

UNIVERSITY OF HULL

The Effectiveness of Intensive Interaction and its Use in Hospital Settings

being a Thesis submitted for the Degree of
Doctor of Clinical Psychology
in the University of Hull

By

Anna Bodicoat

BSc (Psychology)

June 2013

Table of Contents

Acknowledgments	4
Overview	5
PART ONE	
The Effectiveness of Intensive Interaction, a Systematic Literature Review	
Abstract	7
Background	8
Method	10
Results	13
Discussion and Implications	33
References	38
PART TWO	
Using Intensive Interaction in a Hospital Setting	
Abstract	44
Background	45
Method	50
Results	53
Discussion and Implications	66
References	75
PART THREE	
Appendices	
Appendix A: Guidelines for Authors for submission to JARID	81
Appendix B: Quality assessment scale for Single Case Experimental Design (Tate et al., 2008)	88
Appendix C: NICE guidelines for assessing the quality of qualitative research	89
Appendix D: Data Extraction Form	91
Appendix E: Papers rejected after the whole study was read	92

Appendix F: Ratings for quality criteria for Single Case Experimental Design papers	93
Appendix G: Ratings for quality of qualitative papers	94
Appendix H: Epistemological statement	95
Appendix I: Post-graduate Medical Institute Ethical Approval	98
Appendix J: Site Specific Approval for Hull East Yorkshire Hospitals NHS Trust	101
Appendix K: Invitation Letter	103
Appendix L: Semi-structured interview schedule	104
Appendix M: Consent Form	106
Appendix N: Information sheet	107
Appendix O: Worked example of Interpretative Phenomenological Analysis	109
Appendix P: Reflective Statement	111

LIST OF TABLES

PART ONE:

Figure 1: Results of Search Strategy	14
Table 1: Details of studies included in the systematic review	15

PART TWO:

Table 1: Information about the participants	51
Figure 1. Superordinate and Subordinate Themes	56

PART THREE

Table 1: Quality Ratings of Quantitative Studies using the SCED	93 94
Table 2: Quality Ratings of Qualitative Studies using the NICE framework	

Acknowledgements

Firstly I'd like to thank the participants, who took time out of their busy days to speak to me, without their openness and willingness, this research would not have occurred.

Dr Nick Hutchinson, my research supervisor, for his support, encouragement and understanding, especially over the past few months.

Dr Emma Wolverson, whose insights into and enthusiasm for the stories behind the themes enhanced my understanding and contained my anxieties.

Dr Chrissie Blackburn, for such interesting discussions about the implications of the research, and for conducting the training with Theresa Lambert, without which the research would never have been developed.

The wonderful IPA group, who always took the time to add fresh perspectives to the analysis, and provide support.

Finally, I'd like to thank Jak, my family and friends, for their understanding and encouragement over the last few years.

Overview

This portfolio has three parts. Part one is a systematic literature review, in which the theoretical, conceptual and empirical literature relating to the effectiveness of using Intensive Interaction with people with learning disabilities is reviewed. Part two is an empirical paper, which explores the experience of hospital staff using intensive interaction. Part three comprises the appendices.

Total Word Count: 25,172

PART ONE

The Effectiveness of Intensive Interaction, a Systematic Literature Review

Authors: Anna L Bodicoat* & Nick Hutchinson

University of Hull

*Corresponding author: Anna Bodicoat

Please send correspondence to: Anna Bodicoat, Department of Clinical Psychology and Psychological Therapies, University of Hull, Cottingham Road, Hull, HU6 7RX

Tel: +44 (0)1482 464117 Fax: +44 (0)1482 464093

Email address: anna.bodicoat@nhs.net

This paper is written in the format ready for the Journal of Applied Research in Intellectual Disabilities. Please see Appendix A for guidelines for authors

Word count: 8210 (including tables and references)

Abstract

Background: Intensive Interaction is an approach used for communicating with people with profound and multiple intellectual disabilities or autism. It has gained increased recognition as a helpful technique, but the evidence has not been systematically reviewed.

Method: Computerised and hand searches of the literature were conducted using synonyms for 'intellectual disabilities', 'autism' and 'intensive interaction.'

Results: Fifteen quantitative and three qualitative papers were identified examining the efficacy of the approach with participants across the age range in both educational and residential settings.

Conclusions: Studies were limited by the quality of reporting and difficulties conducting good quality, ethically sound research with participants with PMID. Staff support should be considered in training to aid implementation of interventions. It is possible to conclude that Intensive Interaction is likely to be a helpful in building social interactions and there is more limited evidence to suggest its use in reducing repetitive or self injurious behaviour.

Keywords: Intensive Interaction, learning disabilities, autism

Background

Intensive Interaction is a technique of communication with people who do not use words, such as those with profound and multiple intellectual disabilities (PMID) or autism. The approach uses pre-verbal communication techniques such as responsive eye contact, facial expressions, vocal mirroring, and joint focus activities (Nind & Hewett, 2001). Just as a mother would imitate and turn-take with an infant, a practitioner using Intensive Interaction would develop imitations into mutually enjoyable games and build a relationship with a person with an intellectual disability. (Nind & Hewett, 2001).

This approach has increasing recognition among health care practitioners, teachers, and carers. There are several books (Caldwell, 2007; Firth, Berry, & Irvine, 2010; Nind & Hewett, 2001; Zeedyk, 2008) an 'Intensive Interaction Institute' and conferences in both the United Kingdom and Australia. It is recommended in 'Valuing people now' (Department of Health, 2009), as beneficial for people with PMID and suggested as a therapeutic approach with behaviours seen as challenging (Sharma & Firth, 2012). It has begun to be investigated as an approach to be used with people with end-stage dementia (Ellis, Astell, & Zeedyk, 2008).

In some of the literature there is a distinction between social and educational aims of Intensive Interaction; some practitioners see Intensive Interaction as a tool to develop communication skills (Kellett, 2000, 2003, 2004, 2005; Nind & Hewett, 1994; Nind & Kellett, 2002) whilst others see its potential as a route to social inclusion (Caldwell, 2007; Leaning & Watson, 2006). Firth (2009) has developed a model combining these perspectives. In the 'Dual Aspect Process Model,' Firth states that processes seen are

evident at two different time points of using the approach. After the initial adoption of Intensive Interaction, there is an increase in social inclusion and communication resulting from the inclusive responses to the person's communicative behaviour. Firth (2009) states that after a time the client's communication plateaus at a 'transition phase.' Communication abilities subsequently develop long-term. Cited as evidence for the Dual Aspect Process Model is the variable time period of research, with shorter studies (from 3 days to 16 weeks) focusing on developing social inclusion (Elgie & Maguire, 2001; Lovell, Jones, & Ephraim, 1998) and longer studies examining the new abilities (Kellett, 2000, 2003, 2004, 2005; Nind, 1996). This has important implications for teaching, training and staff support.

In reviews of the literature (Firth, 2006; Sharma & Firth, 2012) research on Intensive Interaction has been identified to be limited in scope and scale, with the studies often being case studies as empirical investigation of Intensive Interaction is challenging to conduct. The published research has not been systematically reviewed nor assessed for quality.

This review aims to provide a much needed summary and quality assessment of the published research that can inform the methodology of future studies into Intensive Interaction.

Research question

What are the effects of using Intensive Interaction with a person with an intellectual disability or autism?

Method

Search Strategy

A computerised search on Intensive Interaction and people with intellectual disabilities or autism was conducted on databases up to and including January 2013. Databases included were CINAHL, PsychInfo, Medline, ERIC and Web of Science. The search terms used were synonyms for 'intellectual disabilities' or 'autism' combined with synonyms for 'Intensive Interaction,' as below:

"menta* deficien*" OR "mental* handicap*" OR "mental* retard*" OR "mental* impair*" OR "mental* disab*" OR "mental* subnormal*" OR "learning disab*" OR "learning difficult*" OR "intellectual difficult*" OR "intellectual* disab*" OR "intellectual* impair*" OR "developmental disabilit*" OR "autis*" OR "ASD" OR "Preverbal" OR "Prelingual" OR "develop* dela*"

AND

"Intensive Interaction" OR "augmented mothering" OR "Hanging out program" OR "From Inside Looking Out" OR FILO OR "imitative interaction"

Articles which had the terms in their abstract or title were included. The inclusion and exclusion criteria were applied to the abstract or the full article if this was still ambiguous.

No systematic review had been conducted in this area before, and the literature base is known to be small, so no cut-off date was employed. A research review on the Intensive Interaction Institute website was also consulted, which highlighted 6 further

articles and key authors were contacted to ascertain if there were any further studies which had not been found in the databases.

Inclusion and Exclusion Criteria

It was decided that studies involving people with intellectual disabilities and people with autism would be included, as there is comorbidity between the two conditions. No age restrictions were applied as both intellectual disabilities and autism are lifelong conditions.

Due to Firth's (2009) Dual Process Model, it was decided to include studies from both social and educative backgrounds. It is likely that many studies contain both elements from the Dual Process Model, and dividing such a small literature base would be unwise.

No restrictions were placed on the form or amount of training in Intensive Interaction, as there is no standardisation of training.

It was decided to include studies which focused on the outcome of an Intensive Interaction intervention. Studies could use a quantitative or qualitative methodology; however, purely narrative descriptions of case studies were excluded, due to the difficulty in assessing methodological quality, in particular with regard to controlling for extraneous variables or the author's acknowledgement of bias.

Study Screening

Inclusion Criteria

- Participants in the study must have an intellectual disability or autism.

- The study must focus on the use of Intensive Interaction with people with an intellectual disability or autism.
- Participants can be any age
- The study must examine the effect(s) or outcome (s) of using Intensive Interaction with the participant(s).
- Study must be an intervention
- The research must be found in a peer-reviewed journal, or be in the process of submitting to a peer review journal for publication.

Exclusion criteria

- Literature reviews or non-empirical papers
- Studies which are not written in English

Quality assessment

It was decided not to exclude studies based on quality, as the literature base was small and a thorough description and critique of papers was likely to be helpful in informing recommendations for further studies.

Many studies in this review adopted single case experimental designs, quality assessment has been comprehensively discussed by Smith (2012). The Single Case Experimental Design checklist (Tate et al., 2008) was utilised (Appendix B). No adaptations were made, as it was comprehensive enough to distinguish between papers. This is the only scale assessing single case designs which has been assessed for its psychometric properties. The checklist comprises 11 questions regarding different aspects that add to the quality of single case experimental design.

