

Using Intensive Interaction to Work with People with
Profound and Multiple Learning Disabilities:
Care Staff Perceptions.

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Overview

The use of Intensive Interaction (II) has been gaining in popularity over the last two decades and several important studies have suggested that it has been effective in helping carers to build relationships with people with Profound and Multiple Learning disabilities (PMLD) (Nind and Hewett, 2005).

This thesis is presented in three separate sections and attempts to examine the use of II with people with PMLD from the perspectives of the care staff that are utilizing the technique. Emphasis is placed on the thoughts and feelings of care staff in relation to their clients, their work and themselves.

The first section contains a literature review which outlines the background and development of the research literature around II. This review draws out conclusions about the use and effectiveness of II and discusses the need for further research to examine several areas of the literature that could be developed.

Secondly, the main body of the thesis presents the empirical paper which has been written based on the current research proposal. This paper uses a qualitative methodology to investigate the thoughts and perceptions of care staff who use II with their clients. It focuses on individual meaning derived from semi-structured interview data and attempts

to analyse these results through the use of Interpretive Phenomenological Analysis in order to develop conclusions about staff's feelings about themselves, their clients and their work. Discussion is based around the idiosyncratic contributions of the participants and is related back to the research literature.

Thirdly, the final part of the thesis contains a critical review of the current research project which aims to further discuss the methodological strengths and weaknesses of the study as well as providing personal reflection from the researcher about the process of the study and the conclusions that have been drawn.

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Part 1. Literature review

A review of the use of Intensive Interaction for People with
Profound and Multiple Learning Disabilities

Abstract

Intensive interaction (II) is an approach to teaching the pre-speech fundamentals of communication to children and adults who have severe to profound learning difficulties and/or autism and who are still at an early stage of communication development. This review of the current literature includes an examination of changes in legislation and therapeutic work for people with profound and multiple learning disabilities (PMLD), it explores emotional literacy and the development of mother-infant interaction as a basis for the use of II with people with PMLD, and it criticises the current evidence base for the use of II. Emphasis is placed on staff factors in working with people with PMLD and especially the elements of staff dynamics which occur during the implementation of II. Finally, this review suggests further research which may help to widen the knowledge base about II.

1.0. Introduction

'The sense of being with an other with whom we are interacting can be one of the most forceful experiences of social life and is essential in the development of a sense of core self' (Stern, 1974 p 100).

'I'm trying to help him learn to put on his jacket, but he can't concentrate, can't look in my face, he doesn't want to be with me. What am I doing? I should be teaching him how to be with me' (Hewett, 1995 p2).

This review will discuss current literature related to people with profound and multiple learning disabilities (PMLD). It will summarise important UK legislation which has recently begun to direct and inform services for people with learning disabilities. Secondly, the review will consider the idea of emotional literacy in people with learning disabilities and the development of interaction and relationships through caregiver/child interaction. Staff issues in working with people with learning disabilities will also be considered and the stresses inherent in this role will be discussed. Finally, the literature around the use of Intensive Interaction (II) will be critically evaluated in terms of its aims, process, evidence base and implementation.

The literature was collected through the use of online internet searches on the following sites: Medline, Psychinfo, Intensiveinteraction.co.uk, and Pubmed. The search terms used were as follows: 'Learning disabilities and Intensive Interaction', PMLD and Intensive Interaction', Profound Learning Disabilities and Communication', 'Emotions and PMLD', 'Emotions and Learning Disabilities'. Also, literature was sought from the Journal of Learning Disabilities, the Tizard Learning Disability Review, the Journal of Applied Research in Learning Disabilities and several books authored by M. Nind and D.

Hewett describing Intensive Interaction and its application to people with learning disabilities.

1.1. Changes in Policy and Procedure in Learning Disability Services

Much current literature places the building and maintenance of relationships as a high priority for work with people with learning disabilities. Objective 7 of the 2001 government White Paper is “to enable people with learning disabilities to lead full and purposeful lives in their communities and to develop a range of friendships, activities and relationships” (DoH 2001 p26). People with learning disabilities have the right to be included in society, to have their human rights upheld, their views heard, and to be central in person centred planning regarding issues affecting their own lives (Department of Education and Employment, 2001; Disability Discrimination Act, 1995; Department of Health, 2001a; Disability Rights Commission, 2004; HMSO 1998, 2001). Throughout the last 10 years the rights of people with learning disabilities have been ratified in government policy so that each professional working with people with learning disabilities is now expected to ensure that all interventions are person centred and involve the person in every aspect of the planning and implementing of any change.

Literature describing the future of learning disability services is replete with discussion about person centred planning (O’Brien, 1987), essential lifestyle planning (Small & Harrison, 1992), circles of support (Wertheimer, 1995) and ‘people first’ (Whittaker & McIntosh, 2000). All of these ideas and systems are designed to enable people with learning disabilities to have the utmost amount of control over their own lives without

undue reliance on others making decisions for them that might not fulfill the needs of the individual in question.

1.2. People with Profound and Multiple Learning Disabilities (PMLD)

“Endeavoring to understand the intellectual and emotional needs of the most profoundly disabled members of our society has only recently become a serious consideration, as for generations they have barely been afforded the basic dignity of being human, let alone considered to have thoughts and feelings.” (Lacey, 1996, p.63). It is through changes in government policy and the increasing breadth of positive practice and research that the historic accounts of people with PMLD have been challenged at all. There is now an expectation that the needs and desires of people with PMLD are considered and that there should be an attempt, albeit all too frequently not realized, to communicate changes that are to occur in people’s lives must be communicated as effectively as is possible (DOH, 2001).

1.2.1. Defining PMLD

‘Profound and multiple learning disabilities’ is a term used to describe individuals who have profound learning disabilities with additional impairments or disabilities, for example, sensory disabilities, physical disabilities or autism (BILD, 2002). Ware (1989) describes people with PMLD as functioning at a developmental level of well under two years of age, and the World Health Organisation describes PMLD as signifying a mental age of less than 3 years where the individual possesses little or no ability to care for their own basic needs and requires constant help and supervision (WHO, 1992).

While there may not be any clear consensus about the exact definition, what is clear is that people with PMLD, regardless of their age, are at an early stage of development. They need more support to engage in cognitive, communicative, social and emotional activities. Most definitions of PMLD refer to deficits in all areas of everyday functioning (MENCAP, 2003). The American Psychological Association states that although people with PMLD have considerable sensorimotor impairments, optimal development may occur when a highly structured environment is provided along with constant support and an understanding and individualized relationship is available with a specialist carer (APA, 1994). However, research suggests that carers of people with PMLD find that making relationships can be a complex process, often demanding specialist training and a high level of skill and resilience (Watson, 1985, 1994).

1.2.2. Difficulties in Service Provision for people with PMLD

Whatever progress services have made in providing person centred support to service users, they very much continue to struggle in doing so with individuals with PMLD. One of the suggestions as to why this might be is presented by Sheehy & Nind (2005) who report that people with PMLD are disadvantaged due to the interaction between their disability and the unsupportive environment that is provided from the community. They describe this as neglectful and report that negative attitudes about people with PMLD have been a barrier to greater development. For example, they suggest that people with PMLD have long been thought of as sub-human, not considered to have thoughts and feelings. Thus, research and applied clinical work to understand and support the thoughts

and feelings of this group have largely been considered hopeless. However, in a study examining the quality of life and levels of engagement of people with PMLD Brennan et al. (2003) concluded that even a 5 – 10% increase in engagement with care staff and families would have a significant effect on the quality of life of people with PMLD.

Sheehy & Nind (2005) also suggest that people with PMLD are less likely to be considered by others because they often do not have a voice to highlight their wishes. It has been historically difficult for staff and key workers to interpret the needs of individuals with PMLD due to the extent of their cognitive impairments. Communication approaches that work with other people with learning disabilities are not easily applied to this group because it is much more difficult to ascertain the idiosyncratic expressive communication of people who may not be able to use verbal language, signs or even physical direction to indicate their thoughts and emotions. They further suggest that the only way forward in supporting people with PMLD to have more of a voice to make decisions in their own lives is to emphasise the importance of those around them that know them well, such as family, care staff and teachers who have spent a great deal of time with the individual. The authors state that collaboration between people close to the individual is essential in developing an understanding of their needs and that an historical reliance on specialist professionals to carry out assessments and make judgments is counter-productive.

One valuable text highlighting the current issues for people with profound and multiple learning disabilities is *Valuing People with Profound and Multiple Learning Disabilities*

(PMLD Network, 2002), written as a response to the White Paper. In it the PMLD Network describes the difficulty in balancing a need to increase clients' participation in community life with the need for specialised activities. They document the shortage of therapists with expertise in working with clients with PMLD and the need for training in "effective communication strategies, multi-sensory approaches and intensive interaction" (p25).

People with profound learning disabilities have largely been viewed as passive respondents to environmental stimuli (Evans & Ware, 1987) which means that many attempts at change and development have focused on changing environmental stimuli around the person rather than focusing on the person's emotional life, wishes and relationships. Smith et al. (1983) argued that when people with PMLD are taught in this way from an early age they are not encouraged to direct their own activity. Research has shown that children with PMLD demonstrate lower levels of spontaneous social behaviour than mainstream children and that teachers often don't respond to these pupils' spontaneous initiated interactions (Ware, 1989). This suggests that children with PMLD may have lower levels of spontaneous social behaviour to start with and that these levels may be further reduced through the lack of positive reinforcement. Gleason (1989) found that, in an institutional setting, interactions with adults with profound learning disabilities were always initiated and terminated by staff. Since these observations, some emphasis has been placed on making environments responsive to people with PMLD or increasing their power to be active and interactive, however, as previously described, the application of these ideals is somewhat removed from the ideal.

1.3.Emotional Literacy in People with Learning Disabilities

Gardner & Smyly state that “one area which we have only recently begun to consider is the emotional aspect of clients’ lives” (1997, p26). Recent publications describe a growing amount of individual and group work with people with learning disabilities which takes account of their emotional lives. Whittington and Alexander describe the work of ‘the feelings group’, which aimed to enable people with learning disabilities to understand; “what feelings are; changes and events in life that can affect feelings; and what can help people cope with unpleasant feelings.” (2001, p37). In their recent book Thomas & Woods (2003) remind us of the importance of listening, and outline barriers to communication and the factors needed for a good working relationship. They note that “verbal and non-verbal methods of communicating are not the only way a person can ‘say’ something; consideration should be given to silence and absence” (p93). This point is particularly germane when working with individuals with profound and multiple learning disabilities who may use silence or retreat as a way of communicating.

When it comes to providing therapeutic input for people with PMLD there is a dearth of research and investigation. Watts (1987) suggests that a behavioural approach has been applied almost exclusively to working with this client group. Watts suggests that this single minded approach has led the psychological profession to ignore the broad range of relevant psychological knowledge at the disposal of the practitioners. One practitioner that has been at the forefront of psychotherapeutic input for people with more severe to profound learning disabilities is Valerie Sinason who has written accounts of working

with people who have less ability to communicate and process information (Stokes & Sinason, 1992). Sinason's concept of 'secondary handicap' is important to consider when working with clients in the area of emotions; perhaps particularly when working with clients who do not have language, and who may use a range of behaviours to manage the "emotional sequelae of the primary impairment" (Stokes & Sinason, 1992, p48). Stokes and Sinason discuss the difference between cognitive intelligence and emotional intelligence, and consider the traumatic effects of handicap on the personality. Sinason argues that there might be "emotional intelligence left intact and rich regardless of how crippled intelligence performance was" (1992 p6). Sinason suggests that psychodynamic therapy is possible with people with more severe learning disabilities and draws on literature about mother/infant interactions and the emotional relationships which define an individual's character through early life experiences in order to direct her therapeutic involvement.

1.4. Mother/infant interaction

Sinason (1986) has reported some success in individual psychodynamic psychotherapy with people with severe to profound learning disabilities. Her model of therapy is very much based on exploring the development of the individual through an understanding of mother/child interactions. Sinason (1986) suggests that this first relationship, along with our emerging personality and abilities, is important in laying down patterns for future interactions with others. Research has demonstrated that the baby is an active and competent participant in a dynamic learning process (see Brazelton et al., 1974; Schaffer,

1977b; Brinker & Lewis 1982; Reddy, 1991) and Sinason believes that this active participation is often overlooked in babies with learning disabilities.

In his seminal work, Stern (1977), a psychologist and psychoanalyst, has written imaginatively of the journey that the infant takes within this first relationship. Sobey (1992), discussing the role of mother infant literature in music therapy, considers the value of Stern's writing related to work with profoundly disabled clients. In 'Diary of a Baby' Stern describes vividly the loss of a whole world of intuitive feeling communications when words take over. "For non-verbal clients who have remained stuck in this pre-lingual realm with its highlighted emotional awareness, there is the loneliness of dwelling in a world of language users whose capacity to relate to feelings is blunted" (1992, p20). Accordingly, work with clients with profound and multiple learning disabilities requires workers to find resources within themselves that allow them to make contact outside their usual verbal realm of experience.

Stern (1977) stated that the most important aspect of interaction between two participants is mutual pleasure. Examples of this mutual pleasure are interpersonal games (Trevarthen, 1979) and playful ritualised routines (Bruner, 1983). Infant games, such as 'pat-a-cake' and 'peek-a-boo', occur frequently and are said to provide the infant with a pleasurable way of learning rules about interaction, conversation and taking turns. They also help to develop emotional understanding in interaction because the care-giver can model emotive states and the child can copy these in the correct context.

In a widely quoted description of infant behaviour, Field (1977) found that one way in which caregivers respond to infants is by imitating or mirroring their behaviour. Pawlby (1977) showed that smiles, tongue-pokes, claps, frowns, waves, laughs, yawns, and speech sounds were all imitated. Schaffer (1977b) suggests that these sequences often start with the baby's spontaneous behaviour, then the care giver reacts to the baby's lead and imitates their behaviour. This repetition can validate the baby's attempts at communication and can also be used to elaborate the interaction as the baby understands its effect on the caregiver and will often start to explore the extent of this effect. Thus new behaviours are learnt and new interactive patterns and content are developed. Schaffer and Emerson (1964) state that physical touch is an essential part of the child learning to feel comfortable with the development of new interactive patterns. The warmth and affection inherent in physical touch stimulates the relationship and enhances physiological and emotional well-being in both the baby and the caregiver (Ferguson, 1971).

Hewett (2005) describes the importance of analyzing mother/infant interaction when beginning to work with people with PMLD. He suggests that caregivers do not actively teach their children to communicate and interact, but instead they go and join the infant, ready to acknowledge and elaborate on the infant's expression. In the earliest stages, very simple turn-taking exchanges and episodes of attention are initiated simply by the carer responding to something the baby does. The infant soon learns that they can pleasurably experiment with 'social cause and effect'. Hewett believes that these building blocks pave the way for the development of social relationships in infants.

1.5. Caregivers and Babies with Disabilities

There is still little research undertaken into the relationships between mothers and their disabled babies. However, there is evidence to suggest that caregivers find it much more difficult to interact with babies with learning disabilities and that the amount of exploratory play leading to learning about the effects of behaviour is more limited than with babies without learning disabilities (Stern, 1977). Stern notes that in the case of a handicapped baby “to keep the dyadic interaction mutually regulated, the caregiver has to readjust her own behavioural repertoire and stimulus level to match the infant’s range of responsivity.” (1992, p 73). One could argue that his statement is true also for carers of adults with learning disabilities. Great resourcefulness and patience is needed by the carer who must keep their interactions within a certain range or at a certain level in order to match their clients’ needs. The available literature points to the effect of a disability on the development of a positive relationship. McCollum, talking about the interactive capabilities of disabled babies, states that “pleasurable interaction is no longer so spontaneous. Interactions may be less enjoyable, and may occur less frequently. They are also very likely to differ in structure and/or occur under more restricted circumstances” (1984, p 301). However he also notes that; “studies have demonstrated that parents of handicapped and high risk babies can alter the nature of their interactions with their babies resulting in smoother and more pleasurable exchanges” (1984, p.301).

McCollum (1984), on the basis of a review of eight research studies, concludes that the establishment of mutually enjoyable interactions may be less automatic in caregiver-

infant pairs in which the infant is developmentally delayed. Bakeman and Brown (1980) believe that the caregiver may not receive as much feedback from a disabled baby and this can lead to the caregiver feeling helpless. Klein and Briggs (1987) found that babies with immature central nervous systems were more difficult to arouse and their signals were more difficult for the caregiver to read. It seems that the caregiver is given less positive feedback from an interaction with a baby with disabilities and therefore the bonding process which is contingent upon these types of interactions could be lessened. However, McCollum (1984) states that, even though disability has an effect on the nature of interpersonal interaction, these interactions can be modulated and changed resulting in pleasurable and satisfying exchanges.

Dale (1996) highlights the many demands and difficulties of parenting a child with 'special needs'. She states that parents and carers can be overwhelmed with the anxieties and uncertainties of parenting, including the concerns about their children developing, growing and what the future might be like. Dale also suggests that high levels of anxiety can be brought about by carer's concerns about. In their 'Breaking Point' survey, Mencap (2003) found that these anxieties and concerns continue throughout the life of their child.

