba 1990: 27).

In contrast, Freire articulates action research ontology by saying:

Reality consists not only of concrete facts and (physical) things, but also includes the ways in which the people involved with the facts perceive them.

Therefore:

Concrete reality is the connection between subjectivity and objectivity (Freire 1982: 30).

So PAR owes much to constructivism but also emphasises that concrete facts exist. Between Freire and Reason there seem to be some difficulties in establishing quite what the ontology of PAR might be.

Is the music therapy profession ready for action research approaches?

Until recently, the quantitative/qualitative divide had dominated music therapy research. It had been argued that quantitative research had not been of much value to the holistic music therapy practitioner, and qualitative and quantitative approaches were philosophically incompatible because they are based on different ontological foundations (Amir 1993; Aigen 1995). Since then the debate has moved away from the quantitative/qualitative dichotomy to consider a wider range of paradigmatic frames (Bruscia 1998b, Edwards 1999). Edwards in particular emphasised the paradigmatic scope that the social sciences offer, including critical theory and types of action research.

The nature of the ontological and epistemological basis of the approach determines which paradigm the approach belongs to. The ontology and epistemology of participatory action research approaches are influenced by, but differ from, constructivism, which has been influential in some qualitative music therapy research.

Preserving the role of the music therapist

At first glance, it would seem problematic to use participatory action research within a therapeutic context. Grainger, in a chapter devoted to participatory approaches within arts therapy research, discusses the difficulties in preserving a therapeutic role relationship within a system which aims to 'disarm the experimenter-subject relationship' (Grainger 1999: 101). He finds it unfortunate that these relationships have to be preserved, but maintains that it is to allow the social context to exist 'and be recognisable to itself'. Grainger identifies a fundamental agenda in arts

therapies research, which is to justify the use of the arts therapies. Within healthcare settings, arts therapies professions are in a tiny minority, and are more vulnerable than the medical or nursing professions.

Smeijsters finds that collaboration with a client may cause them problems. He writes:

In some cases, the client may feel confronted, disturbed, or confused by team members' reports and member checking¹³ can disturb the therapeutic relationship (Smeijsters 1997: 153).

Bruscia articulates distinctions between research and practice in a way which leaves little space for PAR approaches (1998b: 241). For him the goals of research are to improve the knowledge base of the profession, whereas clinical work aims to help clients towards improved health. The knowledge generated in research is for generalized application and is primarily used by clinicians, but in clinical work the knowledge is for the benefit of the client and generally remains confidential. By implication, there is no place for context-specific knowledge generation in research. The prime beneficiary of research is the music therapist who benefits from the client; conversely the client benefits in clinical practice.

Smeijsters describes his own action research method in the chapter 'researchers as co-actors' (Smeijsters 1997) but the perspective of the child-client was not included in the research process and the power relationships between the co-researchers were not addressed.

These examples seem to demonstrate that reflexively inquiring into the role of a music therapist with the client might be difficult or dangerous. The client may

¹³ The process of reading and critiquing research interpretations by other research participants, first described by Lincoln and Guba in 1985

be compromised, and also the therapy profession, if the role of the therapist is relaxed too much. However, a number of therapists seem to have been able either to preserve or to rethink boundaries in relation to therapy. For example, in chapter two I introduced the work of Lee, Hoskyns and Rogers who were all influenced by New Paradigm thinking. These researchers have different theoretical orientations, so it is not the case that the research design was dependent on the values they held within their practice. Rather, the researchers were committed to working collaboratively with vulnerable people.

Ecological and systemic practices

There has been a recent move to introduce community approaches within music therapy, and to introduce systemic thinking. Even Ruud emphasised the connection between the individual and community by saying:

I think that a system approach to music therapy may help us plan out music therapy interventions so that behaviour changes are maintained through changes in the whole system surrounding the client (Ruud 1998: 26-7).

Ruud credits the origins of an ecological approach in music therapy research to *The Field of Play* (Kenny 1989), where Kenny applied Lewin's field theory (Lewin 1951). Bruscia makes a distinction between traditional group work and ecological practices (Bruscia 1998b). In group work, the individuals within the group are the recipients of the change, whereas in ecological systems the entire system is the recipient and members are parts of that community. One example of ecological music therapy is Aasgaard's work within a hospital for children with cancer. Every week he would organise a band in which patients, parents, doctors and nurses were able to make music (Aasgaard 1999).

The notion of Community Music Therapy introduced and developed by Stige and Ansdell directly challenges the boundaries of the traditional role of the music therapist and considers various ways of working with the wider community context. PAR approaches have been used in other arts therapies. For example, in dance/movement therapy one project involved the use of pictures and videos to help inform participants about the process of the research and encourage dialogue about this. Clients participated at the stages of design, data collection and analysis of the findings, and used the cyclical process to explore roles, particularly the role of therapist (Meekums and Payne 1993).

Single and double loop learning

In Action Science participants within an organisation confront the assumptions and frameworks within which they are fixed and attempt to reframe their thinking. This indicates a move from 'single loop' learning to 'double loop' learning (Argyris and Schon 1974). Double-loop learning shows that the participant is able to rethink the main strategies which lie behind their actions. Thus a participant moves from 'defensive thinking' to 'open inquiry'. Defensive theories include such elements as defining one's own purpose without reflection, attempting this in a competitive spirit, suppressing negative feelings and emphasising rationality. Open inquiry is characterised by valid information, free and informed choice and internal commitment.

Nikula, writing about healthcare systems in Denmark, argued that although he believed double loop learning was well established amongst healthcare professionals, this reflection was confined to their own practice and rarely applied to organisational or management issues. He explained that:

Where hierarchical and horizontal divisions are particularly strong, information and knowledge rarely flow in a free manner (Nikula 1999: 65).

Bracketing

This is a concept from phenomenology. Husserl (1970) presents two 'epoches' of the phenomenological method. Epoche 1 is becoming aware of our own assumptions and perceptions and bracketing them off allowing more of an encounter with the world being researched. (Hawkins 1988: 61). Epoche 2 involves bracketing the 'whatness' of the data and starting to look at 'how the data has come into being in one's own consciousness'. We need to be able to see ourselves as part of the field that we are now experiencing in the research.

First, second and third person dimensions of inquiry

First person inquiry

The first person aspect of an inquiry involves the researcher in fostering an inquiring attitude to his or her life. The inquiry may bring about heightened and critical awareness of issues such as the cultural values we hold and how life experiences have shaped the patterns of our responses to situations. Reason calls this *critical subjectivity* (Reason 1994: 327). He believes that it is important not to suppress this knowledge or knowing, and to be prepared and able to articulate our own perspective within communications with others during the inquiry. Reason and Torbert suggest that processes such as creative expression through the arts, psychotherapy or autobiographical writing can stimulate 'upstream' first person inquiry, and that 'downstream' first-person inquiry can be developed in self-

reflexive forms such as keeping a research journal or observing oneself on video (Reason and Torbert 2001: 11).

Second person inquiry

This is the practice of inquiring with others. Obvious examples are the processes that take place within a co-operative inquiry, and I examine this in more detail in chapter seven. Some writers have conceptualised second person inquiry in terms of friendship (Torbert 1981; Reason and Marshall 1997), but it may take any form when two or more people inquire together.

Third person inquiry

Third person dimensions move the inquiry process outwards so that larger communities are involved. Here participants may not all meet face to face. The essential nature of this is that inquiry processes continue in a similar mode to the first-person and second-person dimensions rather than being simply findings disseminated by publishing papers or presenting them at conferences. The extent of this dimension may be considerable, such as influencing government policy (Reason and Torbert 2001: 15). The idea that all three types of inquiry are linked seems important, thus third person inquiry should stimulate, encourage and make possible the transfer of first person and second person inquiry skills to a wider community.