Some studies utilised a qualitative methodology, these were assessed using a quality framework from the National Institute for Health and Care Excellence (National Institute for Health and Care Excellence, 2012) (Appendix C). This was developed by reviewing a variety of frameworks for qualitative research and consists of 13 questions. It does not have scores associated with it so to enable comparison each point was assigned ratings of either 0 (omitted or inadequate), 1 (poor), or 2 (good) and these were used to compare studies.

To reduce the potential for bias in the reporting, 20% of the SCED papers and all qualitative papers were rated by a second marker.

Data was extracted from the studies using a data extraction form designed for this review (Appendix D).

Results

The results of the search strategy can be seen in Figure 1. Titles of the papers that were rejected after reading the entire paper can be seen in Appendix E.

Characteristics of papers

15 of the papers were found to be single case or small 'n' designs, three of the papers used a qualitative methodology. The papers are presented in Table 1.

The 53 different participants across the studies ranged in age from five years old to early 60s, there were 22 female participants and 23 male, with the remainder not stating the gender. Twelve of the studies were from the United Kingdom, two were from Australia, one was from Greece and one was from Romania.

One of the papers included (Nind & Kellett, 2002) used data which had been presented elsewhere (Kellett, 2000; Nind, 1996). These studies were included, despite the duplication of participants, as each paper had a different focus, and reported different results from the evidently large amount of data that the researchers collected.

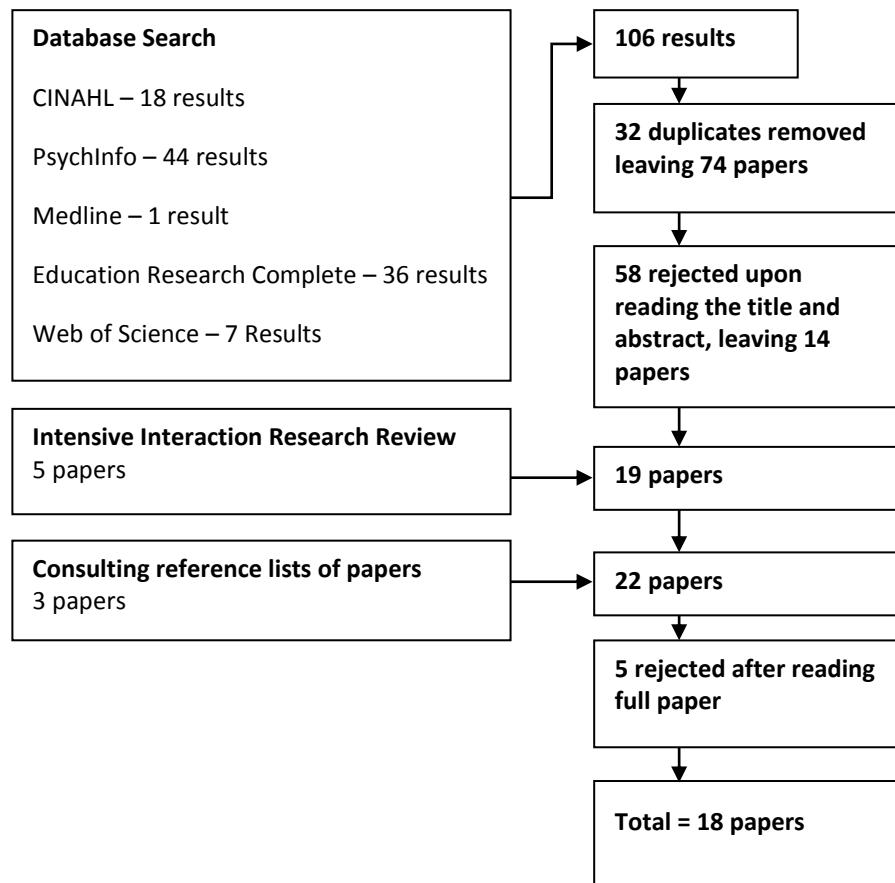


Figure 1. Results of Search Strategy

Table 1. Details of studies included in the review

Quantitative Studies							
Authors and date	Study population (age, gender and setting)	Study objective	Intervention, training and support	Study design	Measures/ analysis used	Outcome/themes reported	Quality Ratings*
Argyropoulou & Papoudi, 2012	6 year old boy 'Philippe' with a diagnosis of autism, and a peer, 'Anna' in an inclusive class at a mainstream school in Greece.	To examine the effect of Intensive Interaction (II) intervention on social interaction peers.	Used by: teacher (the researcher). Training and support: Not stated Intervention: II 'training' sessions occurred 3 times per week for 2 weeks, lasting approximately 12 minutes. Play sessions with a peer occurred directly after the training sessions.	ABA design, video recording of the children's play sessions. Phase A1 = before the training started, Phase B = directly after training sessions, Phase A2 = training sessions discontinued.	Videos were coded for acts from each child that were attempts to initiate social interactions ('initiations') and the children's positive and negative responses to such initiations.	Increase in initiations Increase in positive responses from both children from phase A1 to B but no change phase B to A2. Increase in positive responses from play partner	8/11
Barber, 2008	3 of 11 pupils with autism spectrum diagnoses who attend a special school in Australia	To examine whether an II intervention changes communicative behaviour of pupils and staff.	Used by: classroom staff. Training and support: 10 after-school seminars. Staff reflection groups. Videos to aid reflection. Intervention: 30 weeks of II used during 'downtime'.	AB design. Videos recorded before and after intervention.	Videos coded for 'Indicators of involvement': No interactive behaviours, look at face, smile, socially directed physical contact (SDPC), engagement.	Decrease in 'no interactive behaviours' for all participants. Increase in 'look at face' for 2 participants. Increase in 'smile' for one participant. Increase in SDPC for all participants. Increase in engagement for all participants.	6/11

THE EFFECTIVENESS OF INTENSIVE INTERACTION

16

Elgie & Maguire, 2001	39 year old woman with a profound LD who was blind (UK)	To assess the effectiveness of II with someone who was blind and had a profound LD.	Used by: Clinical Psychologist and Trainee Psychologist Training and support: not stated. Intervention: 3 times per week for 16 weeks.	Hand contact and Self Injurious Behaviour (SIB): AB design, 6 month baseline. Vocalisations: BA design.	Frequency of hand contact. Frequency of SIB in a 25 minute period every 3 or 4 weeks for 16 weeks. Frequency of vocalisations during and after one session.	No change in SIB. Increase in hand contact. Decrease in vocalisations after session.	3/11
Jones & Williams 1998	35 yr. old male with LD and limited eyesight (UK)	To find out whether stereotyped behaviour was influenced by II or a proximity intervention.	Used by: care staff member. Training and support: not stated. Intervention: 1 session, half imitation and half proximity.	Alternating treatments of 100-second intervals.	Frequency of stereotypy during intervals.	Neither condition influenced the stereotypy.	7/11
Kellett, M., 2000	5 yr. old boy with autism and severe developmental delay, 'Sam.' (UK)	To evaluate the efficacy of II.	Used by: staff member at school. Training and support: one day workshop. Intervention: 15-20 minutes per day for 3 months.	AB design of one participant (Part of a larger, multiple-baseline study) 12 week baseline.	Videos coded for 8 indicators of social behaviour: no interactive behaviours, looking at face, happy/smiling face, reciprocal social physical contact, eye contact, joint focus/activity,	Decrease in 'No interactive behaviours' (following unstable baseline). Increase in 'engagement.' Looking at or towards face: increase from near zero to 52% Social physical contact, contingent vocalisation and eye contact: all modest	7/11

					contingent vocalisation, engaged.	increase from very low baseline scores.	
					Pre Verbal Communication Schedule (PVCS) (Kiernan and Ried, 1987) and Physical Sociability Assessment Scale (Nind, 1993)	Joint focus: Following unstable baseline, post-intervention scores increased but variable: attributed to interruptions from holiday periods. PVCS increase from 0% to near 90%. Physical sociability assessment scale: Increase from 1 to 4 out of 8.	
Kellett, 2003	8 year old boy, severe generalised developmental delay with physical impairments and epilepsy, 'Jacob' (UK)	To evaluate the efficacy of II.	Used by: teaching assistant. Training and support: not stated. Intervention: daily time, scheduled for 42 weeks - but week 13 to week 24 missed due to staff injury.	AB design of one participant (Part of a larger, multiple-baseline study) 5 week baseline.	As in Kellett's 2000 study, above. Percentage incidence of stereotypical behaviours during intervention and in class.	Decrease in 'No interactive behaviours.' Increase in 'engagement,' some variability which was attributed to teaching assistant being off work for /the prior weeks. Looking at or towards face and joint focus: increased (from average of 8.4% to 48% and 3.7% to 65% respectively). Variability attributed to teaching assistant's absence.	8/11

Social physical contact, contingent vocalisation, and eye contact: increased.

PCVS increase from 14.3% at baseline stages, to 56.6% at end of study.

Physical sociability assessment scale: Increase from 3 to 8 out of 8.

Drop in incidence of stereotypy in sessions and class.

Kellett, 2004	6 yr. old boy with severe autism 'Finn' (UK)	To evaluate the efficacy of II	Used by: teacher and two assistants. Training and support: one day workshop. Intervention: 15-20 minutes per day for 3 months	AB design of one participant (Part of a larger, multiple-baseline study). 6 week baseline.	As in Kellett's 2000 study above, but PCVS and Physical Sociability Scale not reported.	'Engagement', looking at face, social physical contact, eye contact, and ability to attend to a joint focus all increased, with variability attributed to holidays and illness. Gains were not evident in classroom setting, attributed to a lack of support for the approach.	6/11
Kellett, 2005	11 year old girl with profound intellectual	To evaluate the efficacy of II	Used by: teacher. Training and support:	AB design of one participant (Part of a larger,	As in Kellett's 2000 study above but social physical	There was an increase in eye contact and joint focus.	7/11