1.6. Staff working with people with learning disabilities

Care staff working with people with learning disabilities are increasingly being recognized for their pivotal role and influence in supporting people with learning disabilities on an intimate and day-to-day basis (Jenkins, Rose & Lovell, 1987). Carers support people with learning disabilities in a wide variety of settings (e.g. day services,

access to employment, residential services and respite services) and the relationships that are built between these staff and the service users they care for are often close, personal and long-term (Hastings, 1997). Understanding the relationship between carers and service users is therefore crucial in gaining knowledge about the best way to support individuals with learning disabilities.

Hastings (1997) suggests that the importance of understanding the carer's context is overlooked in traditional studies of care for people with learning disabilities. He depicts a model of carer and client interaction that suggests that the antecedents and consequences of the carer's behaviour towards the client must be incorporated into the picture of the client's behaviour. This model proposes that the thoughts and emotions of the carer towards the client will have an effect on the interaction between the two and the overall emotions of the client. Hastings' model highlights the co-dependence of the carer's and client's feelings towards each other and because of this he suggests that more research should be directed at understanding the carer's feelings towards service users.

1.6.1. Care staff feelings of self efficacy

Self-efficacy has been defined as: "beliefs in one's capabilities to organize and execute the courses of action required to manage prospective situations" (Bandura, 1995, p2). Lazarus and Folkman (1984) reported that the objective measurement of the ability of care staff to manage prospective situations is not as important as the individual's perception of their own efficacy. They found that this perception of their own self-efficacy had an effect on carers' ability to work positively with their clients. Hastings &

Brown (2002a) further found that staff feelings of self-efficacy were predictive of their emotional reactions to clients who present with challenging needs.

1.6.2. Care staff feelings of stress

Caring for people with learning disabilities can be a very stressful job (Mansell, 1995) and evidence suggests that one-third of care staff report significant levels of stress in their job, compared to 16% of the UK adult population (Hatton et al., 1995). Higher levels of stress have been shown to reduce the amount of positive interactions that care staff have with their learning disabled clients (Rose et al., 1998). Staff working in specialist units for people with PMLD have been found to be significantly more emotionally exhausted than staff working in mental health settings (Chung, Corbett & Cumella, 1995).

The most likely causes of stress in care staff has been found to be the unpleasant or challenging characteristics of the clients they support and the level of dependence or severity of disability (e.g., Dyer & Quine, 1998). Bromley & Emerson (1995) confirmed this finding and reported that the difficulty of understanding or predicting the behaviour of clients whilst coping with the 'daily grind' is one of the most prominent sources of carers stress in the workplace.

Difficulties in caring for clients and reports of work related stress were found to be positively correlated with staff burnout (Bromley & Emerson, 1995). Staff emotions most commonly associated with burnout were sadness, annoyance and despair (Bromley & Emerson, 1995). Mitchell & Hastings found that staff who were burnt out were more

likely to avoid interaction with clients and act in a depersonalized way, thus greatly reducing the quality of emotional care provided to clients.

Other factors associated with staff stress, burnout, and mental health include characteristics of organizations/services, client characteristics, and characteristics of staff members themselves. Characteristics of services that have been associated with staff stress include excessive workloads, limited chances for training and advancement, lack of resources, role ambiguity, and institutional as opposed to community settings (e.g., Bersani & Heifetz, 1985; Blumenthal, Lavender, & Hewson, 1998; Buckhalt, Marchetti, & Bearden, 1990; Hatton, Brown, Caine, & Emerson, 1995).

Staff variables identified in research on staff stress can be viewed as serving risk and compensatory functions. Factors associated with risk of increased stress include adopting a 'wishful thinking' coping style to manage the stress of work, perceived conflicts between work and personal and family demands, younger age, illness, and anxiety (e.g., Browner et al., 1987; Hatton et al., 1995; Shaddock, Hill, & Van Limbeek, 1998). On the other hand, several factors have been found to mitigate stress of support staff. For example, Hatton and Emerson (1993) found that the receipt of social support from colleagues predicted a greater satisfaction with life, less stress, and a reduced propensity for turnover.

Thus, there is a developing research literature addressing support staff well-being at work. This has also extended to a number of research studies in which job satisfaction has been measured (e.g., Bersani & Heifetz, 1985; Buckhalt et al., 1990; George & Baumeister, 1981; Hatton & Emerson, 1993; Hatton, Emerson et al., 1999; Hauber & Bruininks, 1986; Parahoo & Barr, 1994). Results from these studies suggest that a core set of factors (support from other staff, income, and agreement with organisational values) may positively predict work stress and negatively predict job satisfaction (e.g. Hatton & Emerson, 1993). However, the predictors of job satisfaction are often different from those associated with work stress (e.g. Bersani & Heifetz, 1985; Hatton & Emerson, 1993; Hatton et al., 1995).

Existing data are supportive of the notion that more positive outcomes (e.g., work satisfaction) may relate to slightly different causal pathways than do negative outcomes and, thus, that they may be relatively independent constructs. This is no real surprise because a number of empirical studies and conceptual analyses suggest that positive and negative well-being are not simply the opposite ends of the same dimension (e.g. Clark & Watson, 1988; Diener & Emmons, 1984; Watson, Clark, & Tellegen, 1988). A particularly useful model that might be applied to explain these support staff experiences is that of the two-factor model of care giving (Lawton et al., 1991; Pruchno, Patrick, & Burant, 1996; Smith, 1996). This model reflects the fact that care giving may lead to two outcome dimensions that are not necessarily related: (a) Problematic aspects of the person cared for (e.g., problem behaviors, severity of disability) are associated with care giving

demands or burden, which in turn may lead to negative caregiver outcomes, such as mental health problems. (b) Positive characteristics of the person who is being cared for are associated with perceived positive contributions or caring gratification, which in turn may result in positive caregiver outcomes, such as life satisfaction.

There is little research indicating the best methods of avoiding burnout when working specifically with clients with PMLD. Nind & Hewett (2005) report that anecdotal evidence exists to demonstrate that care staff using Intensive Interaction with their clients feel more self efficacious and that this could reduce the effects of stress.

1.7. Intensive Interaction

1.7.1. Background

Nind and Hewett (1994, 1998, 2005), and Nind (1996) have developed a specific way of working with children and adults with severe and profound learning disabilities, which they named Intensive Interaction (II). II is an approach used to develop interaction with people who use basic pre-verbal means of communication, and who have difficulty interacting with others. II is designed to enhance the responsiveness of carers thereby improving the interactive and communicative abilities of people with severe and profound learning disabilities and enhancing their social inclusion.

II was based on Ephraim's original idea of augmented mothering (Ephraim, 1982) and was first developed in Harperbury school, where Nind and Hewett were teaching young adults with profound and multiple learning disabilities who did not seem to understand or enjoy interaction with others. When interactive play and the intuitive creativity of caregivers with infants replaced the original behavioural approach, there were noticeable gains in communication and social interaction, as well as a reduction in challenging behaviour (Nind & Hewett, 1994).

The British Institute of Learning Disabilities (BILD) summarise II as “a practical approach to interacting with people with learning disabilities who do not find it easy communicating or being social” (2002 p1). BILD also states that “the [intensive interaction] approach helps the person with learning disabilities and their communication partner to relate better to each other and enjoy each other's company more”. (BILD (2002) p1).

1.7.2. The Philosophical Basis of II

Samuel (2003) suggests the best way of understanding the philosophical basis of using II with people with PMLD is through the use of a contextual model. A contextual model of PMLD takes into account innate maturational factors, developmental age equivalence, reinforcement and contingency awareness, a unique life history of learning experiences, and construes the individual with PMLD as an active participant in their own development (Samuel, 2003). It is through the use of this model that researchers and clinicians have begun to explore the dynamic social context of early life as a starting

point in engaging people with PMLD (Wolfensberger, 1998) and early caregiver-infant interaction has been cited as a model for developing relationships with people with PMLD (Ephraim, 1997). In early caregiver-infant interaction caregivers initiate, maintain and respond contingently to the infant's behaviour (vocalisations, gaze, expression, proximity, gesture and touch) and this enhances motivation to repeat and develop interactive games and acts as a way of shaping a relationship through the use of contingent behavioural reinforcement of interaction. (Carlson & Bricker, 1982; Schaffer, 1977; Stern, 1983). Due to the fact that people with PMLD may be responding to stimuli in a similar way that an infant responds to stimuli, II attempts to use learning theory to reinforce interactive behaviour between the carer and the client.

1.7.3. Aims of II

Nind and Hewett (2005) have conceptualised the aims of II as falling into five main subgroups. Firstly, II aims to develop sociability in people with PMLD by increasing desire and ability to be with another person, increasing the enjoyment of social contact, helping people to initiate social interaction, and starting to develop sensations of emotional empathy.

Secondly, II aims to develop fundamental communication abilities such as eye contact, the ability to interpret facial expression, understand body language, physical contact, the capacity to take turns in exchanges of behaviour with another person, and to enable communicative social behaviours to become more significant and rewarding for the individual than previously more challenging or self-absorbed behaviours.

Thirdly, II aims to develop cognitive abilities where the individual learns to use and understand social cause and effect (the ability to affect the behaviour of others), starts to predict the behaviour of others, begins to explore and experiment with the social world, and starts to understand social rules and principles.

Fourthly, II aims to develop emotional well-being through the building of self-esteem, creating a sensation of 'I am good to be with', and empowering someone to know the joy and satisfaction arising from communicating effectively with other human beings.

Finally, II aims to assist staff and families in promoting emotional well-being and directly supports staff using II to reflect on their practice and the way they feel about their work.

1.7.4. The Process of II

II uses a range of interactive games that have been shown to occur in interactions between infants and their caregivers. The learner is engaged in one-to-one interaction with the emphasis being on pleasure. In its basic form II allows the worker to follow the lead of the participant by using imitative and playful techniques to engage them in interactive games (as seen in interactions between infants and their primary caregivers). This gives control of the interaction to the participant who can begin to explore and develop interaction. The participant thus has the freedom to explore relatedness on their own terms. The focus of the interaction is on games which are built from the learner's actions, sounds or expression. The interactions are often brief in the early stages but as

the learner's involvement increases, the process brings about the development of more complex communication abilities such as use of facial expression, anticipation and turn-taking. With sensitive interpretation of the contact, the learner's behaviours, which may have been regarded as meaningless, can become understood and treated as communications.

II begins with a phase of observation to get a sense of the participant and try out simple techniques. This enables the participant to recognize the practitioner's behaviour and to learn about their ability to control the interaction (Miller & Ephraim, 1988). Many interactive games and playful routines are used, such as tickling, blowing raspberries in turn, peek a boo, and mirroring/copying the other's actions or sounds. The practitioner responds sensitively to the participant's changes and involvement, making sure that the games and interactions are mostly led by the participant. The participant develops a sense of control over the interaction and may often begin to feel safe and secure with the practitioner who is not placing demands on them, is not being directive or instructive, and is empowering the participant to lead in the direction they choose.

The content of the interaction is not pre-planned and each individual is encouraged to explore the relationship in their own idiosyncratic way. Sometimes the interaction can be noisy and rough and sometimes it can be quiet, simply sitting together and using eye contact to interact. Many of the people with PMLD with whom this approach is used start from a position of avoiding all contact with others, therefore sharing personal space and getting involved in simple games like these are achievements in themselves.

The participant may often start being passive in the interaction but learn to become more of a leader. Reciprocity is encouraged whereby the participant has an active role and eventually starts to initiate and lead in the interactive games. Nind & Hewett (2005) propose that this type of process is the same as the development of social understanding, emotional well-being and communication developed in infancy.

1.7.5. Evidence base for II

To date, the evidence base for II is limited. The evaluations and research that have been carried out have been small scale and limited over time. There are several reasons why these studies have been carried out in small scale format.. Firstly, the intensity of II has meant that staff must spend a great deal of time engaged in the process of II which can cause great stress on resources. Therefore, there have been difficulties in securing additional resources for evaluative purposes. Secondly, II is still in its infancy and it is more difficult to launch large scale research projects for new approaches. Thirdly, any research into the field of PMLD has been limited due to the historical neglect of the psychological needs of people with PMLD. The development of research regarding the emotional and behavioural development of people with PMLD has only recently begun to become more popular. In view of the limited evidence base the current review will analyse all published attempts to evaluate II.

During the early years of the development of II, Nind (1993; 1996) conducted single subject multiple baseline designs to search for changes in six of her adult students with

severe and profound learning disabilities. For the purposes of the study, two daily II sessions were offered and progress was monitored over 18 months. Common developments in the students' interactive abilities included more smiling contingent on the activity of the teacher and more time spent in interactive behaviours and games. All six showed improved abilities to reciprocate warm physical contact as measured on the Cuddliness Scale (Brazelton, 1984) and advances in their communication abilities as measured on the Preverbal Communication Schedule (PVCS) (Kiernan & Reid 1987). Follow up data, after the conclusion of the II intervention was not collected and it was difficult to discern from the study whether the changes in the behaviour of the participants generalized to other environments outside of the II sessions or over time.

Kellett (2001) applied the same research design to evaluate the approach with 6 children (aged 4 to 11) in a community special school. Ten minute daily sessions of II occurred over one academic year. The practitioners were 3 teachers and 3 support assistants who had been trained to use II by Nind for the course of the study but who had not had any prior experience of the approach. A multiple baseline interrupted time series design was used to assess change over time. Measures included observations of communication and positive interaction from videotaped sessions. The PVCS and Brazelton's Cuddliness Scale (1984) were used as measures as well as qualitative data collected through interviews with the practitioners. Kellett found evidence of positive (and rapid and substantial) increases in communication and social abilities in all 6 participants. Some even started to use signing and single word communication. Specifically, an increase in participant's attention to facial gaze, joint focus on activities and eye contact were

notably enhanced. Stereotypy was seen to be reduced across all participants and contingent vocalization began to increase gradually as the study continued. This study reported that changes were consistent over time and generalized outside of II sessions. However, it is not clear whether the changes in behaviour of the participants generalized to interactions with other people, or were only evident when the participants were interacting with the II practitioners.

Samuel (2003) similarly adapted the design of Nind (1993; 1996) to evaluate the impact of II used by home support staff with four women with profound learning disabilities. Video taped analysis was used over a 20 week intervention period and a variety of social and communicative behaviours were analysed. The quality of staff relationship with the participants was found to improve and all four women developed improved communication and social abilities. Samuel found some difficulties with implementation. Her practitioners were new to the approach and within a 20 week period of intervention they learned to apply some of the principles to some extent, however, when their practice of II was analysed near to the end of the study it was found that some of the practitioners were not using II as they had been trained. Further limitations to this study included the lack of any follow up data, lack of analysis as to the generalisability of the changes across other environments, and the fact that two of the four participants were receiving other therapeutic input (aromatherapy and music therapy) contemporaneous.

Further evidence that II may work comes from less rigorous studies and narrative case study accounts. Watson and Fisher (1997) studied its use with six pupils aged 10-19 who

were paired with six carers who used II. Four sessions of II were scheduled per week and practitioners kept written records about their experiences. Every 6 weeks the interactions were filmed and analysis was undertaken about the development of the pupils. Over a six month period it was observed that each pair had developed an interactive style specific to the needs of the pupil and that three of the pupils showed significant progress in terms of their ability to communicate and sustain interaction with the carers. Observations of the other three pupils showed less obvious results. Informal interviews were conducted with the practitioners and the anecdotal data from these interviews suggested that there was an overwhelming consensus among the practitioners that II was achieving great benefits for the pupils. (See Knight and Watson 1990; Watson and Knight 1991; Watson 1994; Knight, Watson and Fisher 1997). This study did not use any baseline or control design to demonstrate change in the group of participants and it is therefore difficult to assess where any real change occurred or whether changes which did occur could be attributed to II. Furthermore, there were no checks made that each practitioner was using the same sort of techniques and no definition of what specific techniques of interaction must be included to deem the interaction II.

Nind and Hewett (2005) suggest that those without training in II may be carrying out the techniques wrongly and this type of reduction of the process of II could never be compared with correctly practiced methods. An illustration of their argument is a single case study carried out by Jones & Williams (1998). This study found minimal reduction in the stereotyped behaviour of a 35-year-old man with PMLD in response to II. Jones &

Williams (1998) note that under scrutiny, it appears that the only component of II used by the practitioner, who was a novice in the use of II, was imitation.

Lovell, Jones and Ephraim (1998) used a single case experiment to compare the short-term effectiveness of II with just being in close proximity to the participating 53-year-old man with severe learning disabilities. Nine 5 minute II sessions and eight 5 minute 'proximity' sessions were conducted over a week long period and the data was analysed using 10 second momentary time sampling from video recording. Both conditions were associated with an increase in the participant looking at the practitioner, increased joint attention, smiling, laughter and initiation of physical contact, with these increases being greater in the II condition. Participant illness terminated this study prematurely. Because the two conditions were used interchangeably throughout the week long study and the same practitioner was used to facilitate both conditions with the participant it is possible that the effect of one condition may have influenced the effect of the other.