A critique of participatory action research approaches

Although Yvonna Lincoln sees similarities between action research and social constructivism, she is concerned that underpinning participatory action research is an assumption that the values and goals of the researcher become the *same* as

those of the participants, because initiating researchers are required to be researchers in an egalitarian way (2001: 126).

Constructivists are generally unhappy with the idea of *j'accuse* as a preliminary to getting down to the business of social change. It sets up a context of moral judgement unuseful to open inquiry frames (Lincoln 2001: 129).

Hammersley (1992: 147-8) makes a similar point in relation to practitioner ethnography. He says the interpretation of reflexivity as a concept could be used as a way of importing values into research, such as a simplistic Marxist view of what amounts to emancipation. He is concerned that there is a certain amount of naïve realism when researchers use the word 'emancipation': emancipation, he says, cannot be brought about by research. However, I believe that reflexivity is much more about being open to a change of values than about importing them.

Appendix 4

The Declaration of Helsinki

The World Medical Association Declaration of Helsinki binds doctors and other healthcare professionals to an internationally agreed code of ethical practice. This was adopted by the WMA General Assembly in 1964 and has subsequently been revised six times. The Declaration states that any protocol involving human subjects should be submitted for ethical review to research committees in the home country (paragraph 13), hence the existence of the local research ethics committees (Declaration of Helsinki 2002).

Paragraph 8 reads:

Some research populations are vulnerable and need special protection...Special attention is also required for those who cannot give or refuse consent for themselves, for those who may be subject to giving consent under duress...and for those for whom the research is combined with care.

Emotional Risk

The Declaration clearly states what should be communicated to participants:

Each subject must be informed of anticipated benefits and potential risks of the study and the discomfort it may entail. (Paragraph 22)

Conflicts of Interest

If a subject is in a 'dependent relationship' with a physician then a 'completely independent' physician should be the one to obtain consent (Paragraph 24).

The term 'music therapist' could be substituted for 'physician' for the Declaration to apply in the case of Nick and myself within the music therapy inquiry.

Proxy assent

The Declaration states:

When a subject deemed legally incompetent...is able to give assent to decisions about participation in research, the investigator must obtain that assent in addition to the consent of the legally authorized representative (Paragraph 25).

However, according to British Law, no one can give consent to medical treatment on behalf of another adult (Turner *et al* 1999). It is considered good practice to involve family or carers in medical decisions but they can only give *assent*.

Crossan and McColgan (1999) are right to point out that proxy assent is likely on many occasions to be disempowering to the person concerned. In the case of informed consent being impossible, the doctor is required to act 'in the best interests of the patient' and that decision may be reached with or without consulting the family.

Therefore, the incapacitated adult is possibly at the mercy of both the healthcare professional and family members, all of whom may have different agendas.

Ethical thinking within the discipline of music therapy

Surprisingly little has been written about ethical research issues within the international music therapy community. One exception is Cheryl Dileo Maranto's detailed contribution in *Music Therapy Research: Quantitative and Qualitative Perspectives* (Wheeler 1985), where she emphasises the need for researchers to develop *ethical thinking* (her italics) in order to address the unique demands of

each inquiry and to protect vulnerable 'subjects'. In the context of action research I think this argument must be extended: the ethical thinking of *all* participants must be encouraged to develop during the course of the inquiry. Music therapists working in the UK abide by the code of ethics set down by the Association of Professional Music Therapists and also the Health Professions Council. These form the ethical basis of clinical practice, but not clinical research. The government guidelines on research governance (2001) provide ethical foundations for healthcare research and these aim to be consistent with the most updated form of the Declaration of Helsinki (see Appendix 4). This Declaration was originally developed in response to the experiences of the Nuremberg Trials of where there were revelations of extreme violations of human rights and medical ethics. The spirit of the Declaration and, by implication, of all the related sets of ethical guidelines which followed it, was designed to reduce or limit the power of the healthcare worker over the service user, by ensuring a very specific and internationally agreed accountability.

Ethical guidelines of the British Sociological Association (BSA 1995) and the British Psychological Society (BPS 1993).

Both sets of guidelines are broadly compatible with each other and very similar, although with slightly different language and emphases. Both use the word 'participant' throughout rather than 'subject'. The Sociological Society gives more emphasis to the right of the participant to refuse participation with a wider description of what forms refusal to consent might take. Both guidelines accept that the giving of consent may be needed more than once in longitudinal research, and the BSA describes the giving of consent in some circumstances as 'a process,

subject to negotiation over time'. The Psychological Society enters the realm of behaviour as non-verbal communication. It states that 'when testing children, avoidance of the testing situation may be taken as evidence of failure to consent to the procedure and should be acknowledged'. By implication, this could be applied to people with learning disabilities as well. Both sets of guidelines agree with the most recent update of the Declaration of Helsinki by saying 'where possible, the real consent of children and of adults with impairments of understanding or communication should be obtained' (BPS), although there are no suggestions about how this may be achieved.

Informed consent

There are three widely accepted elements in the process of gaining informed consent (Berghmans and Ter Meulen, 1995, Bartlett and Martin, 2000). These are:

- 1) The person must be *fully informed*;
- 2) Consent is *freely* given (Maranto calls this 'voluntariness'); and
- 3) The person is *competent* or has *capacity* to make the decision.

How *capacity* is determined

Wong *et al* (1999) identify three broad approaches to determining capacity: the outcome, status and functional approaches. The outcome approach has been discredited in law (Kennedy and Grubb 1994), as the implication is that a person does not have capacity if he or she makes a decision which goes against conventional wisdom. The status approach has been discredited in law (Mental Health Acts 1983 and 2001) and also in empirical research (Marson *et al* 1993) and implies that all people with similar status such as being 'learning disabled' lack

capacity. Wong and colleagues argue that this approach makes the assumption that all learning disabled people are alike in their decision-making capacity, and also that all decisions are equally difficult to make, which is clearly not the case.

According to the Law Commission Reports, capacity to make a decision depends primarily on the nature of the decision taken, and the particular circumstances of the person taking the decision at a particular time (Law Commission 1991,1995). Therefore a global description of capacity cannot be given and each decision must be considered on its own merits.

Anonymity

In a study about children with cancer (Grinyer 2002) parents were asked whether they preferred to choose a pseudonym or for their child's real name to be used in any publications related to the study. In some cases, parents felt that protecting the identity of their children resulted in loss of ownership of the project. One mother changed her mind after reading the first article published which used a pseudonym for her son. However, some of the children in the study had died before publication, so issues of loss may have influenced parents' decisions about whether to use the child's real name. In our inquiry, reversals and substantial changes in ethical thinking occurred in the course of this inquiry as a result of bereavement (described in chapter thirteen). Grinyer concluded that researchers should not make assumptions about a participant's preference for anonymity.

Appendix 5

Documents prepared for the local research ethics committee

RESEARCH PROTOCOL

Music therapy with adults with learning difficulties: an inquiry into the benefits of group therapy within a community home

PRIMARY RESEARCH QUESTION

How do participants in the project experience the process of music therapy over the course of a year?

SECONDARY QUESTIONS

In which ways, if any, can people with learning difficulties and behaviour which challenges the service be involved in influencing the direction and nature of the research within an action research design?

What can be learned from the data collected when group members view videos of the therapy sessions?

Definition of terms:

Participants refers to all people actively involved in the research.

Group members refers to all people actively involved in the therapy sessions (i.e. therapist, PWLD, support workers).

Research worker refers to the Principal Investigator.