THE EFFECTIVENESS OF INTENSIVE INTERACTION

	disabilities and a fragile life expectancy, 'Catherine.' (UK)		one-day workshop. Intervention: 4 Sessions, intervention interrupted due to death of participant.	multiple-baseline study) 7 week baseline.	contact and engagement less relevant due to movement difficulties.		
Leaning & Watson, 2006	3 female, 2 male people aged 28-38 with PMID. 2 female and 1 male participants reported. (UK)	Evaluate the effectiveness of an II group.	Used by: music therapist and trainee psychologist. Training and support: not stated. Intervention: 8 week group for 50 mins per week	Multiple participants ABA design. 1 baseline session.	Video recording and coding for: Eye contact (other), eye contact (object), smiling, active avoidance, and self stimulation.	Increase in all social behaviours for 3 participants. Decrease in active avoidance and self stimulation, variable results attributed to session cancellation.	6/11
Lovell, Jones & Ephraim, 1998	53 yr. old man with PMID at a long-stay hospital. (UK)	Evaluate the effectiveness of II to increase social behaviour with a man with PMID.	Used by: Clinical Psychologist. Training and support: not stated. Intervention: 3 days of alternating 5 minute interaction and proximity sessions (17 sessions total).	Alternating treatments.	Video coding: physical contact, client looking at any other person, joint awareness, smiling /laughing, looking at toy, covering at least half of his face with his clothes.	Increase in physical contact, looking at people and joint attention in the II sessions. No consistent changes in vocalisations, smile/laughing, and looking at toy. Reduction in covering face with clothes in II sessions, following an unstable baseline.	6/11
Nind, 1996	6 adults, 27 to 36 years living in a long-stay hospital. (UK)	Evaluate the effectiveness of II in developing the social and	Used by: teacher. Training and support: not stated. Intervention: 12 to 18	Multiple baseline	Video coding: initiation of social contact, response to	Increases in initiation of social contact, and increases in time spent in interactive behaviour in 5	7/11

THE EFFECTIVENESS OF INTENSIVE INTERACTION

		communicative abilities of people with PMID.	months of daily sessions.		physical contact & proximity interactive behaviours. PVCS and Cuddliness scale.	participants. New interactive behaviour in some participants. Advances in PVCS and cuddliness scale for all participants.	
Nind, 1999	Adult (Kris) aged 28 who had a diagnosis of Autism, living at a long-stay hospital. (UK) Questionnaires regarding 'Interactive Approaches' filled out by 58 teachers in a variety of schools, 11 of whom described using II.	Is II useful with people with autism?	Used by: teacher Training and support: not stated. Intervention: 57 weeks	AB design of one participant (Part of a larger, multiple-baseline study). Questionnaire.	Video ratings: organised self involvement, overall time in interactive behaviours, initiation of social contact, responses to proximity and physical contact. No particular analysis of the questionnaires stated.	Unstable baseline prevents full analysis, but there is a drop in self involvement. Increase in sociability. No respondents highlighted difficulties in using II with students with Autism. Benefits for learners: increased self-motivation, and sociability, increased calm. Benefits for staff: improved motivation, feeling positive about the children and work, being receptive to pupil's signals.	6/11
Nind, M. & Kellett, M., 2002	6 Adults in long-stay hospital (As in Nind, 1996) 4 Children at community	Explore thinking around stereotyped behaviour	Used by: teachers. Training and support: not stated. Intervention: 12 to 18 months of daily sessions.	Original designs: multiple baseline. Data presented: mix of multiple baseline and AB design.	Video coding of individual stereotyped behaviours - both in and out of intervention	Reductions in stereotyped behaviour for some participants. Lack of change in behaviour ratings for others attributed to change	6/11

THE EFFECTIVENESS OF INTENSIVE INTERACTION

	special school (As in Kellett, 2001**)				sessions.	in quality rather than quantity of behaviour, or lack of support from wider system.	
Samuel, et al., 2008	4 adult women, 23 to 56 years. (UK)	To investigate whether novice practitioners can learn to use the II approach. To investigate whether II has a positive effect on people with PMID and the relationship between person and communication partner.	Used by: residential care staff. Training and support: half day with II practitioner. Intervention: 5 sessions per week for 12 weeks	Staggered multiple baseline. Questionnaire administered, content analysis used.	Coding of participants on visual scanning, looking at face, engagements, joint focus, initiating social/physical contact. Coding of staff on mirroring vocalisation and movement, contingent responding, forcing/overriding Questionnaire.	Participants – increase in visual scanning, looking at face, engagement, joint focus, initiating social contact. Staff – increase in use of mirroring vocalisation and movement and contingent responding. Completion of reflective logs declined over time. Data from the questionnaire was most often coded as: Team cohesion Benefits for staff: Only 3 out of 58 observer and practitioner comments included ‘reciprocal relationship building’.	9/11
Zeedyk, Caldwell, & Davies, 2009	6 male, 4 female, late teens to early 60s, in residential	To investigate how quickly an increase in engagement occurs during II.	Used by: experienced practitioner. Training and support: not stated. Intervention: 1 st session	Observational, multiple cases.	Section of video of the first II session. Videos coded: eye gaze to partner, bodily	Of 37 measures of engagement, 5 did not show an increase. At least some variables increased for all individuals, 70%	6/11

THE EFFECTIVENESS OF INTENSIVE INTERACTION

centre, day centre or at home. (UK)	of II.	orientation & proximity to partner, emotional valence. Scores summarised as 'engagement score.'	increased on all variables. Some increases in engagement occurred within 3 minutes.
-------------------------------------	--------	---	---

Qualitative Studies

Forster & Taylor, 2006	Young adult man, 'Cameron' with PMID, severe vision impairment and physical disability. Two disability support workers (DSWs) interviewed. (Australia)	To document communication skills and staff perceptions of interactions.	Used by: 9 DSWs. Training and support: 2 hour trial of II, consultation report detailing II recommendations, reflective logs. Intervention: Daily interaction sessions with Cameron, from 15 mins to 2 hours in duration.	Videoed observations of 2 DSW with Cameron and semi-structured interviews with 2 DSWs. Reports and Triple-C checklist of communication. Reflections by DSWs.	Content analysis of reflection sheets. Coding of themes for the interviews	Videos showed positive regard for Cameron & engagement in techniques, new skill and location of interactions. Reflective logs: shift to seeing behaviour as communicative. Triple C: Cameron's communicative skills increased. Themes from interviews: Development of techniques and skills, Use of teamwork, Seeing things from Cameron's perspective, Positive perspective on II Decrease in negatively perceived behaviours.	10/26
-----------------------------------	--	---	---	--	--	--	-------

Jones & Howley, 2010	5 children on interaction program who had Autistic Spectrum diagnoses and/or LD. 4 in mainstream schools and 1 in special school. (UK)	To explore the effectiveness of an interaction programme in schools.	Used by: teachers and support workers Training and support: experienced practitioner alongside novice. Intervention: One to one sessions gradually extended to involve peers.	Case Study Approach: Views collected from involved professionals using Questionnaires, semi-structured interviews and document scrutiny. Interviews recorded, transcribed and collated. Questionnaire given to the parents of the child.	Codes ascribed to segments of data.	Positive outcomes for children: Enhanced communication skills, development of friendships with peers. Outcomes for staff: model perceived to be effective, increased staff confidence. Areas of consideration: trainees being released from other work, availability of suitable spaces, the importance of partnerships within school and with teachers.	15/26
Zeedyk, Davies, Parry, & Caldwell, 2009	9 women and 3 men, aged 16 to 19, who used II in Romania with 10 girls and 8 boys with	To examine the experience of the novice practitioners in II.	Used by: novice II practitioners Training and support: one hour training session. Intervention: 1.5 weeks of daily sessions.	Written accounts of II by the 12 practitioners.	Thematic analysis	Impact of II on children: Increase in social engagement, decrease in distress and self harm, attention to the wider environment. Impact of II on volunteers:	21/26

THE EFFECTIVENESS OF INTENSIVE INTERACTION

24

developmental
delay.

Intensified relationships
with the children,
ineffectiveness, initial
doubts.

*Quantitative studies rated using SCED scale (Tate et al., 2008), qualitative studies rated using framework from National Institute for Health and Care Excellence (2012).

** Kellett (2001) study not included in analysis due to being an unpublished PhD thesis

Quality Assessment

Quantitative studies (N=15). The studies included were all single case or small n designs. When the studies were scored using the SCED (Tate et al., 2008) was used there was a range of 3 to 9 out of 11. The sum of scores can be seen in Table 1, with the ratings for each quality criteria seen in Appendix F. 20% of the studies were rated by a second marker and the ratings received a Cohen's Kappa score of 0.817 which is classed as 'very good' (Fleiss, 1973).

In general the studies reviewed suffered from failing to control potential sources of bias, or, at least, failing to report how they controlled for bias as this was the second lowest scored category of all the checklists. The lowest scored category was statistical calculation, which all but one of the papers (Samuel, Nind, Volans, & Scriven, 2008) failed to do. Statistical calculation in single case designs is notoriously under-utilised (Smith, 2012), so this finding is unsurprising. In addition, sometimes the way results were reported made it difficult for the author's conclusions to be fully supported.

Qualitative studies (N=3). The qualitative studies were reviewed using the NIHC scale (National Institute for Health and Care Excellence, 2012). There was a range of 10 to 21 out of 26. The studies suffered from a lack of clear reporting and reflexivity with regard to the choice of methodology and the researcher's position. The sum of scores can be seen in Table 1, with the ratings for each quality criteria seen in Appendix G. All 3 papers were second marked and received a Cohen's Kappa of 0.643, classed as 'good' (Fleiss, 1973). Of particular quality was the study conducted by Zeedyk et al (2009), as this study clearly stated methodology and process and extensively linked the findings back to previous literature.

Synthesis of Findings

The results will be presented as a narrative synthesis, with themes of: training and length of intervention, effectiveness of intensive interaction, staff experience, anecdotal evidence and sustainability of interventions.

Training and Length of Intervention

The training of Intensive Interaction practitioners and the subsequent length of time for the intervention varied considerably. Ten studies (Argyropoulou & Papoudi, 2012; Elgie & Maguire, 2001; R. Jones & Williams, 1998; Kellett, 2003; Leaning & Watson, 2006; Lovell, Jones, & Ephraim, 1998; Nind, 1996, 1999; Nind & Kellett, 2002; Zeedyk, Caldwell, & Davies, 2009) did not state the training given to the practitioners, for six studies it was a day or less (Forster & Taylor, 2006; Kellett, 2000, 2004, 2005; Samuel et al., 2008; Zeedyk, Davies et al., 2009), for two studies (Barber, 2008; K. Jones & Howley, 2010) it was longer (10 sessions and 6 sessions respectively). Four studies (Barber, 2008; Forster & Taylor, 2006; K. Jones & Howley, 2010; Samuel et al., 2008) stated that there was follow up support afterwards, such as reflective groups for the staff.

As far as can be ascertained in the studies reviewed, the outcomes did not vary according to the length of training given. Several authors did discuss limitations in the training or subsequent support for practitioners, and concluded that lack of support from management negatively affected the efficacy of the approach (Kellett, 2003; Samuel et al., 2008).