Irvine (1998) studied the use of II with 14 adult participants with PMLD over a 6 month period. Progress was monitored using the written feedback of the practitioners. Twelve of the 14 participants were thought to be happier, more relaxed and secure during the II condition, nine were thought to be initiating more interaction since starting with II and eight were allowing more physical contact from the practitioners. This study has significant short-comings including a lack of any formalized observation of behavioural change, baseline measurements or follow-up.

Elgie and Maguire (2001) used II with a 39-year old woman with PMLD who also presented with severe self-injurious behaviour. Video observation was used during the brief sessions of II. Intervention occurred 3 times per week for a total of 16 weeks. Results showed an increase in vocalization and physical contact initiated by the client but there was no change in frequency or severity of self-injurious behaviour. There was no evidence of assessment of these effects being generalized across different environments or with different people.

1.7.6. Problems with II

Critics of II have suggested that the techniques involved in the process do not adhere to age appropriateness (Cambridge & Carnaby, 2000). Interacting with a fully grown participant as though they were an infant, the use of children's games (e.g. peek a boo) and the use of mimicking and turn based play have been cited as inappropriate and not in line with current service policies and philosophies.

Nind and Hewett (2005) respond to such criticism by outlining the philosophical framework of II and argue that II is essentially an approach that is respectful of the individual - valuing the person as a social and communicative being whose behaviours are worthwhile. They note that when using this approach there is no element of eradicating parts of a person's behavioural repertoire which do not make sense to us. They suggest that there is no point in taking away what a person feels safe and comfortable with, and imposing what might seem comfortable and appropriate for service providers. Regardless of Nind & Hewett's counter-argument it is still possible that

adopting II techniques which disregard the notion of age-appropriateness could be construed as unethical for adults with PMLD and it would be important for practitioners to bear these ideas in mind so that their practice remains appropriate to the person they are working with.

Secondly, II has been criticised for its prescription of physical touch (Cambridge & Carnaby, 2000). This also relates to the practice of interacting with a participant as an infant, where physical touch is essential. In a political and social climate where there is a very real concern about abuse it is important to consider the impact of asking caregivers and staff to use physical touch in their interactions with people with PMLD. Nind and Hewett (2005) state that most people of any age who are still at an early stage of development seem to find touch to be a direct and understandable form of contact with another person and a fundamental experience in the development of communication powers. Johnson (2000) describes the 'moral panic' of 'no touch' policies and suggests that, at best they are not followed and at worst they ensure that many clients remain socially isolated as a result of these policies. Furthermore, recent studies have demonstrated the benefits of increased touch through massage therapy for people with learning disabilities (Field et al., 1996). Nind and Hewett (2005) suggest that physical touch in II must always be discussed in a supportive team environment so that practitioners can feel comfortable about the way they practice. Finally, it would be important to ensure that there was some protection afforded to service users with PMLD who may be vulnerable to abuse if policies about physical contact are not so strict. This

may mean that extra observation and joint working may need to be implemented so that interaction of this nature can be properly monitored.

Thirdly, Nind & Hewett (2005) report that II can enhance the attachment of practitioners to services users. Critics suggest that this may be unethical in circumstances where there is high staff turn over (Samuel, 2003). It is suggested that the attachments made during II could create even more disappointment on behalf of both service user and carer when the carer leaves their work or is reallocated to work with someone else instead. However, O'Brien (1987) argues that the less relationships that people with learning disability have with others, the more dependent they are. This represents a strong case for developing social networks and is the cornerstone of the work being undertaken around person centred planning.

Fourthly, II has been criticised for using service users' stereotyped behaviour as a medium for creating the opportunity for communication (Ephraim, 1998; Caldwell, 1996; Nind and Kellett, 2002). Although stereotyped behaviour varies and its function is not always the same, it has been blamed for interfering with learning and for presenting the service user as having a negative social image (Jones & Williams, 1998).

1.7.7. Staff using II

Related to the above criticisms of II is the idea that some staff may lack the skills to use II properly and to interact with services users in such an intense manner (Nind & Hewett, 2005). This may be because staff are unwilling to change methods that they normally use

to interact with service users (Nind & Hewett, 2005). Nind & Hewett (2005) describe the attributes that staff must possess in order to be able to successfully work with someone using II. Firstly, staff must possess an attitude of playfulness. Nind and Hewett state that, without this attitude, there is not much possibility that the skills needed to implement II will develop. Secondly, staff should ideally be able to work intuitively by tuning in to the other person and letting themselves go; thinking too hard minute by minute may diminish spontaneity and interfere with the signals of enjoyment to the other person. Thirdly, good teamwork is important because it can support free and honest reflection on practice, discussion of feelings and problems with different individuals.

1.7.8. Staff reflections on the meaning and process of II

Nind and Hewett (1994) propose that practitioners of II should keep detailed session records so that they may reflect on the process of II and learn from what they have already done. Nind and Hewett (2005) describe these session records as an anecdotal, unstructured discussion of progress together with written narrative recordings. These narrative records should be completed immediately after the session and are seen as an opportunity to reflect on the session. The narratives should describe what the practitioner did and why but are deliberately not limited to what was observable. Instead, practitioners are encouraged to record thoughts, feelings and suppositions. Practitioners are also encouraged to search for understanding in how each session of II has made them feel about themselves and about their clients.

There is only one study which is published exploring the behaviour of staff using II. Nind, Kellett and Hopkins (2001) assessed the interaction style of four practitioners of II whilst they supported their clients. Eight videos were analysed and staff were rated on their use of 'motherese' (a simplified and higher pitched speech using frequent questions and a melodic tone) during II sessions (Weistuch & Byers-Brown, 1987). Staff use of 'motherese' was found to be less consistent than within Melanie Nind's training videos. There was no baseline data provided to ascertain whether the use of II had changed the practitioners level of 'motherese' over the course of the study.

There is some indication that staff and carers feel that using II has a positive impact on their skills as a carer and may change the way they feel about their work and their interactions with clients (Elsworth, 1999). Elsworth explored the views of ten volunteer home support staff that used II with adults with PMLD. In-depth semi-structured interviews were used and the content grouped into six different themes (practitioner's understanding of II, content of II relationships, the effects of II, problems with II, organizational factors, service development issues). Results showed that all staff viewed II very positively and that they perceived an improvement in both participant and practitioner interactive skills and felt that their relationships with clients were more pleasurable. There also seemed to be some evidence that staff felt higher self efficacy in using II with their clients, however, this study was completed on a small scale and there was no formal analysis of the data. Therefore, the evidence is less substantial than would be necessary to draw more concrete conclusions.

1.8. Further research

Further research is needed in order to increase the evidence base for the use of II with people with PMLD. So far, there has been no use of representative, experimental or control groups to compare II with other conditions. There have been studies involving reversible or alternating single subject designs to compare results from baseline and intervention conditions. The quasi-experimental methodologies that have been used so far in the validation of II are not rated highly in systematic reviews of evidence. Also, each efficacy study undertaken about II is context bound and the heterogeneity of people with PMLD weakens any claim to establish external validity. Researchers could further test the validity of II through the use of larger scale studies that use control groups to compare II with other conditions. Randomized allocation to groups could also help to increase the internal validity of findings. Follow up data could be gathered to find out whether any changes in the participants could be sustained after the end of the II sessions and further assessment could be undertaken to find out whether any benefits from II could be generalized across environments or across other individuals in the participant's life who are not using II.

Finally, more research is needed which looks into the impact of II on practitioners, not least in view of the evidence on carer self-efficacy and stress which has been shown to have a detrimental effect on the interactions between carers and their clients. Research into this area could examine the claim that the use of II may have an effect on carers' feelings of self-efficacy. An awareness of practitioner thoughts and feelings about their interactions would seem to be an essential component in understanding the benefits of the

interaction for the learner and could establish a body of evidence about the ways in which II could also be valuable for the practitioner. A qualitative research design could be used to investigate the perceptions of carers about any changes that they have experienced after using II.

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Part 2. Empirical Paper

Using Intensive Interaction to Work with People with Profound
and Multiple Learning Disabilities:
Care Staff Perceptions.

Abstract

Intensive Interaction (II) is a transactional approach that enhances the responsiveness of carers to improve the fundamental communication and social abilities of people with profound and multiple learning disabilities (PMLD). To date there have been several research studies aimed at understanding the benefits of II for the client but there has been no substantial research conducted to examine practitioner considerations. A semi-structured interview schedule was developed to explore the perceptions of care staff using II with clients with PMLD. Interpretative Phenomenological Analysis (IPA) was used to analyse the data from interview transcripts from twelve participants. Three themes emerged from the analysis. These themes were; 'Exerting Control vs. Relinquishing Control', 'Making a Connection' and 'Thoughts about the Wider Care System'. A tentative understanding of the effects of II is suggested and areas for future research in the field are discussed. Possible methodological limitations are explored in the context of the implications these may have for the wider applicability of the results and the implications for clinical practice arising from the study are considered.

1.0. Introduction

'Relationships with friends, family, partners and acquaintances are one of the most important aspects of people's lives (NHS Executive, 2001, p16)

This study focuses on Intensive Interaction (II) (Nind & Hewett, 1994, 2005), an approach that aims to enhance the communication and social abilities of people with PMLD. This introduction reviews the background and evidence base for II and examines the nature of care staff roles in working with clients with PMLD. Finally, the introduction discusses the aims of the current research and sets out a series of questions that will guide the process of the study.

1.1. People with Profound and Multiple Learning Disabilities

PMLD is a term used to describe people who have profound learning disabilities with additional impairments or disabilities, for example, sensory disabilities, physical disabilities and autism (BILD, 2002). People with PMLD have uneven profiles of cognitive deficits in perception, memory, information processing and contingency-awareness, exacerbated by slow maturation, sensory and/or physical impairments and an increased likelihood of mental health problems (Hogg & Lambe, 2000). Research suggests that it can be a complex process to support people with PMLD to establish social relationships and communication, often demanding specialist training and a great deal of perseverance (Watson, 1985, 1994).

Sheehy & Nind (2005) report that people with PMLD are disadvantaged due to the interaction between their disability and the unsupportive environment that is provided from the community. They report that negative attitudes about people with PMLD have been a barrier to greater development and thus, research and applied clinical work have largely been considered hopeless.

Samuel (2003) suggests the best way of understanding the needs of people with PMLD is through the use of a contextual model. A contextual model of PMLD takes into account innate maturational factors, developmental age equivalence, reinforcement and contingency awareness, a unique life history of learning experiences, and construes the individual with PMLD as an active participant in their own development (Samuel, 2003). It is through the use of this model that researchers and clinicians have begun to explore the dynamic social context of early life as a starting point in engaging people with PMLD (Wolfensberger, 1998) and early caregiver-infant interaction has been cited as a model for developing relationships with people with PMLD (Ephraim, 1997). In early caregiver-infant interaction caregivers initiate, maintain and respond contingently to the infant's behaviour (vocalisations, gaze, expression, proximity, gesture and touch) and this enhances motivation to repeat and develop interactive games (Carlson & Bricker, 1982; Schaffer, 1977; Stern, 1983). In practice, many carers of adults with PMLD intuitively use these types of approaches with their clients (Samuel, 2003). It is through consideration of the contextual model described above and the influence of a developmental understanding of caregiver-infant interaction that Nind & Hewett (1994, 1998, 2005) have developed a specific interactive approach called 'Intensive Interaction' which is aimed at engaging people with PMLD.

1.2. Intensive Interaction

1.2.1. Background

Nind and Hewett (1994, 1998, 2005) developed II as an approach aimed at enhancing interaction with people who use basic pre-verbal means of communication, and who have difficulty interacting with others. II is designed to improve the responsiveness of carers thereby improving the interactive and communicative abilities of people with severe and profound learning disabilities and enhancing their social inclusion. When II was first utilized with people with PMLD there was some evidence to suggest that gains were made in communication and social interaction, as well as a reduction in challenging behaviour (Nind & Hewett, 1994).

1.2.2. Aims of II

Nind and Hewett (2005) have conceptualised the main aims of II as; developing sociability and increasing the enjoyment of social contact, developing communication abilities such as eye contact, enhancing cognitive abilities where the individual learns to use and understand social cause and effect, promoting emotional well-being through the building of self-esteem, and directly supporting staff using II to reflect on their work.

1.2.3. The Process of II

II uses a range of interactive games that have been shown to occur in interactions between infants and their caregivers (Nind & Hewett, 1994). The learner is engaged in one-to-one interaction which is built from their actions, sounds or expression (Nind &

Hewett, 2005). The emphasis is placed on mutual pleasure and the participant develops a sense of control and empowered because they can lead in the direction they choose (Nind & Hewett, 1994).

1.2.4. Evidence base for II

To date, the evidence base for II has been limited but there is growing interest in the technique throughout a variety of different applied studies. Since Nind & Hewett (1994) outlined the theory and methodology of II, other studies have provided narrative accounts of its success as described by parents and carers who have used II (Caldwell & Stevens, 1998; Hawkins, 1998; Hewett & Nind, 1998; Nind & Powell, 2000; Kennedy, 2001, Irvine, 2002). These accounts have relied on case examples and subjective evaluations of effectiveness as their main source of evidence and have lacked any formalized observation of behavioural change, baseline measurements or follow up. Only the practitioners' perceptions of change were studied. This review will concern itself with studies of II that are based on more robust methodological designs although most of the evaluations and research that have been carried out have been small scale and limited over time.

As II was being developed, Nind (1993; 1996) conducted a single subject multiple baseline design to search for changes in six adults with severe and profound learning disabilities over an 18 month period. Two sessions of II were provided per day, each session lasting approximately 10 – 15 minutes. Video taped analysis of behaviour was used to assess change. Nind found that participants engaged in more smiling contingent

on the activity of the teacher and interacted more while being engaged in one to one games. All six showed improved ability to reciprocate warm physical contact and demonstrated advances in communication. Follow up data was not collected and there was no evidence of changes in the behaviour of the participants outside of the II sessions.

Watson and Fisher (1997) studied the use of II with six pupils aged 10-19. Four sessions of II were scheduled per week and practitioners kept written records about their experiences. Video tape was also used to observe behavioural change over time. Over a six month period it was observed that three of the pupils showed significant progress in terms of their ability to communicate and sustain interaction with their carers. Informal interviews were conducted with the practitioners and the anecdotal data from these interviews suggested that there was an overwhelming consensus among the practitioners that II was achieving great benefits for the pupils. (See Knight and Watson 1990; Watson and Knight 1991; Watson 1994; Knight, Watson and Fisher 1997). This study did not use any baseline or control design to demonstrate change in the group of participants and there were no checks made that each practitioner was using the same sort of techniques.

Jones & Williams (1998) carried out a single case study which found minimal reduction in the stereotyped behaviour of a 35-year-old man with PMLD in response to II. However, Jones & Williams (1998) note that under scrutiny, it appears that the only component of II used by the practitioner, who was a novice in the use of II, was imitation.

Lovell, Jones and Ephraim (1998) used a single case experiment to compare II with another condition of just being in close proximity to the participant. Nine 5 minute II sessions and eight 5 minute 'proximity' sessions were conducted over a week long period and the data was analysed using 10 second momentary time sampling from video recording. Both conditions were associated with an increase in the participant looking at the practitioner, increased joint attention, smiling, laughter and initiation of physical contact, however, these increases were marginally greater in the II condition. Because the two conditions were used interchangeably throughout the week long study and the same practitioner was used to facilitate both conditions it is possible that the effect of one condition may have influenced the effect of the other. Also, the study was too short to compare these two conditions thoroughly enough to draw accurate conclusions.

Elgie and Maguire (2001) used II with a 39-year old woman with PMLD who also presented with severe self-injurious behaviour. Video observation was used during the brief sessions of II. Intervention occurred 3 times per week for a total of 16 weeks. Results showed an increase in vocalization and physical contact initiated by the client but there was no change in frequency or severity of self-injurious behaviour. There was no evidence of assessment of these effects being generalized across different environments or with different people.

Kellett (2001) attempted to evaluate II with 6 children (aged 4 to 11) in a community special school. Kellett found evidence of positive increases in communication and social abilities in all 6 participants. Specifically, an increase in participant's attention to facial

gaze, joint focus on activities and eye contact were notably enhanced. Stereotypy was seen to be reduced across all participants and contingent vocalization began to increase gradually as the study continued. This study reported that changes were consistent over time and generalized outside of II sessions, however, it is not clear whether the changes in behaviour of the participants generalized to interactions with other people, or were only evident when the participants were interacting with the II practitioners.

Samuel (2003) adapted the design of Nind (1993; 1996) to evaluate the impact of Intensive Interaction used by home support staff with four adults with PMLD. Video taped analysis was used over a 20 week intervention period. It was found that all four women developed their communication and social abilities. However, when the practitioners use of II was analysed it was found that some of the practitioners were not using II as they had been trained. Also, there was a lack of follow up data, a lack of analysis as to the generalisability of the changes across other environments, and two of the four participants were receiving other therapeutic input contemporaneous to the intervention of II.

1.3. Practitioners of II

Nind & Hewitt (2005) report that II can enhance the emotional attachment of practitioners to clients that they are working with. It has been suggested that some staff may lack the skills to use II properly and to interact with services users in such an intense manner (Nind & Hewitt, 2005). Nind & Hewett (1998) and Nind & Kellet (2002) suggest

that good teamwork is important because it can support free and honest reflection on practice, discussion of feelings and problems with different individuals.