INTRODUCTION

This is a project which will primarily employ qualitative research methods, and so does not have a hypothesis which needs to be tested. The research questions above will be central to the focus of the inquiry in place of a hypothesis. There are no predictions for outcome at the beginning of the study, although outcomes will be identified during the process and at the end.

BACKGROUND

Target Population

The target population for the project will be adults with moderate or severe learning disabilities who have:

- a) a background of institutional care,
- b) have been resettled in 'the community',
- c) display behaviours described as 'challenging the service'.

The concept of the project originated from the research worker's experience as a senior clinician in music therapy, where her caseload consisted primarily of this population. Often referrals were made when a resident in a community home was demonstrating such severe behaviour difficulties that he or she was in danger of being moved to another unit. In the new unit the same pattern of behaviour could be repeated. This scenario results in a population of people whose placements continue to fail. This researcher views group music therapy within the community home as:

- a) a possible means of preventing relationships within group homes deteriorating to such an extent.
- b) A way of changing unhelpful patterns of behaviour.

The project aims to take into account the system of relationships within the

home, thereby building a detailed and comprehensive picture of how this therapeutic intervention may be effective.

Scientific background

From a literature review, it has been established that music therapy research has not yet specifically targeted the population described above, either in Europe or in the USA. There have been several projects which have studied the effects of music therapy with child and adult individuals with learning disabilities, notably Bunt (1986), Oldfield (1987) and Lawes & Woodcock (1995). These have utilised primarily quantitative methodologies and have shown a range of findings. These studies have not investigated group therapy but rather therapy in a one-to-one setting. Oldfield and Woodcock have not taken into account the effects of staff/carer support or learning from the impacts of the intervention, which may be significant in supporting the success of the therapy or otherwise.

There are few pieces of research which investigate group processes in music therapy: Aigen details a year's music therapy with four autistic adolescents. Although the project is a qualitative study, the views of the researcher are dominant and the perspectives of other participants marginalized. He also uses personal construct theory. Skewes (2000, unpublished) is working on the development of a theory of group music therapy processes, based on interviews with music therapists.

In the other arts therapies, group therapy research is more established (Gilroy 1993, Schmais 1997). The use of microanalysis of video data has been investigated (Johnson & Sandel 1977).

There is one published action research project involving music therapy.

Smeijsters (1997) used this design when researching family therapy, with positive outcomes in terms of improved family dynamics, and the development of skills for the music therapist. In this case, the researcher was not also the music therapist. Another example of collaborative inquiry is a music therapy project with sexual abuse survivors (Rogers, 1992).

Research which incorporates the views of people with learning difficulties (PWLD) has developed in the last decade (Zarb 1992, Chappell 2000). The attendant difficulties are well documented (Williams,1999, Kiernan 1999). The involvement of PWLD in the research process is welcomed within the community of people with learning difficulties (Simons 1998), and participative inquiry methods which seek to elicit user views are encouraged by recent government publications (NHS Executive 1999).

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PROJECT DESIGN

The project is based upon New Paradigm research design (Reason and Rowan 1981). This is characterised by:

- a) the involvement of all participants as co-researchers,
- b) use of a research cycle.

At the end of each research cycle, the participants will meet in a co-operative inquiry team to evaluate findings, discuss changes to be implemented and any change of emphasis of the project. Therefore, at the end of each cycle, there may need to be a resubmission to the LREC sub-committee to consider any changes to the methodologies used or details of the research process. Rowan states that any action research proposal should make clear the aims and objectives of the first phase of the project, and a description of when and on what basis future objectives will be generated.

Aim of the first phase

To agree a research process mechanism and to begin to collect data as the therapy starts.

Objectives of first phase

To establish the membership of the co-operative inquiry team

It is proposed to involve the research worker, music therapist, two staff from home, home manager, daycare worker and representatives of residents and/or advocates.

To establish the frequency of meeting

It is proposed that this will take place every 6 weeks.

To establish the method of representing the residents' views

It is proposed that each member will be allocated a keyworker/advocate for the research. The resident may choose this person. A speech and language therapist from the local Community Learning Disability team will advise on choice making and communication issues.

To establish what participants understand by research and identify realistic expectations

To establish what different team members wish to find from the research

To establish the methods by which these can be achieved

To establish the methods of data collection

To establish the roles participants will take in relation to the data collection, and evaluation

To set up a mechanism by which all objectives may be reviewed at the end of each cycle

To outline clearly the stages of problem identification, information gathering, reflection, planning, action and evaluation within the first phase.

To begin to critically examine values, beliefs and power relationships within group

Participant roles

Because of the research design, roles are subject to further negotiation, but are envisaged as likely to take the following shape:

The role of the resident in the research will be to attend the therapy group if he wishes, and to attend interviews and communicate his views about his experiences to others who will record these communications. Interpretations of

these views will be acknowledged and incorporated into the planning and delivery of the research. Although in action research design it is important to consider the residents as 'co-researchers', it must be acknowledged their mode of participation will be limited as a result of difficulties in communication, comprehension and lack of self-confidence. The research will focus on how their participation is able to change throughout the project. **The wishes expressed through the communications of the residents will be placed in the centre of any decision-making by the collaborative inquiry group.**

The role of the research worker will be to convene the collaborative inquiry group, to act as advisor in matters of methodology and planning, to record and transcribe the meetings, to co-ordinate data collection, to make data available to participants in accessible form, and to ensure that participants understand and follow appropriate guidelines in relation to confidentiality of data.

The role of the music therapist will be to conduct the therapy sessions in keeping with his normal code of practice, dictated by therapeutic considerations. In this way, the study could be said to be naturalistic. In addition, the music therapist will offer his perspective on the collaborative inquiry team.

The role of the daycare worker will be to assist in the group sessions where appropriate, as negotiated by the music therapist, to support residents in interviews if necessary and to offer his perspective on the collaborative inquiry team.

The role of the home staff will be to represent the views of the staff team on the collaborative inquiry team, to assist in the therapy group if needed, to support residents during interviews if needed, and to assist in the collection of data.

The role of the home manager may be to support the views of the residents on the collaborative inquiry team, or she may support the staff team. In either case, her role will need to be clearly defined and consistent.

Selection of participants from target population

Candidates for this study will all need to live in the same home, and must have identified therapeutic needs that may be addressed by group music therapy.

These needs may include:

- difficulties in relating to other members of the group
- emotional and behavioural problems
- difficulty in adapting to change
- institutionalised behaviours
- severe communication difficulties
- low self-esteem
- lack of awareness of others
- difficulty in taking turns or sharing

As no music therapy group will accommodate more than 5 people with behaviour that challenges, this is the group limit. The process for identifying such a residential group will follow various stages:

Stage One: Contact with local Care Trusts to identify potential collaborators.

Stage Two: Identification of potential residential homes by residential manager and daycare manager of the trust.

Stage Three: Home manager approached.

Stage Four: Research worker visits home to check that participants meet therapeutic criteria, and resources are adequate for therapy to take place.

DATA COLLECTION METHODS

Videotape

After appropriate consent and assent has been secured, group members will operate a video camera and record every weekly music therapy session (45 minutes). These videos will be watched by each group member weekly with the lead researcher, and critical points in the therapy identified by each group member, using a switch, or by significant behavioural response which will be defined by the researcher (e.g. looking, vocalising, singing, pointing, facial expression).

Interviews

Each verbal participant will be interviewed qualitatively by the lead researcher. These interviews will take place weekly for group members (therapist and assistants), and participants will also watch the videotapes. Participants who are not group members (e.g. home manager) will be interviewed every three months, and will not have access to the videotapes. The interviews will be recorded on mini-disc, transcribed by the research worker, and will be subject to content analysis.