Effectiveness of Intensive Interaction

Studies reviewed examined various aspects of participants' behaviour to ascertain what effect Intensive Interaction had, these were social interaction and interactions with peers, self-injurious behaviour and stereotyped behaviour. These will be discussed in turn and evidence examined.

Social Interaction. Social interaction or engagement has been measured differently across the studies, usually by coding videos for behaviours indicating social engagement. Many studies (Barber, 2008; Kellett, 2000, 2003, 2004, 2005; Samuel et al., 2008) use the approach, first developed by Nind (1996), which codes for 8 indicators of social behaviour: no interactive behaviours, looking at face, happy/smiling face, reciprocal social physical contact, eye contact, joint focus/activity, contingent vocalisation, and engaged. The theoretical basis (Nind, 1996) adds to the construct validity of the measures used, and the clear, operationalized measures have added to subsequent studies. Measures such as the Pre-Verbal Communication Schedule (PVCS) and the Sociability Assessment Scale were also used first by Nind (1993) and subsequently by other researchers (Kellett, 2000, 2003, 2005, Samuel).

Nind's study (1996) was a multiple baseline design with 6 adult participants. The results appear to show that all participants improved on measures of sociability and communication. These improvements were not always directly concurrent with the start of the intervention, casting doubt on the intervention as cause. However, Nind adduces persuasive arguments for the link; the participants had long-standing low communicative abilities, many behaviours occurred for the first time after the intervention began, and teacher's logs showed no extraneous events concurrent with

improvements. It was hypothesised that behaviours which increased later were developmentally more complex.

The series of studies by Kellett (Kellett, 2000, 2003, 2004, 2005) are best looked at as a whole, as they originally formed a multiple-baseline study (Kellett, 2001). This was not included in this review, as it has not been published in a peer-reviewed journal.

Separately the studies suffered from an unstable baseline (Kellett, 2000), and variability in scores coded during the intervention period (Kellett, 2003, 2004, 2005), thus limiting the conclusions that can be drawn. When examined together the findings are much more robust, and clearly indicate that an Intensive Interaction intervention had positive effects on the social ability of the children involved.

Barber (2008) utilised an AB design, with the baseline measured 12 months before the intervention point. The extended duration between baseline and post-intervention measurement casts doubt on the responsibility of the intervention for the gains in sociability. In addition, data from only three of 11 students is reported, with no explanation of the excluded data. Similarly, Leaning and Watson (2006) present data from three of five participants. These three did show improvements on the sociability scales, but the missing data are not accounted for and so could raise issues of bias.

Samuel et al (2008) reported an increase in social behaviour using the same method of video coding, but these increases were small (<5% was classed as a 'noticeable increase').

Other papers (Leaning & Watson, 2006; Lovell et al., 1998; Zeedyk et al., 2009) use a similar approach of videoing participants, and coded for slightly different behaviours. Zeedyk summarised the scores into an overall 'engagement' score, this simplifies the

analysis, and makes it easy to see that all participants increased on 'Engagement' over the course of the intervention.

Two papers (Elgie & Maguire, 2001; Lovell et al., 1998) video-coded similar measures of sociability, but added idiographic measures of social behaviour. Lovell (1998) found that 'putting clothes over face,' did not decrease following intervention, whereas Elgie and Maguire (2001) found an increase in incidences of hand contact which was highly significant for the client in their study. Although this was an AB design, the concurrent validity is strengthened by a 6 month baseline at zero before the intervention commenced.

Argyropoulou and Papoudi (2012) measured a child and a peer's 'initiations' of interactions and subsequent responses. Their use of an ABA design, and the concurrent increase and decrease of the child's initiations with the introduction and withdrawal of the intervention, provides strong support for the intervention being responsible for increasing the amount of initiations. The positive responses of both children did not decrease following withdrawal, limiting the extent to which the increase in positive responses can be objectively linked to the intervention. The authors posit that the increased positive responses were maintained due to the relationship that the children had built up over the sessions.

In the qualitative papers reviewed, all three found social interaction related themes and sociability was perceived to be enhanced by the Intensive Interaction practitioners. However, validity was limited in two studies (Forster & Taylor, 2006; K. Jones & Howley, 2010) by a lack of clear methodology.

Based on the papers reviewed, the evidence is building that to suggest that Intensive Interaction increases social interaction. However, the conclusions should be cautious due to findings being limited by unstable baselines, AB designs and small improvements. All papers found at least some increase in sociability so it can still be considered that evidence is building for Intensive Interaction developing communicative abilities.

Repetitive behaviours. Jones and Williams (1998) used an approach labelled as Intensive Interaction to attempt to reduce the repetitive hand movements of a man with PMID. The intervention had no effect on the movements but appeared to utilise only one of the principles of Intensive Interaction, that of imitation. It did not focus on the reciprocal 'conversations' since been posited to be important. This study has since been criticised for its blinkered focus on reducing stereotypy by Nind and Kellett, (2002). A more complex understanding of repetitive behaviours has since been proposed (Kennedy, Meyer, Knowles, & Shukla, 2000) which includes taking into account their functions for the person, and criticises interventions which seek to simply reduce such behaviours.

In their paper examining the effect Intensive Interaction has on repetitive behaviours, Nind and Kellett (2002) discussed the reduction in stereotypy in 6 of the 10 participants. The causal relationship between Intensive Interaction and the reduction was supported by the use of two multiple-baseline studies. The reductions in repetitive behaviour are explained as the participants choosing to spend time in other-directed rather than self-directed activity. Nind and Kellett (2002) also highlight a change in the quality rather than quantity of the stereotypy for some participants where the

decrease was less marked. The clarity of reporting and data analysis suffered in this paper due to its focus being a discussion of the challenges and considerations around stereotypy, rather than a presentation of new data.

The studies above provide limited evidence to suggest that Intensive Interaction results in a reduction or change in quality of stereotyped behaviours.

Self injurious behaviour. One study has examined an attempt to reduce self injurious behaviour using Intensive Interaction (Elgie & Maguire, 2001) This study found no evidence that an Intensive Interaction intervention affected self injurious behaviour. The woman who participated in displayed self injurious behaviours so severe and chronic that she spent most of her time in arm splints. The chronicity of the self-injurious behaviour may have impacted on the capacity of the intervention to effect lasting change.

In the qualitative study by Zeedyk et al (2009), 8 out of the 12 volunteer practitioners wrote about the reduction in distress and self-harm they perceived in the children they worked with, and 7 of the 18 children were mentioned. The validity is well evidenced by quotations and clearly documented analysis.

In summary, there is, at present, limited support for a reduction in self injurious behaviour following Intensive Interaction interventions.

Staff experience. Some studies reported that perceptions or the support of staff affected the implementation of Intensive Interaction interventions (K. Jones & Howley, 2010; Kellett, 2003; Samuel et al., 2008; Zeedyk, Davies et al., 2009). Samuel et al. (2008) reported the use of reflective logs and a support group declined over

time, and suggested that this limited changes in staff behaviour and therefore the clients' social behaviour. Kellett (2003) found that staffing factors, such as limited time and support limited the efficacy of the intervention. Zeedyk et al.'s (2009) study highlighted practitioners' struggles with Intensive Interaction, as themes included 'ineffectiveness' and 'initial doubts'. This may be the case with all novel techniques and, in this study, was counter balanced by the benefits seen for the children that they worked with.

Anecdotal Evidence

The conclusions that could be drawn from the evidence presented were limited in scope, and did not seem to reflect the positive effects reported to result from Intensive Interaction. Authors often included moving descriptions of participants' interactions, such as, *"He seemed happy, as he was laughing and jumping out of joy, whilst being with the other children"* (Argyropoulou & Papoudi, 2012, p. 110). Kellett stated, *"[the child's mother] described the joy of the family in finally being able to 'connect' with Catherine and wrote that those last few months were their happiest times together."* (2005, p. 119)

However in a systematic review, these anecdotal reports are considered 'insufficient evidence', and books and dissertations are excluded due to the lack of peer reviewing. Despite this, the practice of Intensive Interaction is growing, and there is a conference every year discussing pitfalls and successes.

Sustainability of Interventions

In several of the studies, (Kellett, 2002, 2004, Leaning and Watson, 2006) there was variability in the data attributed to disruption in the intervention. This may have been

illness (Kellett, 2001), lack of support for the approach (Kellett, 2002) or cancellation of sessions (Leaning and Watson, 2006), but overall this shows the importance of having a consistent approach when using an intervention with such a relational component.

Discussion

The aim of this research was to examine the effect of using Intensive Interaction with people with intellectual disabilities or autism. The papers reviewed found that studies examined the effects of using Intensive Interaction on social interaction, stereotyped behaviour and self injurious behaviour. Evidence for the positive effects on social interaction is building, and there is limited evidence for its effect on stereotyped and self injurious behaviour. The limited empirical evidence does not appear to fully support the powerful claims made by authors and the anecdotal reports of people conducting the interventions. There are several reasons for this, not least the difficulty in conducting good quality, methodologically and ethically sound research interventions with people with intellectual disabilities. Such difficulties are discussed in Kellett and Nind's paper (2001), this highlights issues around research design, informed consent, duration of baseline, tools of measurement and data ownership. People who are unable to advocate for themselves need stringent ethical frameworks to ensure their needs remain paramount. This often precludes any design where there is a withdrawing or denial of treatment, such as those that use a control group or ABA designs.

One of the studies in this review (Lovell, Jones and Ephraim, 1998) did utilise an alternating treatments design, where 5 minutes of Intensive Interaction was followed by a break, then a 'proximity' intervention. The ethics of providing such an

intervention for the purposes of research are problematic: the research design has parallels to the 'still face' paradigm, whereby babies react with distress to a temporarily unresponsive care giver (Adamson & Frick, 2003); however, whereas the still face paradigm is a time-limited and one-off procedure, the studies utilised the two different interventions repeatedly over a few days. An intervention such as this could be at best confusing, and at worst, distressing, to some of the most vulnerable research participants.

Several papers in the sample devoted a significant portion of their thinking to the ethical and conceptual issues of working with people with PMID or autism (Nind, 1999; Nind & Kellett, 2002). This may have been one of the reasons why their scores on the methodological reporting of the study were lowered. Such discussions included an exploration of the adaptive and functional meaning of 'stereotyped behaviour', and the way it can be seen as a communicative tool for people with intellectual disabilities. At the time it was published, the understanding of such behaviour would have been limited, thus such exploration would have been valued highly as contributing to the knowledge base, and moving it forward.