Nind and Hewett (1994) propose that because II can be an intense experience for practitioners, staff should keep detailed session records so that they may reflect on the process of II and learn from what they have already done. Practitioners are encouraged to record thoughts, feelings and suppositions and to search for understanding in how each session of II has made them feel about themselves and about their clients (Nind & Hewett, 2005).

There is some indication that staff and carers feel that using II has a positive impact on their skills as a carer and may change the way they feel about their work and their interactions with clients (Elsworth, 1999). Elsworth explored the views of ten volunteer home support staff that used II with adults with PMLD. Interviews were conducted and the content analysed into six different themes (practitioner's understanding of II, content of II relationships, the effects of II, problems with II, organizational factors, service development issues). Results showed that all staff viewed II very positively and that they perceived an improvement in both participant and practitioner interactive skills and felt that their relationships with clients were more pleasurable. This study was completed on a very small scale, with no formal method of interpreting the qualitative data and thus, the evidence is less substantial than would be necessary to draw more concrete conclusions. However, one important result that emerged from this study is that several of the participants suggested that using II increased their feelings of self-efficacy. This finding

is particularly important because staff feelings of self-efficacy have been shown to have an impact on their ability to interact positively with clients.

Self-efficacy has been defined as: 'beliefs in one's capabilities to organize and execute the courses of action required to manage prospective situations' (Bandura, 1995, p2). Lazarus and Folkman (1984) report that the objective measurement of the ability of care staff to manage prospective situations was not as important as the individual's perception of their own efficacy. They found that this perception of their own self-efficacy had an effect on carers' ability to work positively with their clients. Hastings & Brown (2002a) further found that staff feelings of self-efficacy were predictive of their emotional reactions to clients that present with learning disabilities.

Hastings (1997) suggests that the importance of understanding the carer's context is overlooked in traditional studies of care for people with learning disabilities. He depicts a model of carer and client interaction that suggests that the antecedents and consequences of the carer's behaviour towards the client must be incorporated into the picture of the client's behaviour. This model proposes that the thoughts and emotions of the carer towards the client will have an effect on the interaction between the two and the overall emotions of the client. Hastings' model highlights the co-dependence of the carer's and client's feelings towards each other and because of this he suggests that more research should be directed at understanding the carer's feelings towards service users.

Further studies related to staff emotions about clients have found that staff working with people with high levels of dependence are more likely to have negative emotions about their clients and are more likely to suffer from stress (Mansell, 1995; Dyer & Quine, 1998; Rose et al., 1998). Staff working in specialist units for people with PMLD have been found to be significantly more emotionally exhausted than staff working in mental health settings (Chung, Corbett & Cumella, 1995). Stress and emotional exhaustion have been shown to have detrimental effects on staff perceptions of their work and of their clients (Bromley & Emerson, 1995). Difficulties in caring for clients and reports of work related stress were found to be positively correlated with staff burnout (Bromley & Emerson, 1995) and staff who were stressed or burnt out were more likely to avoid interaction with clients and act in a depersonalized way, thus greatly reducing the quality of emotional care provided to clients (Mitchell & Hastings, 2001).

1.4. Further Research

Following from Hastings (1997) model and the literature related to stress and burnout it seems that staff feelings about their clients, their work, and their perceptions of their own self-efficacy may have a significant effect on their interactions with clients. Considering that reports of II have found that the technique can have heightened emotional impact on staff (Nind & Hewett, 2005) and that II is used predominantly with people with the highest support needs it seems particularly important to consider the perceptions of staff who are using II to develop an understanding of any significant emotional impact on practitioners.

1.4.The current study

This study will investigate the perceptions of care staff who use II with their clients with PMLD. To date, there has only been one formal study of the perspectives of care staff who are using II (see Elsworth, 1999) and this study was more concerned with practical aspects of II such as; practitioner's understanding of II, content of II relationships, the effects of II, problems with II, organizational factors, and service development issues rather than attempting to extrapolate individual meaning about staff feelings and beliefs.

The intention of the current study is to act as a starting point to resolve this gap in the II literature and consider how an understanding of II from a care staff perspective will help to enlighten current knowledge of the process of II and inform clinical practice. Care staff using II will be interviewed using a semi-structured interview schedule and the results will be analysed using Interpretative Phenomenological Analysis (IPA). In using a qualitative model this study will enable the participants to describe their experience without overtly guiding their responses by imposing rigid predetermined categories. Instead the interview schedule will use much broader categories based around the components of staff interaction, self perceptions and thoughts about clients and work. Therefore the collection of the data will be guided by what is important to the participants, allowing for difference in individual experience.

The project will investigate the following questions:

1. Does the use of II change the way staff feel about their clients, and if so, how is this change manifest?

2. Does II change the way staff feel about their work, and if so, what changes are apparent?

3. Does II change the way that staff feel about themselves, and if so, what do staff report is different?

The study will be aimed at exploring individual meaning and will attempt to examine care staff's perception of II in the context of inclusion and validation.

2.0. Method

2.1. Setting

The current research was undertaken across two different day services for people with learning disabilities. Both were located in the same London borough and incorporated several different teams of staff who support the needs of people with PMLD. Each of these staff teams currently use II to support people with PMLD in their service and all members of staff had been trained in II by experienced trainers who also supplied ongoing weekly supervision.

2.2. Ethical Considerations

Ethical approval for the study has been granted by the local NHS Healthcare Trust Research Ethics Committee (see Appendix 2). An Information Sheet (see Appendix 3) was sent out to possible participants to outline the study and describe what it would entail. Confidentiality was emphasised and participants were reassured that any identifying details of either themselves or any clients that they discussed would not be part of the research study. Also, participants were assured that participation was purely on a voluntary basis and any participants had the right to withdraw at any time. All participants were asked to sign a Consent Form (see Appendix 4) to indicate that they fully understood their participation, the aims of the study and their rights to privacy, confidentiality and to withdraw. Provision was made for participants to talk over any issues that arose from taking part in the research project, before, during and after the interviews took place.

2.3. Participants

2.3.1. Inclusion Criteria

This study included staff who had been trained in Intensive Interaction and had been using this technique to work with adults with PMLD for at least 3 months.

2.3.2. Recruitment Process and Procedure

As described above, participants were recruited from one London borough. Information regarding the aims of the study, the inclusion criteria and the methodology were circulated to relevant staff by posting fliers (see Appendix 1) around the notice boards of several different work places. Prospective participants who phoned to ask for additional information were offered the chance to discuss the project with the researcher prior to taking part.

2.3.3. Demographic details

Of the 12 participants that took part in the current research study, all 12 were employed as care workers for people with PMLD. In terms of working with people with learning disabilities, the average amount of caring experience was 8 years with a range of 2 years to 25 years. Of the twelve participants the average amount of experience using II was 9 months, with a range of 3 months to 3 years.

The age range of the participants was between 27 and 58 years with a mean age of 33 and in terms of gender, 8 participants were female and 4 were male. Of the 12 participants, 5 described themselves as being from a white British ethnic background, 4 described themselves as being from an Asian ethnic background, 2 described themselves as being from a Black African ethnic background and 1 participant reported that they were from a Black Afro-Caribbean ethnic background.

2.4. Researcher's Perspective

It is good practice in Qualitative research for the researcher to state personal biases that might have an influence on their research (Elliot, Fletcher & Rennie, 1999). The idea for the research was influenced by many aspects of my clinical work with people with PMLD and my training in the use of II. I have always been interested in care staff's perception of their work because I believe that feelings of self-efficacy and job satisfaction have a great influence on staff interaction with clients.

As a residential support worker, a day service support worker and an assistant psychologist, I had always been struck by the feeling of hopelessness which accompanied staff working with people with PMLD. Sitting with someone and trying to help them when they are unable to look at you, speak to you or even acknowledge your presence can be a humbling experience. It was this type of experience that led me to search for a better way of communicating with people with PMLD and from this search I found that II allowed me to 'connect' to my clients in a more productive way and helped me to feel less hopeless. I have often felt that the views of 'front line' care staff have been neglected

and through conducting this research I hoped to better understand their feelings about themselves and their clients

2.5. Measures

2.5.1. Procedure

All interviews took place at the participant's place of work. At the beginning of the interview each participant was ensured of the confidentiality of the interviews, of their anonymity, and that they could stop the interview for a break at any time. All interviews were tape recorded with the participants' permission. At the end of each interview the participant was offered an opportunity to talk about how the interview felt and ask any questions that they might have. The researcher also gave the participants their phone number in case they wished to discuss any issues arising from the interview in the future. Participants were informed that they would have the opportunity to review the results of the study with the researcher to check that they had been represented correctly. A summary of the results of the study was sent to each participant at the conclusion of the research project.

2.5.2. Semi-structured interviews

A semi-structured interview schedule was designed for this study. (see Appendix 5). In designing the interview the researcher was informed by literature describing the aims and assumptions of II, and several published vignettes of staff working with people with PMLD.

Themes for the interview questions:

- Job satisfaction
- Staff feelings and emotions during a session of II
- Staff self-efficacy
- Personal development/growth
- Changes in feelings about clients
- Intuition

The interview style was one of directed conversation (Pidgeon & Henwood, 1996). The format was to pose open-ended questions which did not request specific answers but instead aimed to facilitate thoughtfulness and creative exploration.

2.6. Analysis of Qualitative Data

All interviews were transcribed verbatim and were analysed using Interpretive Phenomenological Analysis (IPA; Smith, Jarman & Osborn, 1999).

2.6.1. Rationale for using IPA

IPA is concerned with gaining understanding and insight into the nature and essence of individual experiences within particular contexts and at particular times. It does not try to develop theory about the construct under examination but instead it wishes to freely and creatively value individual meaning and belief. Due to the interpretive nature of the researcher's analysis, IPA also hopes to be able to comment on an individual's thinking about a topic. This technique fits well with the analysis of the perceptions and individual

understanding of a group of staff using II, and in fact, II stresses the importance of staff reflection after each session to record insights into the meaning of their work.

2.6.2. Data Analysis

The transcribed data was analysed through several stages. Firstly, the researcher read through the transcripts several times and noted down meanings and associations. Secondly, these notes were refined into a variety of different sub-themes. Thirdly, these sub-themes were referenced back to the original transcript to find relevant quotations illustrating each theme. Once this had been done for one transcript the same sub-themes were used to analyse further transcripts, and themes were refined or added during the process to come up with larger, more general global themes. An example of an excerpt from one transcript is included in Appendix 6, the main ideas noted down from this transcript are displayed in Appendix 7 and the themes derived from this transcript are shown in Appendix 8. Themes from all 12 transcripts are displayed in Appendix 9.

2.6.3. Credibility Checks

A credibility check of the themes resulting from the analysis was undertaken by a second researcher who is experienced in IPA. After independently reading the transcripts both researchers discussed the themes and a consensus was reached about how accurately the themes represent the data. A final draft of themes and sub themes was agreed by both researchers.

Finally, participants were contacted and were offered the opportunity to meet with the researcher to verify the validity of the results and themes that had been developed. This was to ensure that each participant's data was correctly represented by the results.

3.0. Results

3.1. Notation

Throughout the results section there are two main notation devices used to assist in describing the raw data. Firstly, (.....) is used to indicate where text has been omitted from direct quotations. Secondly, each participant is denoted with a number used to ensure anonymity.

3.2. Organisation of themes

The analysis of data began with the researcher reading through the transcripts several times and noted down meanings and associations. These notes were then refined into a variety of different sub-themes. Thirdly, these sub-themes were referenced back to the original transcript to find relevant quotations illustrating each sub-theme. These sub-themes were then analysed and grouped together when it was felt that they related to the same global theme. Once this had been done for one transcript the same themes and sub-themes were used to analyse further transcripts, and these were refined or added to during the process. At times, sub-themes concerned opposite ends of a continuum (e.g., exerting control vs. relinquishing control). Three main themes emerged. These themes were 'Exerting Control vs. Relinquishing Control', 'Making a Connection, and 'Thoughts about the wider care system'.

The first of the themes is constructed from six sub-themes which relate more specifically to the data, 'Not knowing what to do', 'Fear of clients' behaviour', 'Needing to be in control', 'Enjoyment of working with clients', 'Letting clients lead', and 'Feeling vulnerable'.

The second of the themes, 'Making a Connection' is constructed from nine different sub-themes drawn from the data 'Viewing clients as part of the furniture', 'Being in the clients' shoes', 'Listening to clients' emotions', 'Dissociating from clients' feelings', 'Making sense of emotions about clients', 'Talking about your feelings', 'Confusing roles and relationship', 'Security guard vs. friend, and 'Care worker vs. carer'.

The third theme, 'Thoughts about the Wider Care System', is constructed from three sub-themes, 'Working in an inflexible system', 'Managers want to control Intensive Interaction', and 'Person centred working'.

A summary of how each theme is constructed from the sub-themes is illustrated in Table 1 and a table of how each participant's data contributed to each theme can be found in Appendix 10. This section will describe each theme in turn using excerpts from the transcripts to illustrate the theme.

3.3. Exerting Control vs. Relinquishing Control

This theme is composed of six sub-themes.

3.3.1. Not knowing what to do

When asked how they felt when working with people with learning disabilities before using II, participants frequently talked about not knowing what to do in one to one

Table 1: Summary of themes and sub-themes

Overreaching Theme	Sub-themes
Exerting Control vs. Relinquishing Control	<p>Not knowing what to do</p> <p>Fear of clients behaviour</p> <p>Needing to be in control</p> <p>Enjoyment of working with clients</p> <p>Letting clients lead</p> <p>Feeling vulnerable</p>
Making a Connection	<p>Viewing clients are part of the furniture</p> <p>Being in the clients shoes</p> <p>Listening to clients emotions</p> <p>Dissociating from clients feelings</p> <p>Making sense of emotions about clients</p> <p>Talking about your feelings</p> <p>Confusing roles and relationships</p> <p>Security guard vs. friend</p> <p>Care worker vs. Carer</p>

Thoughts about the Wider Care System	<p>Working in an inflexible system</p> <p>Managers want to control Intensive Interaction</p> <p>Person centred working</p>
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interactions with services users. Many felt that they were unable to communicate with the people in their care, either due to their unusual communication styles or their profound learning disabilities.

‘I didn’t know what to do, she was flapping her arms and saying something about a rabbit, then she bit me’ (P2)

‘We didn’t know what to do so we just had to leave him on his own’ (P2)

3.3.2. Fear of Client’s behaviour

Another theme to emerge amongst many of the participants was, worry about working with services users in their care. Participants described these feelings as scary and upsetting, and it seemed that these concerns were related to the, at times, unpredictable nature of clients’ behaviour.

‘I was going to work just scared of being hit or bitten, feeling like I didn’t have enough skills to help him or help myself’ (P2)

‘How can you work with someone like that and still feel positive?’ (P6)

3.3.3. Needing to be in Control

Some of the participants reported that they worked with service users through exerting control. Participants reported that they would be directive and in control over service users. Some of the participants suggested that this helped them to feel safer.

‘I needed to exert some control over people otherwise I would feel helpless and stupid like I didn’t know what to expect next (P1)

‘It was just such a messy place, having to deal with people in such distress that it was better to get in first and get people busy and sorted before they blow’ (P7)

Other participants suggested that their tendency to be directive and controlling with clients arose due to a fear of things going wrong and being blamed by management.

‘Managers would come in and do spot checks to make sure that all the clients were quiet and occupied, we would get it in the neck if there was any disturbance’
(P2)

3.3.4. Letting Clients Lead

On reflecting on their experiences pre and post the introduction of II many care participants talked about the benefits and difficulties of letting clients lead in the one to one interactions that took place during II sessions. They suggested that letting clients lead could be very beneficial for the development of trusting relationships between staff and

clients as well as feeling rewarding for staff who started to get positive feedback from clients.

‘He took the lead and rolled the ball back to me and that was just incredible, I said “Yes” really loud and scared the life out of him.....even this tiny thing seemed like we had climbed Mount Everest (P2)

Other participants suggested that letting the client take control was worrying because it was not possible to predict what they would do and it might become difficult for staff if clients got used to being in control of the relationship that they had with staff.

‘If I got too close to him emotionally, he wouldn’t see me as someone that he needed to be respectful of’ (P7)

3.3.5. Feeling Vulnerable

When participants described accounts of letting clients lead and of relinquishing control these were often accompanied by feelings of vulnerability and uncertainty about what changes might occur in the staff-client relationship due to using II.

‘When you get too close to people, emotionally, you end up getting badly hurt (P7)

‘You make yourself vulnerable by giving up control and letting them lead and take the initiative’ (P12)

3.3.6. Feeling empowered through relinquishing control

In comparison to the above accounts many staff started to enjoy the relationship that developed with the client after relinquishing control of the interaction. Many of the quotes indicate that care staff started to feel empowered as the relationship with the client developed and flourished.

‘I started working with him using II and developed a really good relationship with him’ (P5)

‘We had a very long and funny dialogue.....it felt really validating and familiar’ (P6)

‘It was almost like he had been waiting for me to let him have a go at certain things that he wanted to do, like he was just putting up with me calling the shots before but now he could show me more of himself’ (P7)

Finally, some of the participants reported that through relinquishing control over interactions they found that even clients who presented with challenging behaviour seemed to thrive in the new way of working.