There is a possibility that participants other than the research worker may conduct interviews; if this is the case, there will be a re-submission to the ethics subcommittee.

EXCLUSION CRITERIA

- Anyone who is unable to indicate refusal
- People with visual impairments because of the use of video/photographs
- People unable to comprehend the notion of choice (yes/no)

Refusers

Refusal will be accepted without any reason being given. The fact that a potential participant declined to take part will be recorded and when, but anonymity will be kept.

If a participant wishes to be involved in the therapy, but not the research project, they can be placed in the room in such a way that they will not be recorded on videotape.

OUTCOME MEASURES

At this stage of the research, it is not possible to predict how outcome measures will be presented. It is possible to predict that there will be outcome measures, in the form of the findings of the collaborative inquiry group following each research cycle. These findings will be presented in writing. Any resultant changes in the practice of the therapy or the research will also be documented in the form of an interim report. Final outcomes will be identified by the collaborative inquiry group and presented in the form of a final report which will include recommendations for changes in practice and policy.

Dissemination will take various forms, including

- Presentations to other community home staff teams within the trust
- Group members showing personal findings to chosen family or friends
- Presentation at Norah Fry research seminars for people with learning disabilities
- Papers published in learning disability journals outlining the process and generalisable outcomes of the research
- Publication in *British Music Therapy Journal* regarding action research design in relation to group music therapy.

For all dissemination, agreement needs to be reached by the collaborative inquiry team as to how findings are disseminated, and what material is to be discussed.

Conduct

All participants will be expected to respect confidentiality. The issues regarding confidentiality of the therapy and anonymity will be explained to each participant by the research worker.

TIMETABLE

The therapy will take place weekly over a period of one year. Some sessions will be missed because of annual leave of the therapist, illness, etc. It may be that the therapy group wishes to continue the therapy beyond this period, but at this point, data will not be collected in relation to the research.

After ethical approval is granted:

Discussions surrounding membership of the co-operative inquiry team will begin, therapy referral made, assent and consent forms sent.

Within 4 weeks:

Collaborative inquiry team meets. Resident individual research packs including photographs are made.

Therapy begins, following negotiation concerning practicalities. The aim is to begin therapy in February, although ideally January 2001.

The collaborative inquiry team (CIT) will meet every six weeks initially.

Evaluation of findings to complete the research cycle will occur in each meeting, which means that there may be up to nine research cycles completed during the year.

By December 2001 the data will have been collected. Further meetings may be

decided upon by the CIT, for discussions and preparation for dissemination. It is envisaged that the lead researcher will withdraw by the end of 2001 for writing up of her PhD thesis. The collaborative inquiry team will need to determine the endpoint, which could be immediately after the data has been collected, or the inquiry may continue for longer.

Time commitments

Participants will be expected to allocate up to two hours per week for the research. In the case of staff, this will take part during the normal working day or shift. For residents, it will take place at the same time each week so that it can be consistent and predictable.

SAMPLE SIZE AND STATISTICAL METHODS

This is confined to one community home and music therapist because of the amount of data generated over the period of a year. Recorded data will be transcribed into words and musical notation. Analysis of the data will use qualitative methods such as analytic memos and content analysis, so will be coded rather than quantified. If any participant wishes to look for findings requiring statistical analysis, for example, if the music therapist wishes to measure the reduction of particular behaviours, then there will be a resubmission of the change to the ethics sub-committees.

Participants who leave the project before completion will not put the research findings at risk. Instead the impact on participants of a group member leaving, for example, will generate more data. Participants who leave the study will be not be pressurised to rejoin, or explain why they have left.

RESEARCH AND POLICY IMPLICATIONS OF POSSIBLE FINDINGS

Findings are likely to have an impact on the following areas:

- Clinical practice for the music therapist involved
- Suggestions for ways in which the collaborating trust may be able to incorporate the users' views in terms of policy-making
- The success of a home-based collaborative inquiry team
- Whether participate research is conducted again within the trust
- The way future participate research is conducted within the trust
- Staff education, training needs and expectations
- Possibility of new initiatives resulting from staff empowerment and learning
- Action research design may be taken up by other arts therapists

Results may be disseminated to:

- Relatives and carers
- Other staff teams within the trust
- Day Services
- Management within the trust
- Other residents of community homes
- Learning disability self-advocacy groups e.g. People First
- Community Learning Disability services
- Primary Care Trusts including GP services
- Local Health Authority
- Learning disability journals

Dissemination may be in the form of presentations by members of the collaborative inquiry team, and in the case of journals, papers written by members of the team, or by the research worker in consultation with the team.

A report of the findings written by the lead researcher in consultation with the team will be made available to the collaborating trust, the University of the

West of England, Bath and Weston LRECs, Avon Health Authority and other appropriate bodies.

Catherine Durham

November 2000

TAKING PART IN RESEARCH

INFORMATION SHEET FOR RELATIVES OR CARERS

Study Title

ACTION RESEARCH WITH A MUSIC THERAPY GROUP

..... is being invited to take part in a research project. Here is some information to help you decide whether or not he could take part. Please take time to read the following information carefully. Discuss it with friends, relatives or your GP if you wish. Ask us if there is anything you do not understand or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

What is the purpose of the study?

The purpose is to find out what people with learning disabilities think and feel about group music therapy. Staff in their home and the music therapist will also be asked about their thoughts and feelings. Five men in the home will be able to attend a weekly music therapy session together. Each session will take 50 minutes maximum.

Why has been chosen?

..... has been chosen because he has been identified by staff as likely to benefit from music therapy. This is because in music therapy he does not need to use words to express himself. Also, the number of residents in the community home is small. This means that all the men can take part. No-one has to be left out

of the group.

Who is organising the study?

It is being organised by a researcher at the University of the West of England. She is also a music therapist. Staff at the home are also involved in some of the organising. The researcher is being paid by the Music Therapy Charity to do this study.

What will happen if takes part?

..... will be offered 45 minutes a week of music therapy. The other residents in the home may also be in the group. The group will be videotaped every week. This is to help to remember what happened. will be asked to watch the video with the researcher after the session. He can refuse at any stage. If he shows a reaction to the video, it will be written down by the researcher. This will happen every week for a year. will be given his own copy of the tape to keep. When he watches the tape, he can have a helper with him if he wants. If he is distressed by the tape, we will turn it off. He will have a series of photographs explaining what is happening. The tape will be kept in his locked cupboard.

What is music therapy?

It is where a people are offered a variety of instruments to play. The music therapist plays music with the person to encourage him. The music therapist listens hard to the person's music or singing. The person does not have to play if he does not want to.

Are there any disadvantages to taking part in this study?

Sometimes people in music therapy can become upset because they become more aware of their feelings. The therapist is trained to deal with this. The person may also get upset by seeing himself on video. If this happens, the video will be

turned off immediately. However, there may also be advantages, and the person may enjoy the sessions.

What are the possible risks of taking part?

There may be risks of harm from other group members. These risks are likely to be the same as at any other time in the house.

What are the possible benefits in taking part?

We hope that will improve in self-confidence, communication and concentration by taking part. However, we cannot be sure of this. By doing this study we hope to find out more about music therapy.

What happens when the research stops?

The music group might continue if the group members want it to. There will not be any more videotapes made. Only people on the videotapes will be allowed to see the tapes.

Are there any restrictions on what should do?

No, there are not.

What happens if something goes wrong?

You can contact the researcher, Cathy Durham, and complain. If you are not satisfied, you can contact Gill Hek, Director of Research at the University of the West of England (tel.no.:).

Confidentiality – who will know is taking part in the study?