Another reason why the studies are limited in the quality of the methodology is the nature of Intensive Interaction: like many good interventions, it is complex and multi-faceted, thus making it difficult to split off the components and conduct a multiple baseline design based on intervention components. The nature of Intensive Interaction also makes it difficult to use ABA designs, as the first intervention session may lead to lasting change. This is seen in Agyropoulou and Papoudi's study (2012) where the two

participants had built up a relationship that appeared to have positive effects on their social behaviour even when the intervention was withdrawn.

Another issue when researching into interventions for people with PMID is the heterogeneity of such a population group. This is even more apparent when considering levels of social interaction. The diversity of participants and their reactions to interventions means that homogenous control groups would be near impossible to construct.

Tools of measurement in these studies included video coding of social behaviours. In a relation approach such as Intensive Interaction, these seem reductionist. Methods of assessing the interactions of people with PMID as suggested by Hostyn et al. (2011) may be more appropriate. Capturing the rich anecdotal evidence woven throughout the studies in this area may be possible using qualitative analysis of the papers; this may be a direction for future research.

With the research obviously limited by the considerations above, it is even more important for future researchers to carefully consider and justify study methodology. For single case designs, referring to guidance such as Tate et al., (2008) and Smith (2012) will add to the quality and strength of research evidence. Qualitative research should consider standards and rigour, as discussed by NICE (2012), to add richness and validity to conclusions drawn.

Critique

Authors were not contacted to ascertain further information about the studies that they conducted, such as their ethical procedures or interview schedules as the focus

was also on reporting quality, essential for effective dissemination. This may, however, have resulted in studies being quality-rated unduly harshly. The quality assessments used (National Institute for Health and Care Excellence, 2012; Tate et al., 2008) can be seen as a strength of the paper as they were both recognised measures and the inter-rater reliability was good. Another consideration is that papers examined were limited to those published in peer-reviewed journals; further studies have been published as PhD Theses or in books. Limiting to peer-review journals does assure a degree of quality and is common practice in systematic literature reviews, yet may result in the dismissal of illuminating research.

Summary

Although such limitations and the difficulties discussed above have limited the evidence found, it is still possible to conclude that Intensive Interaction is likely to be a helpful intervention for people with PMID or autism. Unfortunately no clear guidance for length or scope of Intensive Interaction training can be ascertained from this review, as the training was either not consistent or not reported. Some evidence for positive effects on practice did appear to come from training sessions as short as one hour, but the intervention period was just 2 weeks, leaving no time for such processes as initiative decay, (Buchanan, Claydon, & Doyle, 1999) where positive change in practice reduces over time. A qualitative study of staff experience using Intensive Interaction suggests that this may occur (Firth, Elford, Leeming, & Crabbe, 2008). Based on the studies examined here there may be several ways of increasing the effectiveness of the approach. Those include a team based approach and support, as purported to be helpful in Barber's (2008), and Forster and Taylor's (2006) studies, and

the lack of which found to provide a barrier for Kellett (2003) and Samuel et al. (2008). The need for increased support was also highlighted in Zeedyk, Davies et al.'s study (2009), where a main theme was 'uncertainty' around the new approach. Wider literature (Culham, 2004; Firth et al., 2008) explores staff concerns about the approach. Staff support and in-depth exploration of difficult issues should therefore be a component of any Intensive Interaction intervention.

It would be beneficial if the perceived positive effects of Intensive Interaction could be captured in some way. In order to provide Intensive Interaction with the evidence base it lacks at present, the methodological quality of both quantitative and qualitative studies needs to be examined closely, and research, once finished should be submitted to peer-reviewed journals.

References

- Adamson, L. B., & Frick, J. E. (2003). The still face: A history of a shared experimental paradigm. *Infancy, 4*(4), 451-473.
- Argyropoulou, Z., & Papoudi, D. (2012). The training of a child with autism in a Greek preschool inclusive class through Intensive Interaction: A case study. *European Journal of Special Needs Education, 27*(1), 99-114.
- Barber, M. (2008). Using intensive interaction to add to the palette of interactive possibilities in teacher-pupil communication. *European Journal of Special Needs Education, 23*(4), 393-402.
- Buchanan, D., Claydon, T., & Doyle, M. (1999). Organisation development and change: the legacy of the nineties. *Human Resource Management Journal, 9*(2), 20-37.
- Caldwell, P. (2007). *From isolation to intimacy: Making friends without words*. London England: Jessica Kingsley Publishers.
- Culham, A. (2004). Getting in touch with our feminine sides: Men's difficulties and concerns with doing Intensive Interaction. *British Journal of Special Education, 31*(2), 81-88.
- Department of Health (2009) *Valuing People: Now*. London: Department of Health.
- Elgie, S., & Maguire, N. (2001). Intensive Interaction with a woman with multiple and profound disabilities. *Tizard Learning Disability Review, 6* (3), 18-24.
- Ellis, M. P., Astell, A. J., & Zeedyk, M. S. (2008). A new approach to communicating with people with advanced dementia: A case study of adaptive interaction. In *Promoting social interaction for individuals with communicative impairments: Making contact*. (pp. 119-136). London England: Jessica Kingsley Publishers.

- Firth, G. (2009). A Dual Aspect Process Model of Intensive Interaction. *British Journal of Learning Disabilities, 37*(1), 43-49.
- Firth, G., Berry, R., & Irvine, C. (2010). *Understanding intensive interaction: contexts and concepts for professionals and families*. London; Philadelphia: Jessica Kingsley.
- Firth, G., Elford, H., Leeming, C., & Crabbe, M. (2008). Intensive Interaction as a novel approach in social care: Care staff's views on the practice change process. *Journal of Applied Research in Intellectual Disabilities, 21*(1), 58-69.
- Fleiss, J. L. (1973). *Statistical methods for rates and proportions*: Wiley-Interscience, Inc., New York, N.Y.
- Forster, S., & Taylor, M. (2006). Using Intensive Interaction: A case study. *ACQuiring Knowledge in Speech, Language and Hearing, 8*(1), 12-15.
- Hostyn, I., Petry, K., Lambrechts, G., & Maes, B. (2011). Evaluating the quality of the interaction between persons with profound intellectual and multiple disabilities and direct support staff: A preliminary application of three observation scales from parent–infant research. *Journal of Applied Research in Intellectual Disabilities, 24*(5), 407-420.
- Jones, K., & Howley, M. (2010). An investigation into an interaction programme for children on the autism spectrum: outcomes for children, perceptions of schools and a model for training. *Journal of Research in Special Educational Needs, 10*(1), 115-123.
- Jones, R., & Williams, H. (1998). Reducing stereotyped behaviour: an experimental analysis of Intensive Interaction. *International Journal of Practical Approaches to Disability, 22*(2/3), 21-25.

- Kellett, M. (2000). Sam's story: evaluating Intensive Interaction in terms of its effect on the social and communicative ability of a young child with severe learning difficulties. *Support for Learning, 15*(4), 165.
- Kellett, M. (2001). *Implementing Intensive Interaction: an evaluation of the efficacy of Intensive Interaction in promoting sociability and communication in young children who have severe learning difficulties and of factors affecting its implementation in community schools.* . Oxford Brookes University, Oxford.
- Kellett, M. (2003). Jacob's Journey: developing sociability and communication in a young boy with severe and complex learning difficulties using the Intensive Interaction teaching approach. *Journal of Research in Special Educational Needs, 3*(1), 1-16.
- Kellett, M. (2004). Intensive Interaction in the inclusive classroom: using interactive pedagogy to connect with students who are hardest to reach. *Westminster Studies in Education, 27*(2), 175-188.
- Kellett, M. (2005). Catherine's legacy: social communication development for individuals with profound learning difficulties and fragile life expectancies. *British Journal of Special Education, 32*(3), 116-121.
- Kellett, M., & Nind, M. (2001). Ethics in quasi-experimental research on people with severe learning disabilities: Dilemmas and compromises. *British Journal of Learning Disabilities, 29*(2), 51-55.
- Kennedy, C. H., Meyer, K. A., Knowles, T., & Shukla, S. (2000). Analyzing the multiple functions of stereotypical behaviour for students with autism: implications for assessment and treatment. *Journal of Applied Behavior Analysis, 33*(4), 559-571.

- Leaning, B., & Watson, T. (2006). From the inside looking out - an Intensive Interaction group for people with profound and multiple learning disabilities. *British Journal of Learning Disabilities, 34*(2), 103-109.
- Lovell, D., Jones, S., & Ephraim, G. (1998). The effect of Intensive Interaction on the sociability of a man with severe intellectual disabilities. *International Journal of Practical Approaches to Disability, 22*(2/3), 3-8.
- National Institute for Health and Care Excellence. (2012). *Methods for the development of NICE public health guidance (third edition)*. London: National Institute for Health and Care Excellence.
- Nind, M. (1996). Efficacy of Intensive Interaction: developing sociability and communication in people with severe and complex learning difficulties using an approach based on caregiver-infant interaction. *European Journal of Special Needs Education, 11*, 48 - 66.
- Nind, M. (1999). Intensive Interaction and autism: a useful approach? *British Journal of Special Education, 26*(2), 96.
- Nind, M., & Hewett, D. (1994). *Access to communication: developing the basics of communication with people with severe learning disabilities through Intensive Interaction*. London: David Fulton.
- Nind, M., & Hewett, D. (2001). *A Practical Guide to Intensive Interaction*: BILD Publications.
- Nind, M., & Kellett, M. (2002). Responding to individuals with severe learning difficulties and stereotyped behaviour: Challenges for an inclusive era. *European Journal of Special Needs Education, 17*(3), 265-282.

- Samuel, J., Nind, M., Volans, A., & Scriven, I. (2008). An evaluation of Intensive Interaction in community living settings for adults with profound intellectual disabilities. *Journal of Intellectual Disabilities, 12*(2), 111-126.
- Sharma, V., & Firth, G. (2012). Effective engagement through intensive interaction. *Learning Disability Practice, 15*(9), 20-23.
- Smith, J. (2012). Single-case experimental designs: A systematic review of published research and current standards. *Psychological Methods, 17*(4), 510-550.
- Tate, R., McDonald, S., Perdices, M., Togher, L., Schultz, R., & Savage, S. (2008). Rating the methodological quality of single-subject designs and n-of-1 trials: Introducing the Single-Case Experimental Design (SCED) Scale. *Neuropsychological Rehabilitation, 18*(4), 385-401.
- Zeedyk, S. (Ed.). (2008). *Making contact: Promoting social interaction for individuals with communicative impairments*. London: Jessica Kingsley Publishers.
- Zeedyk, S., Caldwell, P., & Davies, C. (2009). How rapidly does Intensive Interaction promote social engagement for adults with profound learning disabilities? *European Journal of Special Needs Education, 24*(2), 119-137.
- Zeedyk, S., Davies, C., Parry, S., & Caldwell, P. (2009). Fostering social engagement in Romanian children with communicative impairments: the experiences of newly trained practitioners of Intensive Interaction. *British Journal of Learning Disabilities, 37*(3), 186-196.