‘After I worked with her using II for a while, she started to show me the ways that she needed to help herself when she became upset.’ (P5)

3.4. Making a Connection

This theme is composed of nine sub-themes.

3.4.1. Viewing clients as “part of the furniture”

Several of the participants reported that on reflection they did not feel very connected to clients. Some participants talked about clients as not having a proper presence and often being ignored. This was especially prevalent with clients who participants perceived as isolating themselves and avoiding contact with staff and other service users.

‘He used to just sit and rock back and forward, no one ever remembered him come in or go out, he was just there. I guess I stopped seeing him after a while....once, no one remembered his lunch, everyone felt terrible after that.’ (P5)

Some of the participants were able to look back at how they perceived clients in the past after having worked with people using II. From this benefit of hindsight participants were able to see changes that occurred in their clients that were previously ignored.

‘Now when he’s cross he looks cross, and when he’s happy he looks happy. Before he was just blank like furniture.’ (P4)

3.4.2. Being in the client’s shoes

Several of the participants suggested that II helped them to gain empathy with clients and they began to see the world from their perspective.

‘I thought, well if I was in his shoes, I couldn’t talk, I was having seizures, being a bit scared.....maybe I would express my emotions in the same way.’ (P5)

This insight sometimes helped to bring about a stronger connection and made it easier to understand clients’ emotions and develop an emotional relationship with them.

‘Intensive Interaction made me realise that everybody is the same, whether you can talk, whether you can sign, however you express your emotions, whether you have a profound learning disability or if you’re a doctor.....everyone is expressing the same emotions.’ (P12)

3.4.3. Listening to client’s emotions

Closely related to increased empathy and understanding of clients’ emotional lives was the sub-theme of ‘listening to clients emotions’. Many of the participants suggested that by recognising clients’ emotions they were able to start to empathise with them.

‘After using Intensive Interaction with him for nearly a year I started to feel some of the things that he was feeling, like he was telling me his emotions without words.....I would go home feeling a certain way and wonder whether it was his feelings or mine.’ (P3)

Many of the participants reported that clients could sometimes start to connect to staff at an emotional level in response to staff listening and accepting clients' emotions. This reciprocal emotional connection was often described as rewarding and enjoyable.

'He seemed to be looking at my eyes more as though he was trying to figure out what I was doing....then he started to move his body so that he was facing me, he was responding to me giving him time and listening to his feelings.' (P2)

'I was feeling run down and a bit fed up, he came and took me by the hand. It was unbelievable, he was taking the lead, now he was giving something to the relationship.' (P3)

3.4.4. Dissociating from clients' feelings

Through paying attention to the emotions being expressed by clients several participants felt that they had also become more able to recognise their own feelings about clients and about themselves.

'Working with people with profound and multiple learning disabilities and dealing with people's raw emotions means that I used to switch off from them. Otherwise you would always be feeling like what they were feeling.....
....Intensive Interaction means you switch that around and take other people's emotions again, it's hard, sometimes you think more about it after work' (P3)

‘I couldn’t imagine what it must be like to be trapped inside yourself like that, I didn’t want to think about it.....it was easier to just help people with their personal care and eating and moving and handling.’ (P1)

Some of the participants suggested that using II could sometimes be emotionally upsetting because of the difficulty of connecting to the emotions of their clients.

‘Intensive Interaction sometimes confronts you with terrible fearful emotions from clients. Sometimes I don’t want to work like that, I just want to do my job, keep people safe and go home at 4.30 and not think about it.’ (P5)

3.4.5. Making sense of emotions about clients

Several of the participants reported that they became more aware of their own emotions about clients and their reactions to clients’ feelings after using II.

‘Its hard working like that (using II), you feel really drained emotionally by the end of it.’ (P1)

‘It’s not a technique that you can use in isolation because you need someone who understands to listen to your emotions, just like you listen to the clients’ emotions.’ (P1)

3.4.6. Talking about your feelings

Some of the participants reflected on talking about their emotions either in supervision or with colleagues. Many suggested that it was important to reflect on the emotions brought up by using II but also that using II seemed to stimulate a more open discussion of emotions in the work place.

‘I think it is important to be able to reflect on the emotions that come up and to share these feelings of success or failure with others.’ (P10)

‘After using Intensive Interaction staff are more in touch with their emotions. People say “oh my god, he was hitting his head today and I just felt like vomiting”, or “I felt so bad for him I was paralysed with fear”, whereas before we would just talk about his behaviour, not how we felt.’ (P5)

3.4.7. Confusing roles and relationships

Several of the participants disclosed that through the use of II they became confused about the different roles and relationships they were having with clients. This role confusion was usually about the difficulty in reconciling a previous way of working with the new way of interacting through the use of II.

‘Sometimes using II makes me feel a certain way about a client and then I have to go back to working in my normal way for one reason or another and then that just seems strange, to me and to them I think.’ (P1)

‘If I’m in an Intensive Interaction relationship with someone, what happens the next time I’ve got to restrain them?’ (P7)

Two of the examples of such confusing roles are outlined in the sub-themes to follow.

3.4.8. Security Guard vs. Friend

Two of the participants reported that they worked with people who could often present with challenging behaviour. These participants described their role as ensuring that people were safe, ensuring that clients did not hurt themselves or others, and establishing and maintaining firm boundaries for people that needed to know what they should or should not be doing. One of the participants described their role as a ‘security guard’.

‘I’m standing around waiting for something to happen. I’m always on my guard, I have to jump in if things go wrong.’ (P7)

Both of these participants suggested that II was so different to the role they were used to occupying that they did not feel that it would work. There was concern about confusing the clients by acting in two different ways. They also felt if they relinquished their role of ensuring everyone’s safety the environment could become dangerous.

‘I could be trying to do Intensive Interaction, but I know that I have to quickly turn into someone who knows where the boundaries are, I can’t be their friend.’
(P11)

‘When I did Intensive Interaction it felt like I was promising something that I couldn’t always give. It’s too much like saying that I’m their mate, I can’t make deals like that.’ (P7)

3.4.9. Care worker vs. Carer

As noted previously, several of the participants talked about the strong emotions evoked when they used II with clients. Some of the participants were aware of the potential for these feelings to be confusing and problematic.

‘I started to feel quite motherly and that’s weird because I know I’m not supposed to feel that way about clients.’ (P1)

‘It brings out quite a loving feeling, sometimes I feel like I’ve been on slightly dodgy ground emotionally.’ (P10)

3.5. Thoughts about the Wider Care System

3.5.1. Working in an inflexible system

Several participants’ accounts suggested that the use of II led them to reconsider the wider care system they were part of. Mostly, they began to question the philosophy of care and felt a need for important changes.

‘It never feels that we’ve got enough time to be with people in a meaningful way, like using Intensive Interaction, and it’s like the management just make that time smaller and smaller.’ (P2)

3.5.2. Managers want to control Intensive Interaction

Several of the participants suggested that managers wanted to control the use of II. It was suggested by some that this was because of II bringing out the emotions of clients and that this was considered scary and unpredictable.

‘I feel more skeptical about services, they want to impose control because they are scared of challenging behaviour, scared of trying to interact with people who don’t give you feedback, so they try to put these emotions in a box and take control over the environment.’ (P1)

‘I think the managers need to make Intensive Interaction time limited ‘cause it does bring up emotions and people think its powerful and scary.’ (P3)

3.5.3. Person Centred Working

Several of the participants reported that they felt that II was an empowering way of working with people with PMLD and that it allowed staff to get to know people with learning disabilities in a much more meaningful way. Some also suggested that after using II, other methods of working seemed less valid.

‘I can relate to clients in a more meaningful way, that’s what really helps them, not hand over hand finger painting.’ (P1)

‘We still have to try to teach people numeracy and literacy even after using Intensive Interaction has been so successful. Its like I almost feel like I should apologise for this rubbish before we start.’ (P6)

4.0. Discussion

The analysis of the participant’s narratives of the use of II yielded three themes: ‘Exerting Control vs. Relinquishing Control’, ‘Making a Connection’, and ‘Thoughts about the Wider Care System’. This chapter will discuss the findings described at length in the results section and will consider each of the research questions in turn in. Following this, there will be a discussion of the results in terms of what they add to the understanding of the experience of using II with people with PMLD. Methodological limitations and their implications for extrapolating meaning from the results will be considered. Finally, there will be a discussion of the implications of the findings in terms of possible changes in clinical practice.

4.1. Research Questions

In the following the results will be considered in relation to the three research questions.

4.1.1. How does II change the way that staff feel about their clients with PMLD.

Examining the way care staff feel about their work and the people in their care is important (Jenkins, Rose & Lovell, 1987), and investigating factors which may impact on this can hold essential clues for improving work satisfaction and performance as well as client's well-being and quality of care (Bromley & Emerson, 1995). One useful model describing the importance of carers' feelings towards their clients has been developed by Hastings (1997). His model suggests that the emotions of the carer towards the client will have an effect on the interaction between the two and the overall emotions of the client. Hastings' model highlights the dynamic interaction between the carers' and client's feelings and he suggests that staff feelings about clients will have a direct effect on their emotions about themselves.

4.1.1.1 Staff feelings about clients before using II

Many of the participants in the current study described a change in the way they viewed their clients after using II. Through the benefit of hindsight participants were able to reflect on the ways in which they viewed clients prior to using II.

Firstly, many participants reported that they had not connected to clients' emotions in the past in the same way that they found that they did when using II. Sheehy and Nind (2005) suggested that people with PMLD have long been thought of as sub-human, not considered to have thoughts and feelings and thus it has been considered hopeless to attempt to connect to people with PMLD at an intellectual or emotional level. The current study suggests that some participants did view clients as "part of the furniture", perhaps

due to the dynamic interaction between staff and their clients outlined by Hastings (1997). Hastings suggests that negative attributes about clients' avoidant and uncommunicative behaviour can result in staff reducing their interaction with clients. Mitchell and Hastings (2001) found that the greater the negative emotional reactions that care staff reported about their clients the more likely they were to depersonalise clients.

Secondly, several of the participants described themselves as viewing clients' emotions in simplified ways. This notion has been explored by Evans and Ware (1987) who suggested that people with profound learning difficulties have largely been viewed as passive respondents in interactions with others. Following from these perceptions, Smith et al. (1983) reported that previous clinical work with people with PMLD has depicted clients as simply reacting to environmental stimuli rather than using any complex processes of integrating information and responding in an active and determined way. Sinason (1994) distinguishes emotional and intellectual intelligence and suggests that many people have previously equated the emotional intelligence of people with PMLD to that of intellectual intelligence, and thus, clients' emotions were seen as profoundly disabled.

Thirdly, participants reported that before using II they had been reluctant to get involved in the emotional lives of their clients. Psychodynamic writing may help us to understand some of the processes involved in staff-client interactions. For example, Sinason (1994) suggests that carers of people with PMLD are unable to connect to the painful emotions and painful experiences of people with PMLD because of the negative feelings brought

about by such difficult emotions. This can lead to a rejection of the emotions of people with learning disabilities. Many of the participants in the current study recognised that before using II they would frequently dissociate from clients in various ways and that this sustained patterns of negative interaction with clients. Mitchell & Hastings (2001) suggest that dissociating from the painful emotions of clients may be one method of coping with the stress of working with people with learning disabilities.

Fourth, participants talked about clients as being unpredictable and scary. Bromley and Emerson (1995) suggest that care staff working with clients who they consider to be unpredictable have reported that they are anxious about engaging with these clients and are less likely to interact in a positive manner. Because of the reduction in positive interaction Emerson (1995) suggests that clients are less likely to respond positively and the development of a relationship where carers are able to learn about and understand their clients is less likely to occur. This means that negative relationships are sustained because care staff may never adequately understand their clients' emotions and behaviour in order to reduce the perception of their clients' actions as being unpredictable. The difficulty of understanding or predicting the behaviour of clients whilst coping with the 'daily grind' is one of the most prominent sources of carer stress in the workplace (Bromely & Emerson, 1995). This process of sustaining negative interaction styles is apparent within the results of the current study during participant's accounts of their interaction with clients before they started to use II.

4.1.1.2. Staff feelings about clients after using II

After beginning to use II, participants described a change in the ways they thought about clients. Participants felt that the process of II helped them to understand their clients and their client's emotions in a different way, as denoted by the sub-themes, 'Being in the clients shoes', and, 'Listening to client's emotions'.

Participants suggested that they were more able to put themselves in the client's shoes. Nind (1986, 1999) and Nind and Hewitt (1988, 1994, 2005) provide a plethora of anecdotal reports about carers and care staff being able to understand the world from their client's point of view. They suggest that II is useful in developing this empathy and that care staff are often able to build up knowledge about their clients through the long term use of II (Nind & Hewett, 1998). In the current study empathy also seemed to enable participants to gain a better understanding of their client's needs and build more meaningful emotional relationships with their clients.

Nind and Hewitt's (2005) suggest that II helps staff to develop 'deeper' emotional relationships with their clients and that the use of II can make the practitioner reflect on their own emotions in relation to their clients and themselves. Some participants in the current study reported that they were able to identify clients' emotions in a more differentiated way and to recognise similar emotions in themselves. Others suggested that they would feel stronger emotions about clients throughout their working day and hold on to client's emotions after work. This finding also fits with Sinason (1994) who suggested that carers of people with PMLD could learn to 'open themselves up' to their clients'

painful emotions and that this could lead to rumination about these emotions unless carers could express them and understand them.

Furthermore, participants reported that they started to think about clients in more complex ways. They began to recognise that their client's emotions and motivations for certain behaviours were more complex than they had previously recognised. Samuel (2003) reports evidence that care staff started to recognise thoughts and feelings differently in their clients after using II and Jones & Williams (1998) suggested that using II could help in thinking about individuals' behaviour in the context of their environment rather than attributing negative behaviour to internal motivators.

Similar to Nind and Hewitt (2005) the current study found that participants reported that their relationships to clients with challenging needs seemed to change after using II. Some participants reported that clients seemed to develop their own ways of coping with difficult emotions rather than being directed or instructed by staff. This seemed very empowering for care staff and clients and further contributed to care staff beginning to attribute greater complexity to the emotions and thoughts of clients with PMLD.

Finally, some participants felt that their clients started to reciprocate the emotional connection that had been made and participants felt that this 'feedback' was very rewarding. This seemed to sustain and reward the enhanced emotional input and connection that was being made by the participants. Hastings (1997) highlights the co-dependence of carers' and clients' reinforcement schedules and stresses the importance of

mutual and reciprocal rewards being inherent in this dyadic relationship. Hastings and Brown (2002) suggest that carers' attributions about clients' behaviour can be very influential in terms of carers' response to the client's emotions and behaviour. Therefore, the emergence of reciprocal rewards in the emotional relationships between staff and clients could be seen to be important in sustaining the relationship in the future.

4.1.1.3. Summary of the first research question

The current study indicates that care staff perceptions and interactions with clients change in multiple ways after using II. Participants previously described clients in more simplified ways in terms of their emotions and their interactions with staff. However, through the use of II some participants found that they were able to develop an emotional connection to clients. Furthermore, their perceptions of clients' behaviour changed and they started to attribute more positive agency to clients' behaviour, such as perceiving the clients as reciprocating the emotional connection and helping to develop the relationship.

4.1.2. How does II change the way staff feel about their work?

The findings indicate the II can lead to numerous changes in the way staff feel about their work, namely, changes in perceptions about their role, their work environment, and the wider care system.

4.1.2.1. Staff perceptions of themselves as a care worker

Several themes emerged from the data that relate to care staff's perceptions of themselves as care workers.

The need for reflective supervision

Nind and Hewitt (2005) suggest that all II should be carried out with the backing of proper supervision due to the fact that the emotional connection and interactions with clients can be stronger when using II. It was apparent from participant's accounts that care staff needed to be able to discuss these emotions in a reflective way so that they were able to identify their own feelings about clients and themselves with an emphasis on understanding and expressing difficult emotions so that they could go back to clients without having these emotions lingering and affecting their ability to interact in a positive way. Ager and O'May (2001) suggest that a lack of such reflective emotional support poses a significant risk of burnout. There was also evidence that staff felt that they might not be able to sustain the use of II because of the difficult emotions that this way of working sometimes brought up.

Ager and O'May (2001) also found that staff perceptions of support from managers and colleagues was directly related to feelings of self efficacy at work and that self-efficacy was related to the amount of positive interaction directed towards clients. From these findings it seems that the amount of support given to staff using II is crucial in determining their ability to work positively and feel positive about themselves. This relationship emerges in other areas of the discussion as a maintaining factor in staff feelings of empowerment. Due to these findings it may be that where regular clinical/client focussed supervision is not available the introduction of II may be inappropriate.