All information collected about will remain strictly confidential. Any information about which leaves the community home will be made anonymous so that you cannot recognise it.

GP notification

.....'s GP will be told is taking part in this study.

Which ethics committee gave you permission to start this study?

Bath Local Research Ethics Committee and Weston Local Research Ethics Committee.

What will happen to the results of the study?

..... will be told during the study and afterwards what we have found. Staff and the researcher will do this in the way that he is most likely to understand. A copy of any published results of the study will be kept at the home by the home manager. **At no time will any of this research be available on the Internet.**

The research worker, **Cathy Durham, University of the West of England, (0117 344 4401)** will contact you in a few days. She can answer any questions and you can let her know if can take part.

THANK YOU FOR CONSIDERING THIS PROJECT.

ASSENT FORM

FOR TAKING PART IN RESEARCH

TO BE SIGNED BY A RELATIVE OR CARER

I have read the information sheet. I fully understand what may happen if (person's name) takes part in this project.

I understand that I may withdraw my permission at any time. I understand that I do not need to give a reason for this.

I do/do not* give permission for (person's name) to take part in the research.

Signature..... Date.....

Relationship to person (e.g.next-of-kin/carer).....

I do/do not* give permission for videotapes of (person's name) to be made during the music therapy sessions. I understand that these will be kept confidential.

Signature.....Date.....

Relationship to person.....

*please cross out where necessary

A PHOTOCOPY OF THIS FORM WILL BE SENT TO YOU AFTER WE RECEIVE IT

Please return to: **Cathy Durham, University of the West of England, Faculty of Health and Social Care, CRASH, Glenside Campus, Blackberry Hill, Stapleton, Bristol BS16 1DD**

MUSIC THERAPY RESEARCH PROJECT

INFORMATION SHEET FOR STAFF

Introduction

This is a project that is only taking place in community home. It is a joint project between the Brandon Trust and the University of the West of England (UWE). The project is funded by the Music Therapy Charity.

What is the study for?

It is to investigate the impact of a year of music therapy at the home. Resident and staff views will be valued. The project is a type of 'action' research. This means that all those involved are co-researchers. All staff who want to be involved can have a say in the following areas:

- What will be researched
- What role you have in the research
- How the research will be carried out
- Who can and can't look at the evidence
- What will be anonymous and private in the research
- How the research will be publicised afterwards

Do I have to take part?

No, taking part is voluntary. You can leave the project at any time. The

project needs a few home staff to be quite involved, and come to a meeting every six weeks. At the meeting we will look at the findings so far, decide whether we want to continue in the same way, or whether we need to change the way we are researching.

Other staff might not be very involved, but if there is anything they want to say about the research there will be a research diary that they can write in. For example, someone might notice that after every music therapy session, one resident is particularly lively, or anxious, and they might want to write that down in the diary.

Do I have to know about research?

No, you don't. Cathy, the research worker, will help guide the research group. This is a good time to learn some new skills. You may be surprised how much you can contribute.

What kind of things might I end up doing?

You might have a recorded interview with Cathy about what you think of the music therapy. This will be anonymous. If you are unhappy about what you said later, you can ask for the recording to be wiped clean.

You might support some of the men when they meet Cathy. The music therapy sessions will be filmed on video. The men might want to watch this, and we can observe how they respond.

Do I have to be on video?

No, unless you are in the music therapy session at any point. This is the only place where video will be used. *Video will also only be used if assent is given for each man to be filmed.*

If you have any questions about this, you can ask Cathy when she is at the home, or you can ring her on 0117 344 4401 between 9am and 5pm.

The music therapist's name is Nick. He will be in the home for the music therapy session every Thursday morning.

Thank you for reading this. Take some time to think about whether you want to be involved, and in what way.

RESEARCH CONSENT FORM

I have read the information sheet and understand what the research will entail.

Signed.....Date.....

Role in research.....

I give consent to be recorded on mini-disc for any interview I give.

Signed.....Date.....

I give consent for a video recording to be made of me if I am in a music therapy session.

Signed.....Date.....

I understand that any research materials are confidential and not available to anyone outside the home.

Signed.....Date.....

Notes on the participant information resource

This resource will consist of a series of photographs of each participant taken by digital camera. This replaces the patient information sheet for those participants with learning difficulties. The photographs will illustrate the following stages which require consent:

- ◆ You can play music with Nick
- ◆ There will be a video camera in the room
- ◆ Shall we turn on the camera?
- ◆ You can turn off the camera
- ◆ You can take the tape out of the camera
- ◆ You can put the tape into the TV
- ◆ You can watch yourself on TV
- ◆ The tape belongs to you and
- ◆ The tape can be kept safe
- ◆ Who can look at the tape?
- ◆ Can ... look at the tape?
- ◆ Cathy can watch the tape with you
- ◆ You can have (keyworker) with you if you want

The writing will also accompany the photographs. The photographs will be of each participant because it will help encourage understanding that it is *them* in each situation.

Examples of the photographs are attached (with photos of actors). This shows the size of photographs, but not the colour or quality which will be considerably better.

In addition there will be Yes and No cards available at all times which can be used in relation to the questions above.

Information sheet for GP

Dear GP,

Action research with a music therapy group

GP information sheet

I am writing to inform you that the following patient of yours, has been selected to take part in a study. This is an action research project, which will be taking place at, one of the trust's community homes for people with learning difficulties.

What is the purpose of the study?

This will involve inquiring into the benefits of a year of music therapy for a group of five people with learning disabilities and challenging behaviour.

Participants in the research will be the residents, care staff, home manager and music therapist. The reactions of each participant to the therapy will be followed over a year.

Who is organising the study?

The researcher is a PhD student from the University of the West of England. She is also a state registered music therapist who previously worked for the Phoenix NHS Trust. The research is being funded by the Music Therapy Charity.

What does participation involve for the patient?

The patient will be offered a weekly 45 minute session of group music therapy, with a state registered music therapist employed by NHS Trust. The therapy will take place in Four other residents will also be offered a place in the group.

Because of the challenging nature of some of the behaviour of the men, there may be other staff present in the room. The need for this will be determined by risk

assessments made by home staff and music therapist. These staff will be interviewed after each group. Each session will be videotaped, if assent is obtained from carers and consent, where possible, from the men. The participant will be asked to watch the videotape with the researcher. If he agrees, any reaction he has to it will be recorded.

Confidentiality

The participant will own his own copy of the tape which will be kept secure for him. Master tapes will be held in a locked cupboard at UWE. Tapes will only be viewed by group members, so staff not present in the group will not have access to them, to preserve confidentiality. Any information about the patient which leaves the community home will be anonymised so that his identity is protected.

Benefits and risks

We anticipate that the participant will benefit from being involved in the research in terms of development of self-awareness and an increased feeling of empowerment. The therapy itself may offer benefits in relation to increased self-confidence, improved relationships within the group, improved self-expression and improved communication skills, although we cannot be sure until the study is completed.

The risks involved relate to

- a) possible emotional upset caused by the therapy, or watching the video
- b) risks from other group members' challenging behaviour

Staff are aware of these risks and will take measures to be available to offer emotional support if necessary at any point during therapy or during interviews.

Endpoints of study

The study is expected to start in February 2001 and will end in February 2002. If

the music therapist wishes to continue after this date for therapeutic reasons then this will happen, but no further data will be collected.

A written copy of the research findings will be produced by the collaborative inquiry team consisting of staff and residents in the home, and will be available for you to access if you wish.

Ethical approval

Both Bath and Weston Local Research Ethics Committees have approved this study.