PART TWO

Using Intensive Interaction in Hospital Settings

Authors: Anna L Bodicoat*, Nick Hutchinson & Chrissie Blackburn

University of Hull

*Corresponding author: Anna Bodicoat

Please send correspondence to: Anna Bodicoat, Department of Clinical Psychology and Psychological Therapies, University of Hull, Cottingham Road, Hull, HU6 7RX

Tel: +44 (0)1482 464117 Fax: +44 (0)1482 464093

Email address: anna.bodicoat@nhs.net

This paper is written in the format ready for the Journal of Applied Research in Intellectual Disabilities. Please see Appendix A for guidelines for authors

Word count: 8335 (including tables and references)

Abstract

Introduction: People with intellectual disabilities face significant inequalities in health care settings, due, in part, to attitudes of hospital staff. Intensive Interaction may benefit patients with an intellectual disability.

Method: Interviews with seven hospital staff who had been trained in Intensive Interaction were analysed using interpretative phenomenological analysis.

Results: Hospital staff did not conceptualise Intensive Interaction in line with the literature. Nine subordinate themes were clustered into three superordinate themes of 'Using Intensive Interaction,' 'Attempting to Improve the Patient's Experience in Hospital' and 'Involving Others.' The overarching concepts of 'The Ideal' and 'Struggles Identified' highlighted difficulties using Intensive Interaction.

Conclusion: Despite difficulties understanding and using Intensive Interaction, hospital staff were able to use some of the principles in their work. The themes of 'looking closer' and 'building relationships' in particular have positive implications for the potential of this approach to improve the care of hospital patients with intellectual disabilities.

Background

Health problems in people with intellectual disabilities

People with intellectual disabilities, especially those with profound and multiple intellectual disabilities (PMID), have more physical health problems than people without an intellectual disability (Disability Rights Commission, 2006; van Schrojenstein Lantman-de Valk et al., 1997). People who have PMID have a lower life expectancy than people with mild or moderate intellectual disabilities or people without an intellectual disability (Patja, Iivanainen, Vesala, Oksanen, & Ruoppila, 2000). Therefore it is likely that during the course of their lives people with intellectual disabilities will have more reason to access primary and secondary health care services. In spite of this increased access, people with intellectual disabilities face significant inequalities when accessing health care (Disability Rights Commission, 2006) including, amongst other issues, limited access to information, and 'diagnostic overshadowing,' where the difficulties are seen in terms of the intellectual disability rather than a health concern.

In an extensive review of worldwide literature, Krahn, Hammond and Turner (2006) found that despite a higher prevalence of health conditions in people with intellectual disabilities, there were inadequacies in attention to care needs, health promotion, and accessing health care services.

This has serious implications for the person's experience of hospital and health outcomes. A review by Backer, Chapman and Mitchell (2009) found that people with intellectual disabilities experienced a number of negative emotions whilst in hospital, including distress, boredom and frustration. This is supported by a more recent review by Bradbury-Jones, Rattray, Jones, and MacGillivray (2013) which highlighted the

evidence that secondary care for people with intellectual disabilities was inadequate. Health outcomes have been shown to be negatively affected, with Mencap's 'Death By Indifference' report (2007) focusing on the failings in secondary healthcare so great that they led to the death of 6 people. In the 'Confidential Inquiry into premature deaths of people with learning disabilities' or 'CIPOLD' (Heslop et. al, 2013) it was found that people with intellectual disabilities died significantly earlier than people in the general population, and this could be changed by better quality healthcare.

Studies and reviews have suggested several reasons for this inadequacy. Mencap suggest ignorance, lack of education and indifference amongst health care professionals as the main factors in healthcare inadequacies, (2007). Krahn, Hammond and Turner (2006) also label negative attitudes as contributing factors, in addition to difficulties in communication and health professionals' struggle to fully support autonomy and empowerment for people with intellectual disabilities and their carers. Backer et al (2009) also attributed the shortfalls in healthcare to attitudes, knowledge and communication style of hospital staff, as well as inaccessible and confusing physical environment, and lack of recognition and support for the carer's role. In a recent literature review of eight qualitative studies into health and welfare of people with intellectual disabilities in hospital, communication, staff attitudes, staff knowledge, valuing the carer's role and the physical environment were again found to be key factors (Bradbury-Jones et al., 2013).

In a qualitative study of people with an intellectual disability and their carers' experience of the hospital system, Dinsmore (2011, p. 11) summarises these concerns by stating that '*attitudes and communicative habits displayed by hospital staff are of*

paramount importance to the hospital experiences of people with learning disabilities’.

In summary, many studies consider the staff at the hospitals to be one facet affecting hospital care for people with intellectual disabilities. Lack of understanding and knowledge, and negative attitudes of health professionals towards people with intellectual disabilities are thought to contribute to poor hospital care, as well as a lack of training around the specific needs of people with intellectual disabilities.

These studies did not focus particularly on people with PMID; however, it is reasonable to assume that the same sorts of feelings would be experienced, if not multiplied.

There have been several initiatives and interventions in the United Kingdom which are designed to improve the experience of people with an intellectual disability in hospital.

Learning Disability Liaison nurses provide support and education (Brown et al., 2012) and hospital ‘passports’ are becoming more common (Backer et al., 2009). There are fewer structured interventions reported in the literature which aim to improve health professionals’ knowledge, communication and attitudes (Backer et al., 2009; Bradbury-Jones et al., 2013). One such intervention might be training in Intensive Interaction.

Intensive Interaction

Intensive Interaction is a technique of communication with people who do not use words, such as those with profound intellectual disabilities or autism. Practitioners using the technique see people’s sounds and movements as potential for communication, and use these to engage in interactive games (Nind & Hewett, 2001). Often imitations of these sounds and movements are developed so the interaction becomes a turn-based conversation (Barber, 2007). In this way a relationship can be built between the person with an intellectual disability and their communication

partner (Caldwell, 2007; Zeedyk, Davies, Parry, & Caldwell, 2009). It has been applied across the age range, and in schools and residential settings (Sharma & Firth, 2012).

In a review (Firth, 2006) research on Intensive Interaction was identified to be limited in scope and scale. However, positive effects of increased social responsiveness, including smiles and increased eye contact, were found consistently across the studies reviewed (Caldwell, 2007; Kellett, 2005; Samuel, Beinart, Kennedy, & Llewelyn, 2009; Williams, 2005) and a reduction in distress attributed to the intervention (Caldwell & Horwood, 2008; Zeedyk, Davies et al., 2009). These studies show that Intensive Interaction can improve the quality of life for people with PMID, and it may be that these positive effects can occur even in a busy hospital environment. Effects have been found to occur even after three to 14 minutes (Zeedyk, Caldwell, & Davies, 2009) and with sufficient competency gained in as little as one hour training session (Zeedyk, Davies et al., 2009). Nind and Hewett (2001) suggest that Intensive Interaction should be used in an opportunistic way such as during personal care, and treated like a conversation technique.

It is possible that the use of Intensive Interaction techniques in hospital may help to improve the experience of people with PMID in hospitals. The use of this technique may also affect staff feelings. In a qualitative study (Firth, Elford, Leeming, & Crabbe, 2008) it was found that residential care staff spoke about vicariously gaining enjoyment from the use of Intensive Interaction and the subsequent enjoyment of their clients. However, this study did not explicitly examine any further effects on the staff of using the approach, such as attitude change, and attribution of behaviour, and no other studies have examined in depth the effects of using Intensive Interaction on

the staff members. This could do with further exploration and research, as if it is shown to have positive effects such as job satisfaction, increased liking and confidence in working with people with intellectual disability, this implies that not only could it assist people with an intellectual disability, it could change staff attitudes and improve their ability to communicate with people with intellectual disabilities.

This study aimed to discover how hospital staff, who had attended a training course on Intensive Interaction, experienced using the approach with people with intellectual disabilities subsequent to its use. Due to the highly specific and small population, the limited research in this area, and a desire to explore in-depth the experience of this population, a qualitative approach was appropriate. Interpretative Phenomenological Analysis could capture a 'detailed and nuanced analysis of lived experience' (Smith, Flowers, & Larkin, 2009, p. 209) and provide some insight into the challenges, benefits and effects of using the technique. An epistemological statement which explains further the rationale for using IPA is included in Appendix H.

Research question:

What is the experience of hospital staff using Intensive Interaction?

Secondary research questions:

What are the barriers and facilitators to using Intensive Interaction in a hospital setting?

Does using Intensive Interaction affect how hospital staff view the people they have used it with?

How do hospital staff feel Intensive Interaction fits in with their job role?

Method

Recruitment

This study interviewed care staff who had trained in Intensive Interaction and said they had subsequently used it with a patient. The day-long course at Hospital in the North East of the United Kingdom is conducted by a clinical psychologist and a community nurse who work in intellectual disability services in the area. It discusses the principles of Intensive Interaction, namely close observation of the person, tuning into the person's actions, and joining with them for fun, interactive games. It uses a mix of techniques, including activities, discussions and videos of people using Intensive Interaction to show attendees the Intensive Interaction approach.

Following ethical approval granted by Hull University Post Graduate Medical Institute (Appendix I) and site specific approval from Hull East Yorkshire Hospitals NHS Trust (Appendix J), details of the 64 people who had attended the course was obtained from the hospital trust's training department. 58 of these were emailed with an invitation letter (Appendix K); the remainder did not have an email address. Two people responded who were eligible and willing to take part. The main researcher then attempted to contact by telephone 50 of the attendees, focusing on those who worked directly with clients. 29 people could not be contacted, five people were too busy to be interviewed, and ten people said they did not feel they had used the techniques.

Participants

Seven participants were included after verbally stating they had used the techniques. The amount they claimed to have used Intensive Interaction was not an exclusion criteria, as one study has shown that positive effects can occur in as little as three

minutes (Zeedyk, Caldwell et al., 2009). All participants were women, this perhaps reflected the amount of women trained in comparison to men (four out of 60 were men).

This study included seven participants. This is in line with the number of participants recommended by Smith, Larkin and Flowers (2009) for an IPA study (8 to 10).