Stress vs. Job Satisfaction

The notion of stress and its relation to burnout and emotional problems in carers of people with PMLD has been well documented in the Breaking Point Study (MENCAP, 2003). Furthermore, Lawson and O'Brien (1994) found that staff that were burnt out were more likely to avoid interaction with clients and act in a depersonalized way, thus greatly reducing the quality of emotional care provided to clients. Many accounts from participants in the current study suggest that they had previously found that interacting and working closely with their clients with PMLD could be difficult and lead to stress in their job. Many of the participants suggested that this affected their level of interaction with clients and their feelings about themselves as workers. Research confirms the reflections of the participants, suggesting that occupational stress leads to ill health (Rose, 1995), poor professional performance (Hatton et al, 1995), reduced job satisfaction and the likelihood of leaving employment (Guppy & Gutteridge, 1991).

Donaldson (2002) suggests that care staff stress may be partially ameliorated by feelings of successful work with their clients with learning disabilities and Hatton & Emerson (1993) report that job satisfaction and the decrease of staff stress were partly predicted by peer recognition of success. Participants' accounts in the present study suggest that after using II there was a reduction in stress in their jobs and an increasing job satisfaction. From the data it can be seen that stress may have been reduced because staff felt that they were more successful and efficacious in their jobs after using II.

In contrast, some of the participants suggested that the use of II could bring about anxiety and stress because of a heightened awareness of emotion in themselves and in clients.

Sinason (1994) suggests that people caring for people with PMLD often 'shut off' from the 'unbearable' emotions that they perceive in their clients and that when confronted with these emotions carers can find it very difficult to sustain emotional engagement with their clients. In the current study it was suggested that II was sometimes "put it a box", or kept separate from other aspects of care workers responsibilities because of the anxiety of taking on board clients' painful emotions and dealing with the feelings that this brought up in staff. Sinason (1994) suggests that dissociating from painful aspects of work with people with learning disabilities can be a defence against taking on board the painful emotions of clients.

4.1.2.2. Staff perceptions of the wider care system

Throughout participants' narratives it was evident that the use of II led to a re-evaluation of care practices and the wider care system.

Nind and Hewitt (2005) suggest that II should be used throughout the day and in every interaction with clients with learning disabilities. Some of the participants in the current study suggested that their managers wanted staff to be in control over clients and over the environment because they were scared of unpredictable and unsafe emotions and behaviours of clients. Nind and Hewitt (2005) suggest that only using II during limited weekly time periods may not be as beneficial as using it in a more global context throughout the week, however, in view of the lack of empirical evidence, at present it is

impossible to understand the consequences of using II in a separate time tables manner compared to a fully integrated manner.

Recent government literature has suggested that people with learning disabilities must be empowered to take the lead in their own lives (DoH, 2001a; Disability Rights Commission, 2004) and the need for the wider care system to empower people with learning disabilities to take an active role in developing relationships has been highlighted (DoH, 2001a; Ware, 2004). Some of the participants in the current study noted that the wider care system did not always share the philosophies underpinning II. Many of the participants reported that they felt that using II was very empowering for the client and allowed the staff member to achieve greater understanding and empathy with client. However, several of the participants suggested that this work was in direct contrast to other activities that were seen as valuable by the wider care system, such as activities that emphasised the production of a tangible outcome (e.g. finger painting, arts and crafts, and numeracy and literacy exercises).

4.1.2.3. Summary of the second research question

From the current data it can be seen that II may have an effect on the way care staff feel about their work, in terms of the changes in roles, changes in the way they perceive themselves as workers, and changes in their perceptions of managers and the wider care system. The need for reflective supervision was raised and this related closely to the idea that II triggered more emotions and more emotional talk from care staff working in this way. Some staff felt that II helped to alleviate stress and increased job satisfaction while

others experiences concern about the intense feelings triggered and their capacity to continue with II. A full understanding of the impact of II on staff stress would seem very important because stress has been shown to have significant negative effects on many areas of relationships and working lives. Finally, the basic aims and objectives of the wider care system in terms of working in a person centred way and empowering clients came under scrutiny after using II.

4.1.3. How does II change the way staff feel about themselves?

The third question posed by the current research study was to ask about how staff feel about themselves. The results of the current study show that there are changes in staff feelings of self-efficacy, staff perceptions of control and their understanding of the different roles that they play as a care worker.

4.1.3.1. Staff feelings of Self-efficacy

Hastings and Brown (2002) found that staff feelings of low self-efficacy were predictive of less positive emotional interactions with clients. The data from the present study suggest that prior to using II, many of the participants experienced themselves as not knowing what to do, being confused, helpless or deskilled when it came to working with clients with PMLD.

Staff feelings of lower self-efficacy have also been shown to result in higher levels of fear/anxiety reactions to clients (Hastings & Mitchell, 1998). This can lead to a reduction in positive interactions with clients, greater feelings that clients are unpredictable and less feelings of self-efficacy in staff (Hastings & Brown, 2002). In the current study it was found that the use of II led to an increase in care staff feelings of self-efficacy. In light of the evidence cited regarding the association between self-efficacy and interaction with clients this area clearly merits further investigation.

Nind and Hewitt (2005) provide similar reports from staff that they have supported to use II and their anecdotal evidence of increased staff efficacy is mirrored by the results of the current study. From participants' accounts it seems that staff using II reported more positive experiences of mutual fun and enjoyment, along with the positive feedback from clients, leading to feelings of self efficacy. This example of interdependent reward fits with the model of carer/client relationships depicted by Hastings (1997) in that it seems that carer's interaction with clients has been positively reinforced by feedback, leading to an increase in future interaction and engagement. This new pattern of interaction and mutual reward seems to have broken the circular relationship of negative experiences and low self-efficacy described previously by care staff before they started to use II.

4.1.3.2. Staff feelings of Control

Whittington and Burns (2005) found that staff often felt vulnerable and out of control when working with their clients and that many of them would become more directive and controlling in their interactions when they felt this anxiety. This finding fits with the

current research because participants reported feeling vulnerable and out of control when working with their clients with PMLD. In an attempt to alleviate these feelings participants suggested that they attempted to control their environment through being directive and authoritative with clients to ensure that they were in charge and that there was a limit to the unpredictable and anxiety provoking behaviour of clients.

Also, several of the participants suggested that managers and professionals were also anxious about the behaviour and emotions of the clients and that they stimulated this anxiety in the participants and sometimes even enforced the need for control over the environment.

The current data show that subsequent to using II many of the participants suggested that they began to empower their clients to take more of a lead in the interactions that they were having. This led to the perception that their clients had more control over their relationships and interactions and that they as staff were relinquishing control. Nind and Hewett (2005) provide several anecdotal reports from staff using II demonstrating an increase in feelings of trust of clients and felt empowered through relinquishing control in interactions. The current study provides evidence to support Nind and Hewett's (2005) findings in that some of the participants felt empowered through letting go of control. In some circumstances, this led to a trust of clients to lead in the interactions.

In contrast to the reports by Nind and Hewett (2005) some staff in the current study suggested after using II and relinquishing control over the interaction they felt vulnerable.

Several of the participants reported that when they started to use II and let the client lead in the interaction they felt anxious about what would occur when clients were in control rather than staff. Dyer & Quine (1998) suggest that any major changes or uncertainty in staff perceptions of their role in relationships with clients may cause high levels of stress.

4.1.3.3. Staff roles

As previously indicated, several of the participants suggested that using II could bring up anxiety about changes in their roles with clients.

There is some evidence from Nind and Hewett (2005) that the use of II can cause intense emotions in staff using the technique. This can sometimes develop to the extent that staff can feel very attached to the clients that they work with. Some of the participants in the current study suggested that they started to feel strong emotions towards their clients. Sometimes these emotions seemed to develop feelings of attachment and there was even some suggestion that participants felt ‘loving’ emotions and ‘motherly’ emotions towards their clients. This seemed to cause anxiety in participants who suggested that they felt that they should not be having these emotions and that their feelings were inappropriate. Nind and Hewett (2005) suggest that there is a need for reflective supervision to discuss the emergence of these types of emotions.

Dyer and Quine (1997) suggest that role ambiguity can cause anxiety and can influence performance at work. In the current study some of the participants reported that they felt like they were playing two seemingly opposite roles. One as a “security guard”,

controlling clients (often using physical interventions) to ensure that they were safe, and another as an II practitioner, letting clients take the lead and control interactions. One participant suggested that they felt that they were lying to clients by playing contradictory roles. This particular concern about role ambiguity has not been discussed in the II literature but it seems that this insight is an important one to consider in future research.

4.1.3.4. Summary of the Third Research Question

Many of the participants suggested that they previously lacked a positive connection with clients and that this may have contributed to staff feelings of low self efficacy, less understanding of clients, fear and anxiety reactions and avoidance of clients. It also seems that anxiety and fear could lead to feelings that staff needed to be directive and in control.

After using II many staff were able to make a connection with clients and this often led to positive feedback from clients resulting in feelings of increased self efficacy. It seemed that through the increase in positive interactions staff were more likely to understand clients better and have less fear and anxiety about the unpredictability of clients. However, some staff started to feel vulnerable about relinquishing control and there was an increase in anxiety about the change in staff roles.

4.2. Methodological issues

There are several important methodological issues that need to be considered in interpreting the results.

Firstly, the data was collected through semi-structured interviews and the interview schedule will have undoubtedly influenced the nature of the data collected. However, during the design of the interview questionnaire and the application of the interview, care was taken to avoid using technical terms and leading questions so that the data was not a direct reflection of the questions. Throughout the interviews it was perceived that the questions allowed the participants to talk broadly about their personal experiences.

Secondly, the nature of the recruitment process meant that the sample was self selected. Therefore, it could be suggested that the study suffered from a sampling bias in that the sample may in fact be representative of a smaller sample within the target sample. For example, it may be that care staff who chose to take part in the study were more motivated to do so because of positive experiences that they had undergone whilst using II. However, based on the author's contact with the individual participants it seemed that there were no indicators of this type of bias within the sample.

Thirdly, the sample for the study was taken from only one specific geographical area. It may be that there are practices and philosophies that are specific to this area that are not shared by other geographical areas of the UK. This means that the results may not be generalisable to other groups of people using II in other areas of the UK.

Fourthly, the sample of the current study was very small and there was no control group used to compare the results of this sample to another set of care staff. Therefore the results may be a result of extraneous factors rather than being attributable to II.

Finally, the accounts of the participants were all given in retrospect. This means that their recollection of their past practice may have been biased by their current knowledge and practice. This means that any evidence of changes in staff thoughts and feelings pre and post II must be considered tentatively.

4.2.1. Validity Checks

Throughout the analysis process effort was made to ensure that the quality of the data and the results was maintained through the use of a series of validity checks. The first of these was for the author to own his own perspective so that this may be taken in to account when readers were evaluating the results for themselves. In this study the author's perspective has been acknowledged in the method section. It was recognised that the author held the view that people with PMLD and the staff working with them often had superficial and non-emotive relationships driven through the actives and structure of the system that was to some extent dictating the nature of the interaction. This possibly influenced the study and its findings in that during the interview process, participants were asked to tell their stories in an environment where the interviewer may have been inadvertently validated some experiences and not others.

Secondly, the method section contains a description of the sample of the participants interviewed in the study. This allows the reader to consider the results in relation to the sample and make judgments about the range of experiences and people to which the results may be applicable.

Third, throughout the coding of the interview transcripts and the analysis of the data the author's research supervisor audited each step of the process in order to review reliability. The research supervisor audited six of the twelve transcripts in this way and the results were discussed so that sub-themes could be agreed on and validated.

Fourth, each of the participants involved in the current study were given the opportunity to meet with the researcher following the analysis of the data in order to discuss the overall findings of the study in terms of the themes that had emerged through the analysis process. This was done to ensure that the results resonated with the participants so that they felt that an accurate representation of their views and opinions had been made by the research. Six of the twelve participants chose to meet and discuss the results with the researcher and all six agreed that the themes that emerged from the analysis were a fair representation of their views.

4.3. Clinical Implications

4.3.1. Staff Support

Many of the participants suggested that they took on board emotions from clients and some reported that these emotions were carried with them after work. Others disclosed

that they needed to either off load these emotions in supervision or try to forget about them in other ways so that they could continue with their work through out the week. This act of increased awareness and the necessity of holding painful and upsetting emotions had sometimes led to staff dissociating from II with clients and putting II in a box to differentiate it from other roles that staff took in their workplace. This meant that many of the participants were reporting the need for enhanced support and supervision, whether it is through peer supervision or managerial supervision.

4.3.2. Greater understand of clients

Secondly, the current study has demonstrated that participants using II were able to develop a more knowledgeable and supportive relationship with clients that they previously felt that they were unable to help. Through seeing the world from a client's perspective participants reported that they felt better able to advocate for clients needs and have a greater understanding of the desires of their clients.

4.3.3. Changes in staff feelings about their clients

It can be seen from the current research that there was a trend around staff feeling helpless, anxious and negative when working with people with PMLD being confounded by lack of a connection and lack of any rewarding feedback with clients. Through the use of II many staff experienced a reversal of this circular relationship and found that with increased positive feedback and a more emphatic understanding of client's emotions they were able to feel more empowered and had less need to control or avoid relationships with clients.

4.3.4. II being “put in a box”

From the current study some participants suggested that II was segregated from other work with people with PMLD, either by the management system where II was put on a timetable to last for an hour per week, or by staff who felt that II needed to be contained in one area of their working lives. Many participants suggest that II should be used in a more global way so that staff and clients have the opportunity to engage in II relationships throughout the day.

4.4. Further Research

Throughout the course of the current study there have been a plethora of questions that have been raised. Due to the fact that the data collected from the participants was very rich it does seem that there have been many themes brought up which are worthy of further enquiry.

Firstly, the current study needs to be replicated in different localities. This is due to the fact that the participants were all from the same geographical location and there may have been a sampling bias in the current data because of this.

Secondly, the notion that using II can lead to an increase in staff feelings of self-efficacy is an idea that is worthy of further investigation. It would be important to distinguish which specific features of II were responsible for participants perception that they felt more self-efficacious and then these components would need to be assessed. A

quantitative measure of staff self-efficacy would be useful to compare staff using II with those from a control group.

Thirdly, the data from participants suggested that II may have helped staff to understand and empathize with clients in a more developed way. Research could aim to measure staff empathy before, during and after using II so that comparisons could be drawn. A longitudinal study which utilised a multiple baseline, across participants design could be developed with a quantitative measure of empathy so that results could be compared across time and across participants.

Fourthly, further research would be valuable to investigate the effect that using II has on staff teams. For example, baseline and follow up assessments using the Staff Support and Satisfaction Questionnaire (3SQ) (Harris & Rose, 2002) could be undertaken in order to measure staff job satisfaction pre and post the use of II. Also, other factors such as staff retention and sickness absence could be included to find out whether any trends in staff behaviour were changed through the use of II.

Fifthly, research could be directed to investigate the meaning of role ambiguity experienced by staff who use II but who also use assertive methods to control challenging behaviour. Qualitative analysis could be used to extrapolate meaning from discussion with care staff so that this confusing phenomenon could be explored.

4.5. Summary

In this qualitative study, twelve care workers working with people with PMLD using II were interviewed to develop individual narratives regarding any changes in their thoughts about their clients, themselves, or their work after using II. Using IPA, themes were developed from the interviews which were used to tentatively develop an understanding of care staff's perspectives. The results showed that care staff perceptions and interactions with clients change in multiple ways after II was introduced. Participants described changes in their role as a care worker, changes in the way they perceive their clients, and changes in their perceptions of managers and the wider care system. Some staff felt that II led them to connect to clients and to understand their needs in more complex ways, thus reducing anxiety and feelings of helplessness. Others felt that II helped to alleviate stress and increased job satisfaction and feelings of self efficacy. Some participants experienced concern about the intense feelings triggered and their capacity to continue with II. The discussion addressed the issues arising from the results in terms of the relevant research literature. Several important methodological concerns were raised in order to understand the results in the correct context. The clinical implications of the study were examined and further research was indicated to replicate the study and to test out the questions raised by the study.

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Part 3. Critical Appraisal

1.0. Why Study Care Staff's Experiences of Intensive Interaction (II)?

1.0.1. Intensive Interaction

In the present study I intended to add to the research evidence about the effects of using II with people with profound and multiple learning disabilities (PMLD). Recent government initiatives about the rights of people with learning disabilities stress the importance of developing emotional relationships as one of the most important aspects of people's lives (NHS Executive, 2001). Furthermore, the essential need for people with

learning disabilities to be involved in every aspect of the planning and implementing of any life changes in a person centred way has also been highlighted by a variety of important sources (Sanderson et al., 1997; DOH, 2001).

II is inherently an approach aimed at developing meaningful relationships for people with PMLD who have often experienced great difficulty in interacting with others. Carnaby (2002) suggests that II is one of the best approaches aimed at developing relationships with people with PMLD who have been historically neglected in clinical intervention. Furthermore, II attempts to increase understanding of clients with PMLD. With a greater understanding of clients, those working with people with learning disabilities may have more of an awareness of the needs and desires of their clients so that they can involve their clients in all aspects of change. Therefore, the aims of II fit well with two key government targets for people with learning disabilities, especially those with more profound disabilities, making it unique in its attempts to support people with PMLD to develop emotional connections and to increase a focus on choice by involving the person directly.