If you are interested in this study and would like to attend any presentation of the findings, please contact the research worker who will invite you to an appropriate presentation. If you have any queries about the study or any thoughts on your patient's involvement, please contact the research worker,

Cathy Durham on 0117 344 4401.

Thank you.

Appendix 6

The use of images in research

Schratz and Steiner-Loffler suggest that images can become 'important pieces of testimony for living out forgotten (or suppressed?) reasoning' (Schratz and Steiner-Loffler 1998: 247). They presented a school-based action inquiry where pupils took their own photographs of school territories; one striking image contains children holding their noses and pointing to the toilet. Ball explores the use of photographs as text in a Himalayan ethnography (Ball 1998: 131147). In art therapy research, images produced by therapy clients can form the basis of the researchers' interpretations and analysis, but the reproduction of them allows the reader to form her own opinions (Schaverian 1991). Participants in the co-operative inquiry used a choice of photographs (Marsh 1988) to add a layer of analysis when considering the changing relationship between Pete and his fellow participants (see chapter nine).

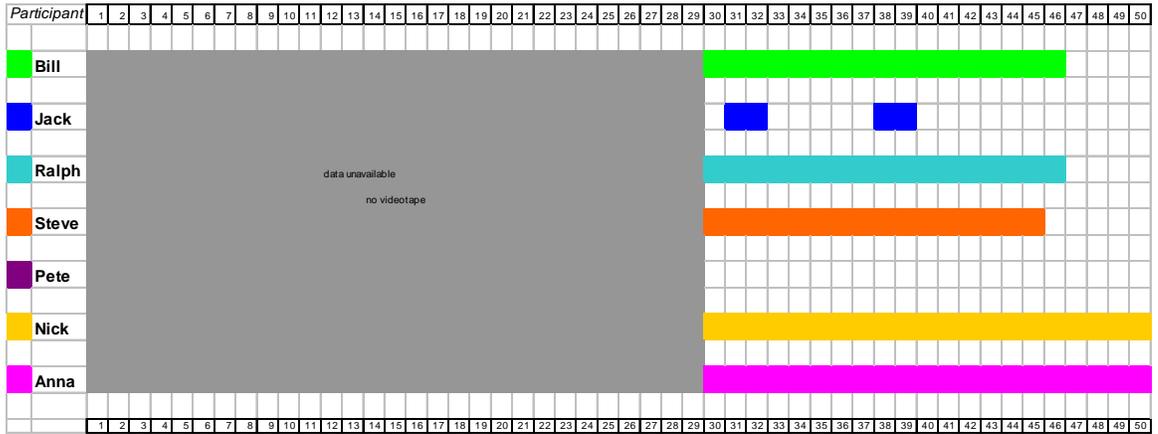
Appendix 7

Glossary of Instruments

| | |
|----------------------|---|
| <i>African drum:</i> | The type used in the inquiry was a djembe (large Gambian drum). |
| <i>Beanshaker:</i> | A collection of large dried seeds tied together, making a raucous shaking sound. |
| <i>Bird whistle:</i> | Imitates the sound of an owl call when blown. |
| <i>Buffalo drum:</i> | A large frame drum held by grasping strings tied across the back. |
| <i>Congas:</i> | A pair of large upright drums which may be played with the flat palm of the hand. |
| <i>Cymbal:</i> | One cymbal on a stand. |
| <i>Glockenspiel:</i> | Small metal xylophone with a high pitch. |
| <i>Guiro:</i> | A wooden instrument with a ridge down the side, which is scraped. |
| <i>Guitar:</i> | Acoustic Spanish guitars were used in the inquiry. |
| <i>Hand drum:</i> | A small African drum played with one hand. |
| <i>Maracas:</i> | A standard pair of Spanish maracas. |
| <i>Metallophone:</i> | Like a xylophone but with metal bars producing a pure sound which continues for a long time. |
| <i>Mouse:</i> | Small wooden instrument which is hit with a stick. |
| <i>Ocean drum:</i> | An enclosed frame drum which contains ball-bearings: when it is tipped the sound is like waves breaking on a shore. |
| <i>Rainstick:</i> | Sometimes called a 'rainmaker', this is a long tube with beads |

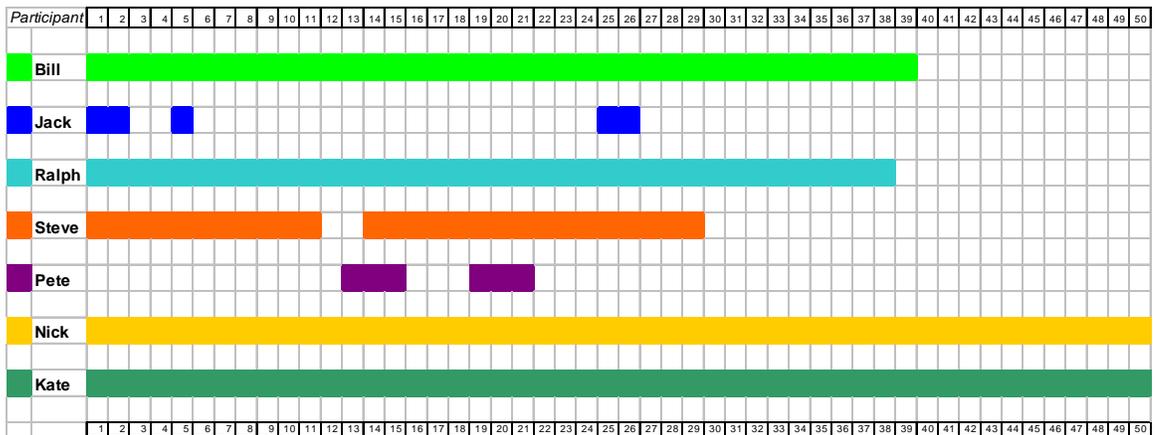
inside: when tipped it sounds like heavy rain.

- Rattle:* The rattle used in the inquiry was African and was made of woven basketwork.
- Reed horns:* These have the shape of a trumpet bell but make a sound quite easily when blown. There is a reed in the mouthpiece.
- Seed shaker:* Thin seedpods which rattled when shaken (about 50 cm long).
- Seedpods:* Alternative term for seed shaker.
- Shekere:* Sometimes known as a cabassa: it is an empty gourd with beads incorporated within a thread lattice hung around the gourd.
- Swanee whistle:* A whistle with a sliding plunger which allows the pitch to swoop when pulled.
- Tongue drum:* A drum with slits cut into it in the shape of tongues. If the tongues are hit, a gentle hollow sound is produced.
- Tympanum:* A rotary drum which changes pitch if it is rotated, by tightening the drum skin.
- Vibraslap:* This is a box with a rattle which is activated by slapping a wooden ball connected to the box by a curved piece of metal. It makes quite a loud sound.
- Windchimes:* There were about thirty of these metal chimes hung in parallel on a stand.
- Xylophone:* The bass xylophone (with wooden bars) used in the inquiry was about 80cm long and 60cm high.
- Zither:* A plucked box instrument rather like a harp.