Details of the participant's pseudonym, the length of time since they attended the course, their ratings and the characteristics of patients with whom they used the techniques are found in Table 1. The ratings include the self-reported knowledge and experience of Intensive Interaction out of 10 (10 being the most knowledgeable or experienced).

Table 1. Information about the participants

Participant Pseudonym	Professional Background	Length of time since attending the course	Self rating of Intensive Interaction Knowledge	Self Rating of Intensive Interaction Experience	Characteristics of patient(s) with whom techniques had been used (and their approximate age)
Charlotte	Support Worker	1 year 11 months	7	5	A woman with intellectual disabilities (in her 50s) & a boy with autism (about 11 years old)
Stephanie	Physiotherapist	2 years 1 month	1	1	A woman with end stage dementia (in her 80s)
Jade	Staff nurse	1 year 11 months	10	8	Struggled to identify a particular patient, but spoke about using it with people with intellectual disabilities
Amy	Auxiliary nurse	2 years 1 month	7	10	Couldn't identify a specific patient
Samantha	Auxiliary nurse	2 years 1 month	7	5	A man with dementia (did not say his age)

Rose	Ward housekeeper	1 year 11 months	7 or 8	5 or 6	A man with down syndrome (did not say his age)
Karen	Auxiliary nurse	1 year 4 months	8	8	A man who had had a stroke, A woman with intellectual disabilities

Design

This study used semi structured interviews to produce qualitative data, and interpretive phenomenological analysis (IPA) to explore the data and produce results. Interview schedules were developed through discussion with people who have knowledge of Intensive Interaction, an awareness of the hospital environment and awareness of difficulties faced by people with intellectual disabilities, The semi-structured interview schedule (Appendix L) included open questions in line with the research questions but had enough freedom to discuss any further concerns. (Smith, Flowers et al., 2009).

Procedure

Before the interview, any questions the participants had were answered as fully as possible and written informed consent was sought (Appendix M). Demographic information was collected, to ascertain where the participants worked, their profession and when they undertook the training. Participants were also asked to self-rate how knowledgeable and experienced they felt they were. Any questions they had about the project were answered and their written consent to the project and the audio-recording of the interview was obtained. The interviews lasted between 25 and 45 minutes. The recordings of the interviews were transcribed. The transcription was in line with the style recommended by Smith, et. Al (2009) and was a semantic

transcription, with significant non-verbal features such as false starts or laughs included. The transcripts were analysed using IPA.

The information sheet (Appendix N) included information regarding the occupational health department at the hospital, in case the participants were distressed by any of the topics they discussed and wished to have further support.

Data Analysis

The data were analysed through IPA. This involved a process of annotation and re-reading, following the steps suggested by Smith, et al., (2009). Initial descriptive, linguistic and conceptual comments were noted, and emergent themes of the participant's experience were identified. Connections across emergent themes for each participant were identified and then links between the themes across participants were developed. A worked example can be found in Appendix O.

To validate the themes and analysis, the process and transcript extracts were discussed in depth with supervisors and a peer discussion group. The researcher's personal experiences of the data were examined using a reflective log, a reflective statement summarising key issues can be found in Appendix P.

Results

Statement of position

In line with the recommendations by Elliot, Fischer and Rennie (1999) and subsequent guidelines for good quality qualitative research (National Institute for Health and Care Excellence, 2012), the following is a statement of perspective of the principle

researcher, to aid interpretation of the analysis, and to aid the reader's consideration of alternative ways to examine the data:

I had the opportunity to work with a young man using Intensive Interaction as an assistant psychologist. I was stunned by the effect that the approach had on him, and amazed at the possibilities for building meaningful relationships with people with profound and multiple intellectual disabilities, something I had not previously thought possible. Over the time I have been working with people with intellectual disabilities, I have been shocked by the inequalities they face, and I found the Death By Indifference report a difficult insight into those inequalities in a hospital setting. I came to this research believing in the capacity for Intensive Interaction to make a difference to people's lives, and wondering about it's potential to affect staff members' views of those that they work with.

What is Intensive Interaction?

The participants conceptualised Intensive Interaction in ways not necessarily in line with the definitions in the literature. This needs to be considered when examining emergent themes. Some participants described techniques that were in line with adapting communication:

"Don't talk above them all the time just talk at their level" (Jade)

"We've got picture cards, like picture boards, um all different types like um writing things down for them if they can't hear you" (Amy)

Others spoke about meeting patient needs in practical ways:

“I found out that he he liked Dad’s army, and we have TVs which they have to pay for, so and he he, and I got in touch with the TV company and I got him so many hours a day free TV” (Rose)

As well as the other techniques mentioned, many of the participants saw Intensive Interaction as *“observing somebody really well” (Charlotte)*

“Um I think mostly look at people’s expressions and movements” (Samantha)

Two participants used mirroring. Interestingly, Stephanie was the only one to use mirroring with a person who had no verbal communication:

“So I sat opposite her and got hold of her hands and tapped with her, the same rhythm that she used” (Stephanie)

It could be argued that this was one of the clearest examples of Intensive Interaction; however, this participant rated herself as 1 out of 10 on both knowledge and experience of Intensive Interaction.

Emergent themes

Nine subordinate themes were discovered, which have been grouped into three superordinate themes. When analysing the data it became apparent that there were contradictions within individual transcripts and participants seemed to struggle with aspects of the approach. As such, the themes have been presented as tensions between ‘The Ideal’ and ‘Struggles Identified’ (Figure 1).

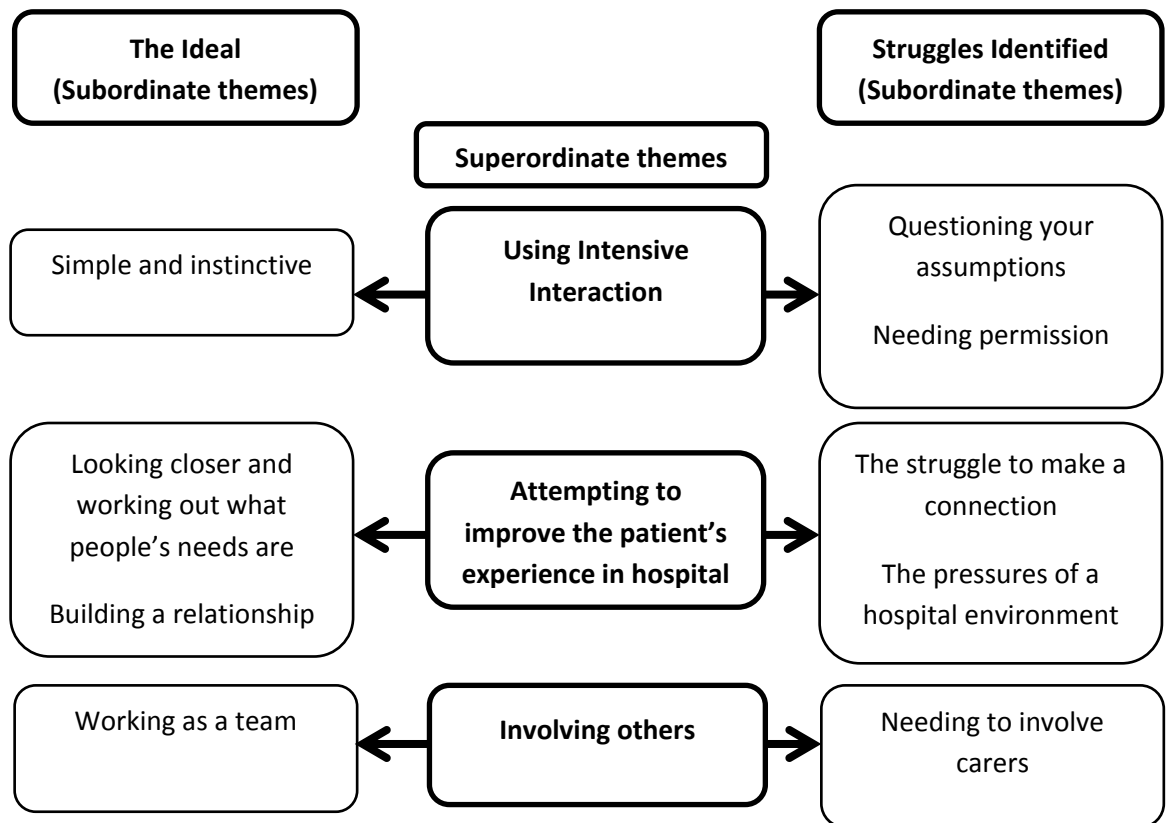


Figure 1. Superordinate and Subordinate Themes

Using Intensive Interaction

Participants spoke about how they perceived using Intensive Interaction, stating that they saw it as simple, using skills and knowledge they already had. This contrasted with their discussion of needing to question assumptions that they made about people, and needing permission to be able to use those instinctive skills.

Simple and Instinctive

The participants conceptualised the approach as “*common sense*” (Samantha & Rose) and as one which they already had the skills to use. They had the idea that little things made a big difference and that they were able to show their personalities through the use of the approach.

“You don’t need any equipment to use it, you don’t need a quiet room to use, you can use it in any situation at all that you find yourself in” (Stephanie)

*“It’s just showing your compassionate side isn’t it? It is part of my job anyway.”
(Charlotte)*

“You’re using like your skills on a day to day basis and you’re using them constantly sometimes you don’t know you’re doing it” (Amy)

“I always do it so it’s not, nothing unusual to me because I’ve always done that with the elderly” (Jade)

This theme could be seen in two ways. To a certain extent, this perception of the approach matches with the principles of Intensive Interaction, in that it is an approach based on pre-verbal communication, and therefore one which is instinctive, just how parents communicate with infants. However, the participant’s understanding of what Intensive Interaction actually is is limited in some ways, and it may be that they have a more superficial understanding of Intensive Interaction than would be beneficial.

Questioning your assumptions

Despite the participants seeing the approach as instinctive, or ‘something they’ve always done,’ there was a sense that their assumptions were challenged by using it, they had to question what they thought they knew about how the patients were acting.

“you don’t assume that somebody can’t answer” (Jade)

“But it was just that little few minutes made me realise she’s not just doing that cos it’s her you know, that’s her way of telling ya” (Karen)

“I hadn’t thought about that disruptive behaviour as being a form of communication before and I think that’s the difference now” (Stephanie)

For three of the participants, it seemed as if one of the assumptions that were challenged was their perception of behaviour that they saw as difficult to deal with. Perhaps the approach opened their eyes to seeing behaviour as communication.