1.0.2. Staff Factors

I was interested in the increasing body of literature which describes the importance of staff feelings about themselves, their clients and their role at work and the impact these may have on interactions with clients (Bromley & Emerson, 1995; Hastings & Brown, 2002a; Hastings & Mitchell, 1998). These considerations are of optimal importance

because negative patterns of interacting, related to staff feelings of self-efficacy, can often be self sustaining and circular in nature (Hastings & Brown, 2002a).

Through examining possible changes in staff perceptions after having used II, I intended to explore how an II relationship may develop and how this new relationship may be different from previous relationships that staff and clients were engaged in. I was keen to access the reflections of staff who use II in their day-to-day work because the focus of previous research and intervention for people with PMLD has mostly neglected the views of direct care staff (Whittington & Burns, 2005). In summary, by conducting this study I wanted to add to the body of evidence on II by focusing on the experiences and views of care staff who have used II.

1.1. Methodological Issues Arising from the Current Study

1.1.1. The Strengths of the Current Research Methodology

The current study utilised IPA because it placed an emphasis on gathering information from front line staff and extrapolating individual meaning so that a deeper level of understanding could be achieved. Nind and Hewitt (2005) emphasise the importance of staff perceptions and emotions when they are using II and report a great deal of anecdotal evidence from staff using II. Much of this evidence has proven to be positive in its support of II but there has been no formal research to investigate the views of staff

Epistemologically, phenomenological approaches are based in a paradigm of personal knowledge and subjectivity, and emphasise the importance of personal perspective and interpretation. As such they are powerful tools for understanding subjective experience, gaining insights into people's motivations and actions, and cutting through the clutter of taken-for-granted assumptions and conventional wisdom. This epistemological base is important to the current research because it begins from the basis that the essential understanding of the work is placed within the knowledge and experience of the front line staff rather than imposing a theory onto the process of developing relationships and searching for proof of that theory through attention to some factors rather than others.

Phenomenological methods are particularly effective at bringing to the fore the experiences and perceptions of individuals from their own perspectives, and therefore at challenging structural or normative assumptions. Adding an interpretive dimension to phenomenological research, enabling it to be used as the basis for practical theory, allows it to inform, support or challenge policy and action. This aspect of IPA was particularly important in my decision to use a qualitative approach because I recognised that much of the literature around II drew from historical research about how individuals learn to engage emotionally with others. This meant that nearly all of the subsequent research about II has been based on long standing notions of what it is to interact at an emotional level with another person. Therefore, I wanted to start from a basis where I would assume very little about the process of II and the interaction of staff and clients so that the research would be open to finding new and previously unconsidered factors.

In multiple-participant research, the strength of inference which can be made increases rapidly once factors start to recur with more than one participant. In this respect it is important to distinguish between statistical and qualitative validity: phenomenological research can be robust in indicating the presence of factors and their effects in individual cases, but must be tentative in suggesting their extent in relation to the population from which the participants or cases were drawn. In the current study I found that many of the central themes were consistent across a number of different participants. I specifically wanted to illustrate the consistency of themes across participants so that the results were transparent to the reader so I used a table to demonstrate which themes matched to each participant. In this way the strength of qualitative validity can be independently assessed by the reader.

The final strength of the current research is that I was able to revisit six of the 12 participants subsequent to the analysis of the data to share the general themes that I had come up with as well as highlighting my interpretation of how these themes fit with each of the individual participants' narratives. When I did meet with these six I found that all of them agreed with the themes I had extrapolated from the data and viewed them as a reasonable and recognizable reflection of their accounts. This process lent weight to the results of the current study because it felt that my representation of the participants' narratives was accurate. I was only able to arrange meetings with six of the participants due to time constraints.

1.1.2. Methodological Weaknesses

Writers in qualitative research have emphasised that the results of any qualitative study may well be biased by the thoughts and perceptions of the researcher and that this indicates a relative threat to the internal validity of the findings (Stanley & Wise, 1993). It is therefore important to make the researcher visible in the 'frame' of the research as an interested and subjective participant rather than a detached and impartial observer (Stanely & Wise, 1993; Elliot, Fischer & Rennie, 1999). During the process of transcribing the interviews I recognised that through the intonation of my voice and the enthusiasm with which I responded to participants' comments, I had occasionally attributed more emphasis to certain aspects of the participants' responses that were more in line with my own views. Through this process I may have inadvertently contributed to the data by reinforcing certain responses, thus making it more or less likely that participants would expand on certain themes but not others. In line with the philosophy of IPA I have attempted to provide clarity around my perspective and to be transparent about the possibility that some of the results may be biased by my personal beliefs and experiences.

Phenomenological studies make detailed comments about individual situations which do not lend themselves to direct generalisation in the same way which is sometimes claimed for survey research. The development of new evidence from phenomenological findings needs to be done transparently if it is to have validity; in particular, the reader should be able to work through from the findings and see how the researcher has arrived at his or her interpretations. I feel that the present study does develop some new ideas about the interactions between staff and clients. I feel that the interpretations which are proposed by

the current study must only be seen as building blocks needing extensive development through further research.

Finally, the results of the current study may have been influenced by a sampling bias due to the fact that the participants were largely self selected and were all from the same geographical location. Nind & Hewett (2005) suggest that some organisations that have started to use II have reported great success with the technique and this has sometimes meant that II has permeated through to all levels of the system, whereas, other organisations use II sporadically and with limited success. Due to this inconsistency in the application and success of II it is difficult to relate the findings of the current study to other organisations or geographical areas. This means that the findings of the current study have low external validity and that a replication of the study in a different area may come up with quite different results and conclusions.

1.2. Personal Reflections on the Research Process

I would like to raise a number of issues that are pertinent to my own position in planning and conducting this research.

Within psychology at least, people with PMLD have been largely neglected as a focus for research. In thinking about possible reasons for this apparent lack of interest I have reflected on my experiences. I spent many years working 1-1 with people with PMLD as

a care worker and found that it was a long and frustrating process coming to understand the clients that I was working with, even to the point where continuing at times seemed fruitless. Sitting down next to someone who is unable to indicate whether they have noticed you or not can be a humbling experience. I feel that it is possible that researchers may have avoided this client group due to the feelings of powerlessness and helplessness that have been evident in my own experiences but also in the experiences of the participants described in the present study.

Secondly, I have read several pieces of literature about the paucity of research for people with PMLD, notably Jean Ware (1988) who suggests that as a client group, people with PMLD have been ignored and dehumanized. From my own experience, when I have been working with someone who is unable to respond or provide any sort of comment about what you are trying to do I started to feel that they were not comparable to me and that their emotions and thoughts were not comparable. The gap between myself and my clients was so vast that I felt helpless to understand their needs and at times it felt easier to ignore the possibility of communicating. Instead, I found myself talking to colleagues and ignoring my clients even when I should have been devoting my attention to them during tasks such as helping them to eat lunch or use the toilet.

There was a sense from the research results that many of the participants using II started to feel more powerful emotions about clients after they started to use II. This is also an experience that I have observed in myself and in others who have worked alongside me and it is often difficult to recognise and own up to after working with someone for many

years. In retrospect, when I started using II I started to worry about my clients more and even began to dream about them. At the time I did not acknowledge that I may have had an increase in emotions towards my clients and instead I ignored these signs and wondered what was wrong with me. I did not bring this up in supervision because I didn't understand what was happening and I didn't want to appear as though I couldn't cope with the demands of my job. Several years later I started to supervise other staff to use II and I began to recognise some of their feelings in myself. Two years too late I was able to begin to reflect on my own experiences through listening to others. Throughout the course of this study I have continued to learn about my own reactions to working with people with PMLD and the use of II and many of the participant's narratives have resonated with my own reactions and experiences.

Many of the participants suggested that they felt cut off from clients because they took on a particular role or because they dissociated from the painful emotions of their clients. I have also been aware of this in myself and feel that being 'forced' to deal with an increase in emotions and increased attachment to clients can be a confusing process. This seems to lend weight to the need, highlighted in the results, for the provision of good quality supervision to contain and support this change. However, from my experience of being a care worker, this type of continuing and reflective supervision is particularly rare. Normally, supervision is about the running of the work place, personal responsibilities and individual targets for clients. Supervision which supports staff to thrive in a new emotional way of working and the development of skills and reflections in II may need to

be from a supervisor or supervision group that is more specialist and informed about the processes that may be occurring.

1.2.3. Staff feelings of self-efficacy

From the current study it seems that many of the participants felt low self-efficacy in working with their clients with PMLD. It has been demonstrated through research that staff feelings of staff efficacy, job satisfaction have been predictive of how staff related to clients in their care and of staff sickness, stress, burnout, and staff turnover (Hastings & Brown, 2002a). Some of the data in the present study suggests that the use of II may help to increase staff feelings of self-efficacy, and this has obvious knock on effects for the way that staff feel about themselves and their clients. In reflection this seems to be an important role for further research to aim towards an increased understanding of staff factors in learning disability services because I found some of the reports of feeling helpless and the need to exert control to be quite alarming. It felt that if these patterns were to continue to be prevalent then the system of care work, especially of care for people with PMLD, is likely to continue to be stuck and under-developed.

It is possible that II may be more than anything, a new technique that helps staff to rekindle enthusiasm for their work, as many new techniques initially do. If this is the case then it is possible that it is not the specific components of II that are resulting in increased feelings of self-efficacy, but instead, the feelings of hope offered by a new technique that may have played a part in increasing staff motivation. As someone who has been a care worker in the past, I would have been enthusiastic about any input from professionals or

trainers that I felt could help me in dealing with feelings of helplessness which came about through many unsuccessful attempts at engaging clients with PMLD. Just the fact that professionals were taking notice of my work may have inspired me to a new lease of life in my work. Accordingly, the outcome of II should be carefully compared to other new techniques to find out what aspects of II, if any, are most important in helping people to feel more self efficacious.

In conclusion, I feel that the present study, keeping in mind the limitations highlighted, goes some way to demonstrate some of the effects on staff using II with their clients with PMLD. It highlights the difficulties that staff face in working with this client group and reflects on care workers' emotions, self-efficacy and different roles that are reported in the results. I recognise that my own feelings about being a care worker and my work with people with PMLD may well have influenced my thinking about this research study, but hope that I have succeeded in making the potential impact of my position on the research process and results more transparent. Overall, I feel I have been able to reflect on my own feelings about II and people with PMLD and to better understand some of my perceptions of caring for this client group. I hope that I have been able to examine these issues in a context of inclusion rather than exclusion, and with a sincere desire for learning.

1.3. References

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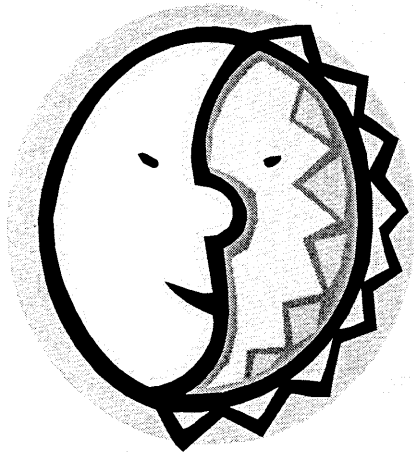
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Appendix 1

Advertisement for Participants

Do you use **Intensive Interaction** with clients who have
Profound and Multiple Learning Disabilities?



If you have been using this approach for 3 months or more, would
you be interested in taking part in a research study?

The study would involve meeting with the researcher, Brian Leaning, and being
interviewed about your experiences of Intensive Interaction.

If this sounds interesting please phone:

Brian Leaning on
to find out more information.

If you choose to participate, all information that you give would be treated in strict
confidence.

Appendix 2

Letter of Ethical Approval

Appendix 3

Participant Information Sheet

Patient Information Sheet Version 1

1. Research Title

The use of Intensive Interaction with People with Profound and Multiple Learning Disabilities: Carer Staff Perceptions.

2. Introduction

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish.

- Part 1 tells you the purpose of this study and what will happen to you if you take part.
- Part 2 gives you more detailed information about the conduct of the study.

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

3. What is the purpose of the study?

The aim of the project is to explore how staff working with clients with profound and multiple learning disabilities feel about using Intensive Interaction.

4. Why have I been chosen?

You have been chosen to participate in the study because you have indicated that you work with people with Profound and Multiple Learning Disabilities using Intensive Interaction techniques.

5. Do I have to take part?

Your participation in this study entirely voluntary. If you do decide to take part you will be asked to sign a consent form. If you decide to take part you have the right to withdraw at any time without giving a reason. Any decision, not to take part or to withdraw during the study will not result in any adverse consequences. Any information that you have been given up to this point will be kept confidential.

6. What will happen to me if I take part?

The whole study is expected to take approximately 1 year to complete. If you decide to take part in the study, the researcher, Brian Leaning, will meet with you on one occasion. This meeting can take place at your home or at your place of work. The meeting will include an introduction and an interview with the researcher, which may last between one and two hours.

7. What are the possible disadvantages and risks of taking part?

The study involves you responding to questions about service users that you have worked with using an Intensive Interaction approach. At times, work with people with learning disabilities may bring up emotions for you. During the interview you may experience these emotions again as you recall your experiences. It is important to note that you do not need to answer any question that you feel uncomfortable about discussing and that you can stop the interview at any time.

8. What are the possible benefits of taking part?

It is hoped that the interviews and resulting conclusions may benefit many people using Intensive Interaction by collecting information on how the practice of Intensive Interaction affects those who use it. It is hoped that the results of the study may help people to understand their own working practice and allow reflection and development in the use of Intensive Interaction for the benefit of themselves and clients that they work with.

9. What happens when the research study stops?

After the conclusion of the study the researcher will send you a copy of the summary of the main themes that have come out of the interviews and any conclusions that have been drawn. There will be an opportunity for you to contact the researcher to discuss these conclusions if you wish to do so.

10. What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed'. The detailed information on this is given in Part 2.'

The contact person for complaints is Dr Katrina Scior who is supervising the research. Her address is: Dr K. Scior

Department of Clinical Health Psychology
1-12 Torrington Place, London W1 1YH

11. Will my taking part in the study be kept confidential?

All the information about your participation in this study will be kept confidential. The details are included in Part 2.

12. Contact Details:

Brian Leaning

Department of Clinical Health Psychology
1-12 Torrington Place
London W1 1YH
Phone:

This completes Part 1 of the Information Sheet.

If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making any decision.

Part 2

12. What will happen if I don't want to carry on with the study?

You are free to withdraw your involvement in the study at any time and there will be no consequences to your withdrawal. Your interview and data from it will be destroyed and will not be used.

13. Complaints:

If you have a concern about any aspect of this study, you should speak with the researchers who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from Camden and Islington Mental Health and Social Care Trust I

14. Harm:

In the event that something goes wrong and you undergo harm during the research study there are no special compensation arrangements. If you are harmed and this is due to someone's negligence then you may have grounds for a legal action for compensation against (UCL Biomedical Research and Development Unit) but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you (if appropriate).

15. Will my taking part in this study be kept confidential?

Any information that is shared during the interviews will be treated with strict confidence, and once the study is completed it will not be possible to identify an individual's interview. Throughout the study only the researcher and his supervisor, Dr. Katrina Scior will have access to any information about you. Procedures for handling, processing, storage and destruction of data will be compliant with the Data Protection Act 1998.

16. What will happen to the results of the research study?

The results will be made available to all participants in the form of a written summary. Participants will not be identified in any report and any identifying information will be anonymised.

27. Who is organising and funding the research?

The research is being organised and funded through the Department of Clinical Psychology at University College London as part of Camden and Islington Mental Health and Social Care Trust.

25. Who has reviewed the study?

This study was given a favourable ethical opinion for conduct in the NHS by the Ealing Research Ethics Committee.

If you require any further information, please do not hesitate to contact Brian Leaning on

Thank you for taking the time to read this information sheet.

Brian Leaning
Trainee Clinical Psychologist

Appendix 4

Participant Consent Form

Confidential

Centre Number: :
Study Number:
Patient Identification Number for this trial:

CONSENT FORM

Version 1

Title of Project: The use of Intensive Interaction with People with Profound and Multiple Learning Disabilities: A Carer's Perspective.

Name of Researcher: Brian Leaning
Name of Research Supervisor: Dr Katrina Scior

Please initial box

1. I confirm that I have read and understand the information sheet dated .
(version 1) for the above study. I have had the opportunity to consider the
information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time,
without giving any reason, without my legal rights being affected.
3. I understand that relevant sections of any of the notes and data
collected during the study may be looked at by the researcher,
Brian Leaning and his research supervisor, Dr Katrina Scior.
I give permission for these individuals to have access to these notes and data.
4. I agree to take part in the above study.

Name of Participant

Date Signature

Name of Person taking consent
(if different from researcher)

Date Signature

Researcher

Date Signature

Appendix 5

Interview Schedule

SEMI-STRUCTURED INTERVIEW SCHEDULE

Intensive Interaction (II) with People with Profound and Multiple Learning Disabilities (PMLD): The Experiences of Care Staff

BEFORE THE TAPE IS TURNED ON

Introduction about the interview.

Remind the participant about confidentiality.

Obtain consent for material to be used in research (signed form).

TURN THE TAPE ON

Getting to know the participant

Demographics: Age.

Gender.

Job Description.

Years experience (LD)

(PMLD)

1. Can you tell me a bit about your experience of working with people with learning disabilities?

Prompts: Different types of jobs?
First experiences?
Positive experiences?
Negative experiences?