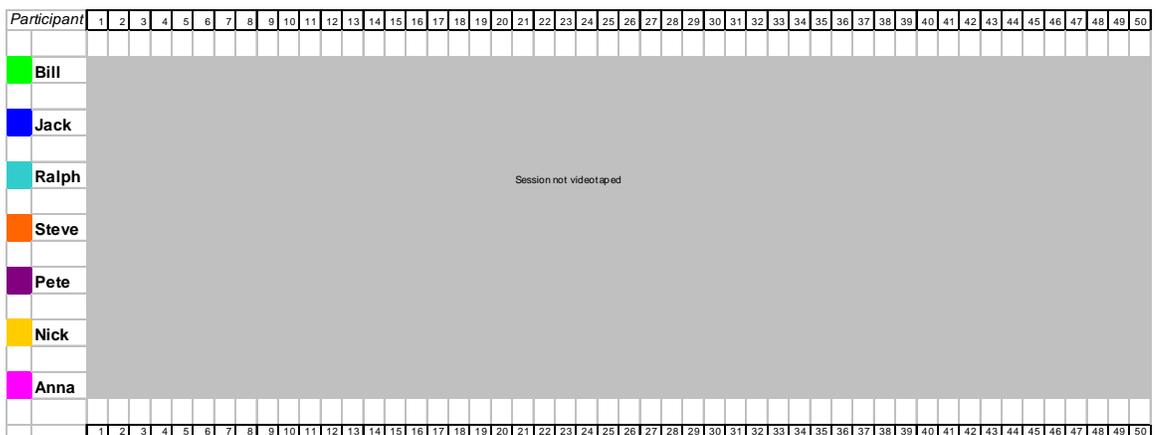
Minutes

Session 3 22/2/01



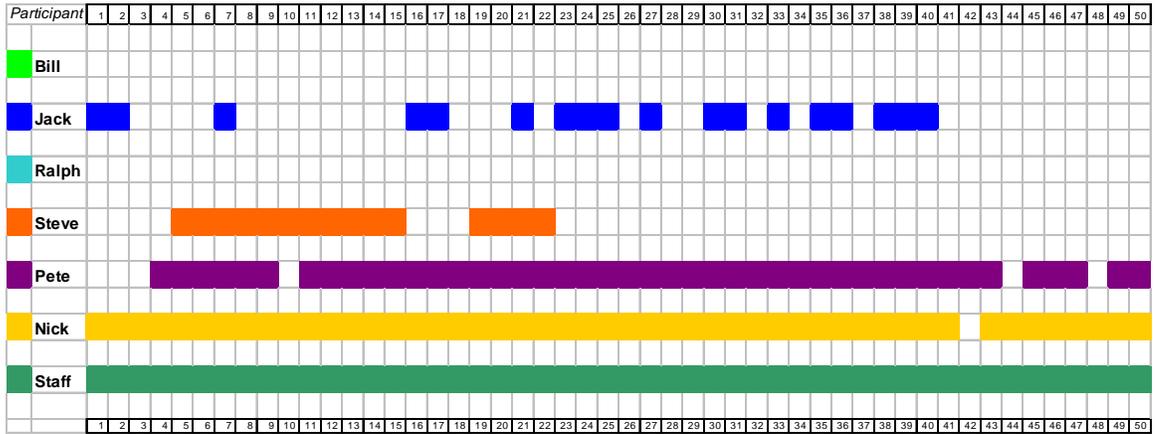
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Session 4 1/3/01



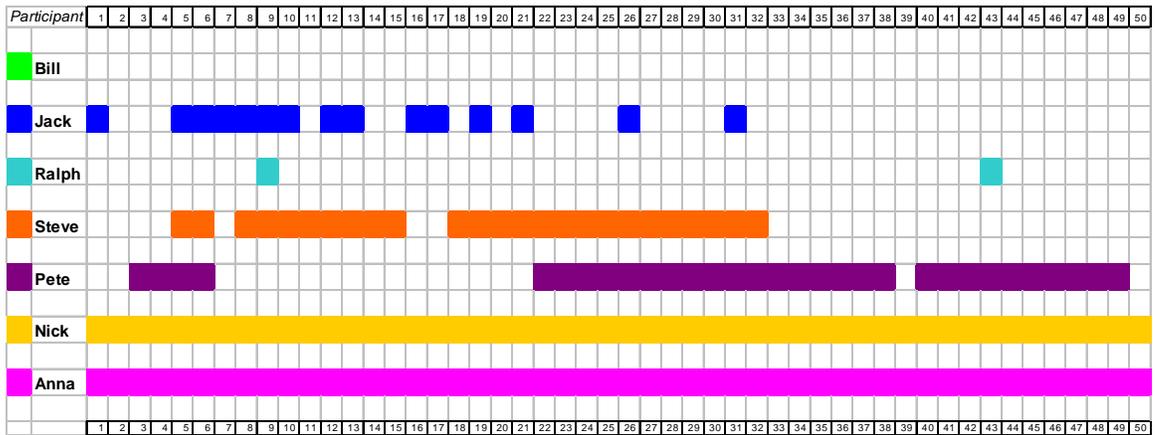
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Session 5 8/3/01



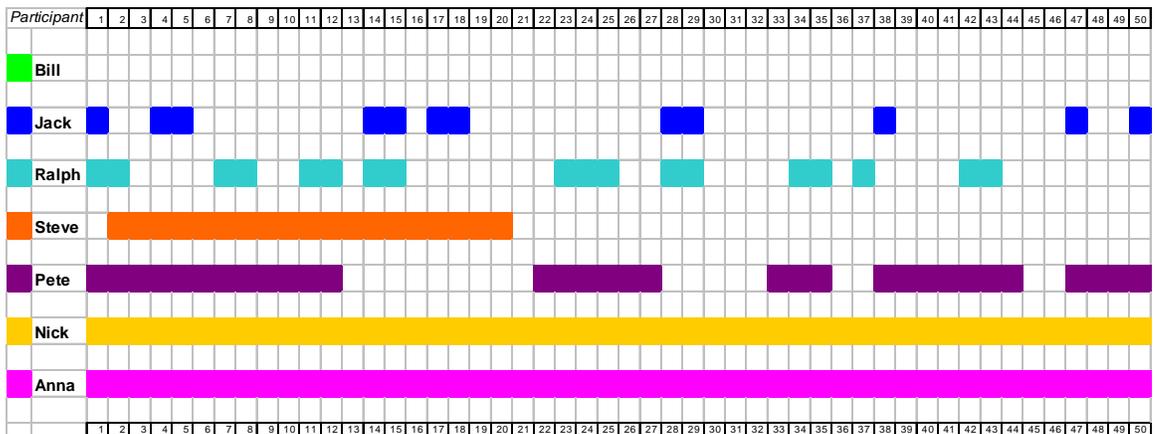
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Session 9 19/4/01



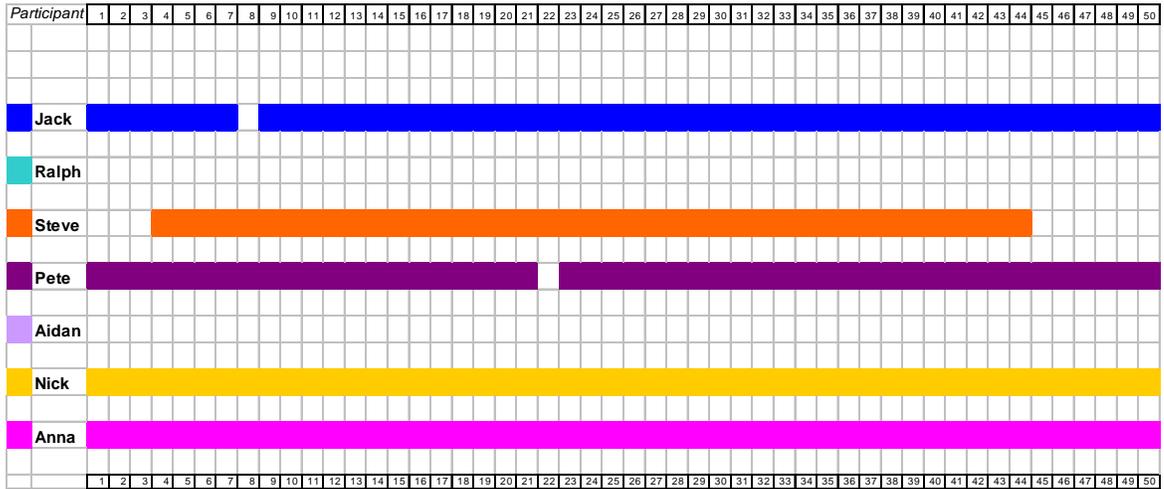
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Session 10 26/4/01



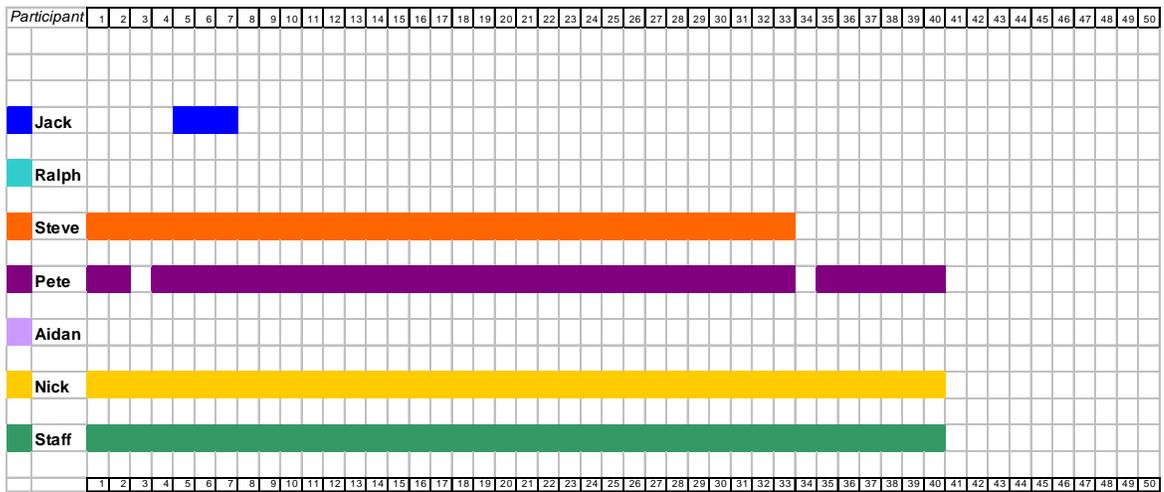
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Session 11 3/5/01



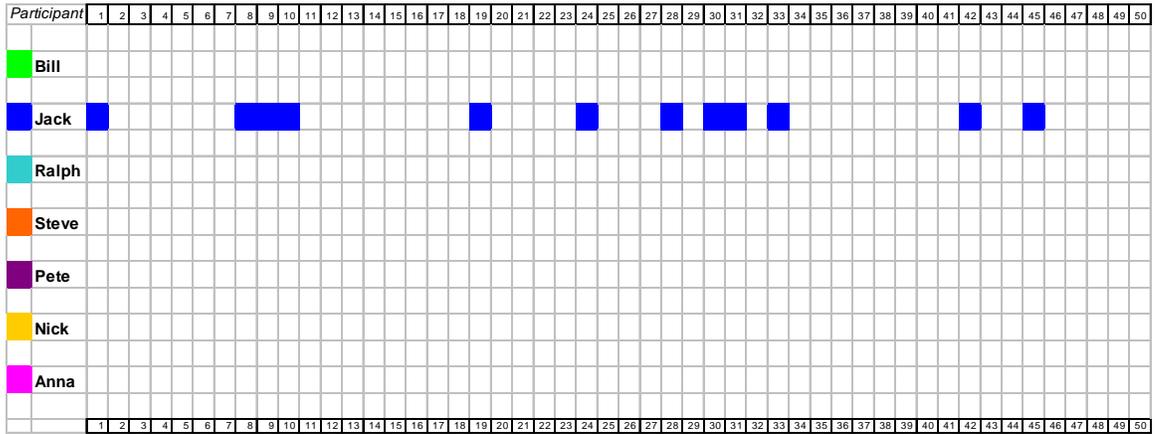
Minutes

Session 30 4/10/01



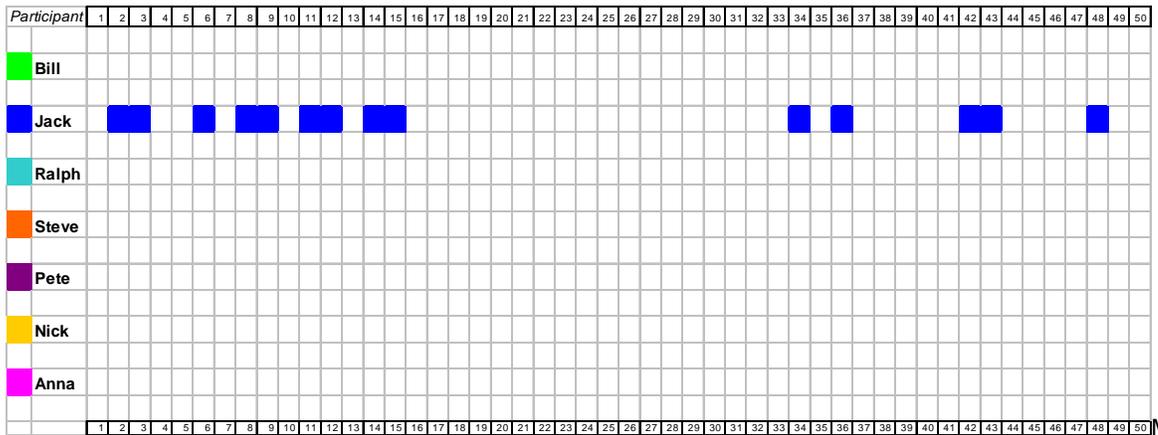
Minutes

Session 31 11/10/01



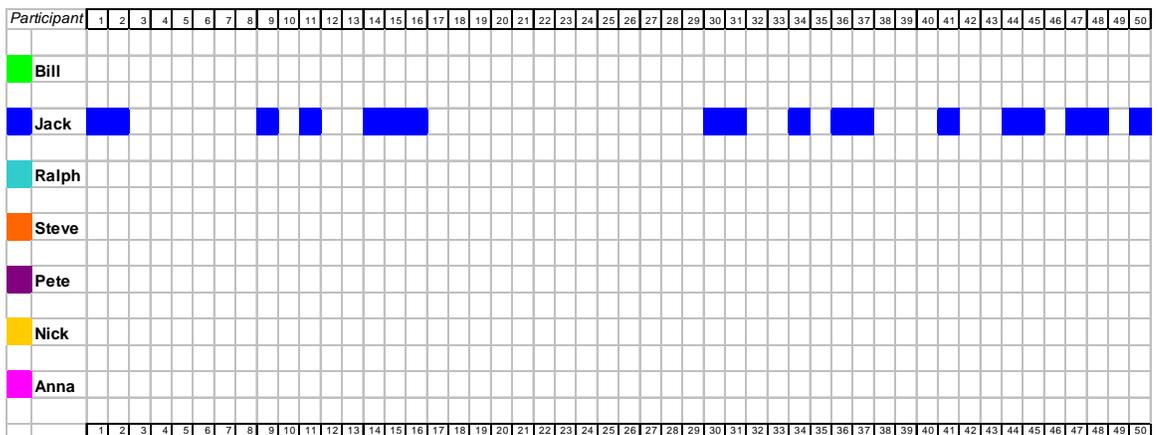
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Session 6 15/3/01



minutes

Session 7 5/4/01



Minutes

Session 8 12/4/01