2. Can you tell me what was the reason that you started working with people with learning disabilities?

3. Can you tell me what happens during a typical day at your current work?

Prompts: How many clients do you see during the day?
How long do you spend (on average) with each client (1-1)?
If you work with groups, how large are the groups?

Beginning to use Intensive Interaction

1. Can you tell me how you first got involved in using Intensive interaction (II)?

Prompts: How long ago did you start using II?
How did you come to use II?, whose idea was it?
Who trained you to use II, was it formal or informal?

2. What were your first thoughts about II?

Prompts: Did it seem to make sense, (yes/no) Why?
Did you feel enthusiastic, or perhaps somewhat apprehensive about using II?
Did learning about II make you question any of your previous thought/beliefs about people in your care/your work?
If yes, I what way?
If yes, was this reconciled, how?

3. Can you remember the client that you first used II with, can you tell me about the experience?

Prompts: What did you expect to happen?
Did you have any worries/concerns about using II?
What was it like in the early stages?
Did this change over time?
How long did you use II with this first person?
If you are now finished working with this person, how long did your work with them last?

4. Were there any changes in the client that you noticed, immediate, or long term due to II?

Prompts: Changes in client's behaviour
Changes in your relationship with them
Changes in the way you thought about this client

Specific Clinical Examples

1. Can you describe, in detail, an example of II that you felt positive about?
2. Can you describe a recent session of II with this person?
3. Over the course of your work with this person can you describe any changes that took place?

Prompts:

- Changes in client's behaviour?
- Changes in client's mood?
- Changes in interactions with you?
- Changes in interaction with other staff, other service users?
- Changes in how they occupy their time on own?
- Was there anyone else in the client's life that noticed a change, if so, what was his or her experience?
- Any particular feelings in you that developed or changed over the course of the interaction?

4. Can you describe an example of II that perhaps did not go so well?
5. Can you suggest anything that might have improved your, or the service users, experience of II?

Personal Changes

1. Can you describe what it feels like to use II with a client?
2. What do you think you are getting out of working in this way?
3. Have your thoughts about your clients changed since you started to use II, if so, can you give me a specific example?

4. Has using II changed the way you feel about yourself as a worker, if so, please describe this change?

Prompt: What sort of things are you doing differently?

5. If I asked a colleague of yours to describe any changes they have seen in you since you started to use II, what might they say?

6. Has using II changed the way you feel about your work? If so, how?

Prompts: How you feel about the clients you work with?
 How you feel about your colleagues?
 How you feel about the wider care system?

7. Has using II had any impact on your stress levels at work, if so, how?

8. Has using II had any effect on your feelings of job satisfaction, if so, how?

9. Some people who use II have reported that they have difficulties with some aspects of II, such as; the use of physical touch, getting physically close to the service users, and age appropriateness (talking to clients as though they were young children or babies). Have you had any difficulties with these aspects of II?

10. Some people suggest that II evokes more feelings in staff than other types of interaction with people with PMLD. Is this something you have found? If yes, can you give an example?

Changes in the Organisation

1. How many people are working in your organisation?
2. How many people in your organisation are using II?

3. Has the use of II in your organisation meant that there have been any changes at any level? If so, can you describe these changes?
4. Do you feel that these changes have benefited you? (yes/no) explain why?
5. Do you feel that these changes have benefited some, or all of the service users (yes/no) explain why?
6. In what ways do you get support from your organisation to use II?
7. Do you feel that you receive the right amount of support to enable you to use II as best you can? If no, what could your colleagues, manager, organisation be doing differently to support you?
8. Do you think that your use of II affects the other staff in your organisation? If so, how?
9. Have there been any concerns or disagreements with other staff/managers about the use of II? If so, can you describe a specific example?
10. Have there been any concerns or disagreements with parents/carers about the use of II? If so, can you describe a specific example?
11. Have there been any concerns or disagreements with clients about the use of II, if so, can you describe a specific example?

Closing the Interview

Thank you very much for taking part in the interview.

- Is there anything further that you would like to say?
- How has the interview felt for you?
- Do you feel that the interview has covered all of the important aspects of using II, if not what else should be covered?
- Do you have any questions for me?
- Thank you again.

Appendix 6

Excerpt from Transcript

I Can you tell me about some of your first experiences of working with people with LD

P My first experience was when I applied for a job working in a day centre with people with challenging behaviour. My first recollection was walking into this room with people with strange behaviours, no communication that I could see at all and so I just went around saying hi my name is but got no response at all. I didn't know what to do

I Can you tell me about some positive experiences of your first job.

P Loads of positive experiences. I couldn't believe that I was being paid to do that work, I enjoyed, not every minute, but most of it. Absolutely. Yeah, cause I was working with people with challenging behaviour there was quite a high staff ration and I was able to do lots of 1 – 1 work and lots of outreach work, and yeah I had a really good time.

I And any negative experiences of your first job.

P The strongest memory that I have got of a negative experience was staff restraining service users when it was not necessary at all. Abusing service users. I felt anger, I didn't really know what to do cause I was so used to those members of staff and they were like a little group of friends. It wasn't their fault in a way cause I think that they weren't told how to work with people and they were frustrated and then when people were challenging they tried to take back control. I wanted to stay friends with them so I felt quite powerless and I wanted to justify what they were doing but really couldn't at all.

I Can you tell me what was the reason you started working with people with LD.

P I left college and worked for a bank but hated it and then there was nothing that I could do. But my mother used to work with people with LD and I thought perhaps I could do that for a living. So mum encouraged me and I started doing that then.

I Can you tell me what happens during a typical day at your current work

P Well it varies so much but a typical day would be um, perhaps going to see a SU and their family or staff that had been recently referred to me so I would be going a long finding out about the person and about their needs and a little bit of information about their challenging behaviour. See what the person needs. I might do staff training as well. But unfortunately a lot of my time is spent in the office writing reports and coordinating things for people over the phone.

I would see about 4 or 5 SUs over the period of my day

I get to spend maybe an hour to maybe an hour and a half

I Can you tell me how you first got involved in using II

P Well I was invited to a peer supervision group with some colleagues where I work and I was working with a young lady with severe LD and autism and probably quite severe challenging behaviour and I was working with her for quite a while and I thought I needed to work directly with the lady to take her out for walks in the community and my previous experiences of trying to do this was that I would get attacked and I would get scratched and bitten and things like that so I was getting really worried about going to see her. I brought that as a case example to the peer supervision group and a couple of the other people there had been using II with clients similar to my lady and they said oh why don't you try this. It sounded like it may be really beneficial to the lady that I was

working with so I thought yeah I would give it a try. So I read a few books and went on a formal training program for a day to learn about II and then gave it a try.

I What were your first thoughts when you heard about it, did it make sense.

P Yeah it seemed to be exactly what I needed in that moment in time to work with that particular SU, cause she does use a few words and phrases at times but mainly she is non-verbal and I couldn't get a handle on the challenging behaviour and I just felt stuck with this case and I couldn't think of a way forward and finding out about II it sounded very humanistic and gentle which I was pretty sure that she would respond to.

I Did learning about II make you question any of your thoughts about this lady

P Not necessarily my thoughts about this person cause I had tried to work in a very non-aversive way and stay in the background cause her challenging behaviour was about the fact that she was frightened of people in different situations. But it did make me think of people I had worked with in the early days, especially the first few years, when I would go in and be just talking at people and giving people demands and requests and not using gestures or thinking about my body language and that sort of thing and just expecting to exert some control over the person, whereas II is just the reverse.

I Can you remember the client that you first used II with and what can you tell me about that

P I was really quite worried cause I felt that if it didn't work then I didn't have anything to fall back on cause I had tried lots of different ways of working with, I will call her Sally, and those ways hadn't worked. They hadn't worked for me cause I had been attacked so I felt that this was my last shot. So I was kind of nervous about that but at the same time I was so convinced that it could work for her that I was relatively

confident. I didn't know what to expect but I thought it might help. I did have previous experience of ending up in quite a lot of pain after working with her.

I And how did it go in the early stages when you first started using it

P I was absolutely amazed, I was over the moon, cause a spent about an hour with her in a minibus where myself and Sally were being driven to a park and it was quite confined space with her then we walked around the park and saw some dogs, which Sally finds quite frightening, and I was using II and I started to feel that I was beginning to connect to her and get a bit of an understanding about what her world was like and she didn't present with any challenging behaviours at all with was just unheard of and I had thought that II would work pretty well for her but I wasn't expecting it to be so spectacular straight away. I think that the best bit of it was that I let her take the lead around the park and I didn't speak to her as much as a usually did but instead I mirrored her facial expression and her body language, and in the bus when she looked at me I just smiled to her and looked back, like I held her gaze and when she looked away I just gave her some more space. When we were in the park I tried to walk in step with her but I bounded up and down more than necessary and she thought that was hilarious, so she started doing it too and smiling even more and then so did I. It was a brilliant feeling.

I Great, did your experiences with her change over time

P It just got better and better really, I kept playing little games with her and following what she was doing instead of leading the way and talking to her and directing her like I had been doing before. I was going to the park with Sally 3 times per week for about 16 weeks for an hour each time and I built such a good rapport with her that she would link her arm with me and if she saw a dog or a person coming that she was

frightened of she would come and link arms with me without becoming challenging. It was going so well just building rapport and getting her to trust me that I thought I could use this relationship to help her to do other things. Oh yeah and also, you see Sally does have some language and she uses that language to reflect her mood rather than to ask for things and stuff like that and she would normally say things like 'Sally bad no good' and it was all very negative and I think that she was telling me that she wasn't feeling well in herself. But really quite quickly that began to change and she started saying things like 'Sally pretty, Sally pretty girl' and she just began to laugh and giggle and honestly I had known her for a few years before using II and I had never even seen her smile let alone laugh, so that was amazing.

I And how did it make you feel seeing these changes.

P It was just so cool that she felt relaxed in my presence, I hate the fact before that she didn't. And that I knew that every time I would be with Sally that she would be anxious so after using II she was able to share space with me and for her to be relaxed and comfortable was very very empowering, but kind of sad as well cause if we had of known this since I started working with Sally we could have been doing this all along.

I Ok, and did it make you see her differently

P oh yeah, absolutely, because for I started using II with Sally I used to dread home visits and I knew that she would come downstairs and want me to leave straight away and if I didn't she would start to attack me. I had always felt out of my depth but also wanting to help her and at a personal level wanting to because it was my job to, so I felt like a failure but that changed completely. And that changed cause I persevered.

Appendix 7

Example of Key Points from a Transcript

People with strange behaviours (1,1)
 I couldn't get any communication (1,1)
 I got no response at all (1,1)
 I don't know what to do (1,1)
 I enjoyed every minute of it (1,1)
 I felt anger (1,1)
 I felt quite powerless (1,1)
 I was scared I would get attacked (1,2)
 I was getting really worried about seeing her (1,2)
 I would get scratched and bitten (1,2)
 I felt stuck (1,3)
 I would go in and be just talking at people, giving
 people demands (1,3)
 Not using gesture or thinking about my body language (1,3)
 Exert some control over people (1,3)
 She would want me to leave straight away (1,5)
 I felt out of my depth (1,5)
 Other staff expected me to go in take control of a situation
 whereas I knew if I did that its gonna cause so many
 problems (1,7)
 Some of my colleagues have got into this work for a power
 trip, because when you work with people with learning
 disabilities you can be in a power position, we've always
 got control (1,8)
 Most care systems pigeon hole clients, they are expected
 to fit into services, why should they anyway (1,8)
 I think people want me to go in and wave a
 magic wand and then all the challenging
 behaviour would disappear (1, 11)
 It was very humanistic and gentle (1,3)
 This was my last shot (1,3)
 Nervous (1,3)
 I didn't know what to expect (1,3)
 I started to feel I was beginning to connect to her (1,4)
 I was over the moon (1,4)
 I let her take the lead (1,4)
 I didn't speak as much as a usually do (1,4)
 She thought it was hilarious and then so did I (1,4)
 It was a brilliant feeling (1,4)
 I built such a good rapport with her (1,4)
 When she was frightened she would come and link arms with me (1,5)
 I had never seen her smile let alone laugh (1,5)
 She felt relaxed in my presence (1,5)
 She was able to share space with me and be relaxed and comfortable (1,5)
 It was very empowering (1,5)
 It was kind of sad because I could have been doing this all along (1,5)

She was happy to go out with me (1,5)
 Happy to be with me (1,5)
 Her family were all very pleased with me (1,6)
 She is a lot less aggressive (1,7)
 I felt so confident working with her (1,7)
 I think I pushed a little too much (1,7)
 I had to go back a few steps to regain her trust (1,7)
 I thought we should show people some tangible progress (1,7)
 The temptation to be more directive and to do new things led to her backing off a bit (1,7)
 She was trusting me a lot more and she knew that she didn't need to be so extreme in her behaviour (1,7)
 It is so gentle and everything was on her terms (1,7)
 I'm not triggering off her anxieties anymore (1,7)
 I find it very empowering (1,7)
 I'm being quite useful (1,7)
 Not imposing myself on the person (1,7)
 My job is less stressful (1,7)
 I'm more confident and less scared (1,7)
 I feel calmer in my work (1,8)
 I feel more skeptical about services, they want to impose control because they are scared of challenging behaviour, scared of trying to interact with people who don't give you any feedback, so they try to put them in a box and take control over the environment (1,9)
 I can relate to clients in a more meaningful way, which obviously gives me a lot more satisfaction (1,9)
 I have actually felt quite motherly and that's weird cause I know I'm not supposed to feel that way about clients (1,10)
 It brings out quite a loving feeling (1,10)
 I've been on slightly dodgy ground emotionally (1, 10)
 Getting so close to people and getting into their world makes you feel for them a lot (1, 10)
 I feel possibly too dependent on the client liking me (1, 10)
 I'm worried about at some point being rejected and that would be more of a loss to me because I had grown quite attached to that person (1, 10)
 Staff learn how to learn more about how to understand clients and their needs are met more effectively (1,10)
 I think it has been important to be able to reflect on the emotions that have come up and to share these feelings of success or failure with others (1,10)
 I don't think that it is a technique that you can use in isolation (1,10)
 It's good to brainstorm with other colleagues who have experiences using II (1,11)
 My worry is that using II would escalate their behaviour, especially people who present with quite dangerous self-injurious behaviour (1, 15)
 This gentleman in question just worries me generally so I would be concerned about using anything that meant I got very close to him (1,15)
 I would be very scared that I would trigger off his self injury and he would end up in hospital and that's too frightening (1,16)

Appendix 8

Example of Themes from One Transcript

Transcript 1

not knowing what to do

fear of clients behaviour

needing to be in control

enjoyment of working with clients

letting clients lead

feeling vulnerable

Viewing clients are part of the furniture

Being in the clients shoes

Listening to clients emotions

Talking about your feelings

Confusing roles and relationships

Security guard vs. friend

Working in an inflexible system

Person centred working

Appendix 9

Themes from Across Transcripts

Overreaching Theme	Sub-themes
Exerting Control vs. Relinquishing Control	<p>not knowing what to do</p> <p>fear of clients behaviour</p> <p>needing to be in control</p> <p>enjoyment of working with clients</p> <p>letting clients lead</p> <p>feeling vulnerable</p>
Making a Connection	<p>Viewing clients are part of the furniture</p> <p>Being in the clients shoes</p> <p>Listening to clients emotions</p> <p>Dissociating from clients feelings</p> <p>Making sense of emotions about clients</p> <p>Talking about your feelings</p> <p>Confusing roles and relationships</p> <p>Security guard vs. friend</p> <p>Care worker vs. Carer</p>
Thoughts about the wider care system	<p>Working in an inflexible system</p> <p>Managers want to control II</p> <p>Person centred working</p>

Appendix 10

Contribution of Individual Participants Transcripts to Themes

Overreaching Theme	Sub-themes	1	2	3	4	5	6	7	8	9	10	11	12
Exerting Control vs. Relinquishing Control	not knowing what to do	*	*	*		*	*	*	*	*	*	*	*
	fear of clients behaviour	*	*	*		*	*		*	*	*	*	*
	needing to be in control	*	*	*	*	*	*		*		*		*
	enjoyment of working with clients	*	*	*	*		*	*	*	*	*	*	
	letting clients lead	*	*		*	*	*	*	*		*	*	*
	feeling vulnerable	*		*	*	*			*	*		*	
Making a Connection	Viewing clients are part of the furniture	*		*	*		*		*	*			*
	Being in the clients shoes	*	*	*	*		*		*	*	*	*	*
	Listening to clients emotions	*			*		*	*		*	*		*
	Dissociating from clients feelings		*	*		*				*	*		
	Making sense of emotions about clients		*				*		*	*			*
	Talking about your feelings	*		*		*			*				
	Confusing roles and relationships	*			*	*	*		*		*	*	
	Security guard vs. friend	*	*	*		*		*				*	*
	Care worker vs. Carer		*		*		*	*				*	

Thoughts about the wider care system	Working in an inflexible system	*	*	*		*		*	*		*	*	
	Managers want to control II		*		*	*		*	*			*	*
	Person centred working	*	*		*		*	*	*			*	*