Needing permission

Intensive interaction often involves the use of touch. Participants spoke about their feelings prior to the training that it was not permissible to touch patients or do the things that they felt would show that they cared. This contrasts with the approach as instinctive and natural. They spoke about now feeling it was ok to touch or to show that they cared, and saw the Intensive Interaction training as giving permission to use their skills.

“I wouldn’t have got too close, I wouldn’t, I don’t think I don’t think ‘Oh, or shall I ask him to go for a walk or I don’t know, I don’t think I should be.’ But with that course they were saying, you know urm ‘hold their hands,’ you know ‘stroke people’s head, there’s nothing up with it’. Where before I would have thought, shall I, shan’t I, political correctness you know yeah so, I did bring back from the course you know, to go closer.” (Rose)

“It just reconfirmed, cos us nurses nowadays, you’re not supposed to touch patients and things like that. It just reconfirmed how you would have treated

somebody years ago, you used to touch them if you thought they wanted you to hold their hand or touch them, so it just reconfirmed you are allowed to do that, you know, permitting that the circumstances are right and if it puts them more at ease” (Jade)

As well as being given permission to touch, participants also seemed to be referring to being permitted to show that they cared in other ways, such as going for a walk or spending more time with patients.

Attempting to improve the patient’s experience in hospital

The participants saw using the approach as a way to improve patient experience in hospital. There was a tension present in this theme which highlighted what a struggle it could be to improve that experience.

Looking closer and working out what people’s needs are

This process of looking closer, working out what the individuals’ needs were and treating them as individuals was seen as a way of improving their experience in hospital and making patients feel calmer and happier for all the participants.

“Because if you can help your patients it’s a bonus aint it? Down to a little silly thing - why are they not eating their breakfast, just maybe cos they don’t like it or they’ve got something wrong with their mouth or just different points is what you can look for what, maybe what you wouldn’t normally see.” (Samantha)

“You learn that different people like different things and lot of people like touch, you know, holding hands, even big burly men you know, will feel more comforted if they know, and usually a bit of a banter with them as well and, you

know, and things like that, and try to put people at their ease and, um, yeah, its judging each person as an individual and, um, I think that's the main thing."

(Charlotte).

This was often conceptualised as very practical things such as what the patient wanted to eat or drink, what time they liked to get up, whether they liked the television on or off or how they wanted the environment to be:

"you just try and um, change the situation to how you think that would suit them best. If they need to be in the quiet bit of the room then we can pull the curtains a bit, or um sometimes they like watching certain things on the tv"

(Jade)

"he likes to sit up at ten o'clock or he likes to watch telly between nine and ten and he likes coffee with white sugar" (Rose)

The participants acknowledged that *"different people like different things"* (Karen) and they felt it was important to *'treat them as an individual really, as you would anybody else'* (Jade).

Building a relationship

The consequence of this attention to individual needs was often a sense of connection or building a relationship between the staff members and patients.

"I felt um... Like I had a connection with her really, yeah I did feel like I'd yeah definitely that I'd found a connection and you know and it worked, and yeah yeah, it was good." (Charlotte)

"I thought we was friends, we'd become friends, you know and I'd like to think that he felt he could trust me" (Rose)

"I think we've made a bond now, when he sees me you know he smiles it's great, so he probably trusts me now um he knows I'm gonna hopefully look after him" (Samantha)

The building of trust and connection was a clear way of improving the patients' experiences in hospital for most participants: however, Stephanie spoke about using the approach in much more ambivalent terms. Whereas other participants using words like *'it was good,'* or *'it's great,'* she spoke about it being *'better than nothing,'* this phrasing suggests her ambivalence towards the approach, and it is telling that she is the one who both seemed to be using techniques closest to the definition of Intensive Interaction, as well as the one who rated herself lowest. It is interesting that she came from a different professional background than other participants, being a physiotherapist, rather than nursing or housekeeping. It may be that there is more reflective space in the profession that she is from, hence a chance to evaluate the techniques, notice her difficulties in using them, and consider the impact they have on practice.

The struggle to make a connection

In almost direct contrast with the participant's focus on individual needs, there were limitations to the participant's perception of people as individuals. Some participants struggled to remember individual patients they had worked with:

"I was racking my brains actually before you came (Stephanie)"

“Interviewer: Is there one particular patient that you feel like you’ve used it with in particular that you can think of?”

Amy: No, no sorry I can’t pin it down to one,

Interviewer: No that’s alright.

Amy: It’s a fast turnover of patients.”(Amy)

Despite the participants desire to see people as individuals, the language used to describe the people that came into hospital was often depersonalised, and the use of terms suggested a tendency to talk about and view people in terms of their disability or diagnosis.

“The lady that ran the course, she often comes down with her disableds, um people that she works with” (Jade)

“There’s a lot more medical elderly in these hospitals now” (Amy).

Also highlighted in the transcripts were the difficulties hospital staff had in seeing and responding to the needs of patients who were more vulnerable, even so far as those patients being overlooked, or left. The staff interviewed tended to talk in terms of seeing others do this, acknowledging that it could be a problem, but not necessarily a problem they had.

“I just think I’ve got to be more aware of people that have got difficulties because they are vulnerable do they can get like left and be without a drink or without something not being spotted” (Samantha)

“I do feel sorry for these patients who are hard to reach because people don’t even seem to try and um and so I think it is pity more than anything else,

because these people tend to get over looked, the fact that they might be in pain, the fact that they might be uncomfortable is overlooked because they don't actually verbalise it." (Stephanie)

This seems at odds with the theme of 'looking closer' and responding to needs, and highlights the difficulty of responding even at a practical level to people who struggle to communicate, let alone responding at a personal or emotional level.

The pressures of a hospital environment

Participants spoke about the difficulties in building a relationship and making a connection in the hospital environment and in some ways this limited the relevance of the techniques. All participants struggled with time constraints and in the hospital and saw patient care suffering as a result.

"I suppose the time constraint and staffing constraints you know if we haven't got enough you know you can't spend that time a decent amount of time with somebody to gain their confidence" (Charlotte)

"I just don't feel as though there's time for 'em and that it, it sounds horrible but, you know, like if you've got two qualified and one auxiliary on and you've got thirty patients on a ward, you don't have time for any of the patients to be honest and if you're independent you're alright, if you're not it's tough."(Karen)

Some participants spoke directly about other hospital procedures distressing patients and limiting the care given, like not being able to take a doll into a scanning room or lots of visitors and health professionals coming onto a ward when the patients 'might

want some quiet time of things' (Amy). The procedures and time limitations were seen as preventatives to building a relationship with patients.

"Even if you sit down with a patient for 2 minute you get '[Karen] there's something to do'" (Karen)

These factors may have been part of perceived lack of relevance of the Intensive Interaction techniques; some participants felt that they would be unable to use the techniques they had learned about, or perceived other wards as being able to use them more. It was interesting that across the variety of participants, who worked across a variety of settings within the hospital, they all stated that other areas would use the techniques more than they could. There was also a sense of not seeing the patients that they could use Intensive Interaction with.

"It's slightly different then what you would be doing on the ward " (Jade)

"Other wards would use it a lot more than we would" (Samantha)

"I mean ours is like a quick turnover, it's not like a residential where they're there a long time" (Rose)

Working as a team

Participants highlighted the importance of, and difficulties in, getting others involved.

Team-working

In some ways the involvement of others was helpful, and participants generally spoke about their colleagues as helpful members of a team.

"It's very much teamwork" (Jade)

“Really good team work and that’s a good, you know factor to have, you know, for the patients cos you all work together, everybody’s always really happy you know smiling and that’s always a good positive thing to have.” (Amy)

The need to involve carers

The influence of carers was sometimes seen as helpful, for example, as information givers:

“Speaking to the families and families and the friends, you know, that’s always, you know, good if they can’t physically tell ya what is wrong” (Amy)

“Carers come in with them and tell you sort of what they like and what they don’t like” (Karen)

The outside supporters were seen as being able to provide information when the patients were unable to inform staff themselves.

In some ways, however, the involvement of others was seen as unhelpful, such as a barrier to forming a relationship with the patient,

“So having that outside influence isn’t always easy cos you can’t get that you know that focused sort of you know connection with somebody.” (Charlotte)

“Well I wouldn’t overly touch him cos he’s got a carer with him” (Jade).

This ambivalence might reflect the difficulty in managing both patient and carer’s needs. Jade highlighted the importance of not just assuming people couldn’t tell you what they liked, or give consent, and spoke about her attempts to involve both the person and their carers:

“You do try and involve them, you never talk over them, I always look at them and say and look at the person next to them as well and sort of so that you’re not assuming that they can’t understand you” (Jade)

Discussion

The discussion will focus on how the themes that have emerged answer the research questions and what implications the results have for training, hospital care, and further research.

What is hospital staff’s experience of using Intensive Interaction?

The disparity between the participants’ understanding of Intensive Interaction and the definition of Intensive Interaction according to the literature means that any results or interpretations of the data cannot be fully understood in terms of ‘Intensive Interaction’. The participants do not use the approach fully, but many rated themselves highly on knowledge and experience in the approach.

Instead, the themes reflect what the participants learnt from the day of Intensive Interaction training and have subsequently used in their practice. Fortunately the aim of IPA is to examine in depth a particular experience from the point of view of the participants (Smith, Flowers et al., 2009). It can take into account the difference, and enable the researcher to look past the difference and fully explore the participants’ experience.

Some of the themes are in line with the principles of Intensive Interaction: ‘Looking Closer’ and ‘Building a Relationship’. Using Intensive Interaction leads to practitioners challenging their assumptions about the people they use it with, (Caldwell, 2007) just

like the hospital staff discussed. Intensive Interaction has been described as an approach which is instinctive and fun, (Nind & Hewett, 2001) paralleling the theme of 'Simple and Instinctive.' There are clear similarities between the use of Intensive Interaction and the hospital staff's approach to working with people who struggled to communicate. It may be that the training course introduced them to the principles of Intensive Interaction, such as closely observing people with PMID in order to work out and meet their emotional needs. The participants seem to have taken those principles on board and are using them in their experience with patients up to two years later.

The disparity of definitions may be down to a lack of concrete experience. The participants spoke about not feeling the approach was completely relevant to them, and not seeing patients on the wards with whom they felt the approach was appropriate. It is unclear whether those patients are not in attendance at the ward, or whether participants are missing opportunities where they can use the approach, perhaps due to seeing the presence of carers as a barrier to making a connection, as in the theme 'The Need to Involve Carers.' Perhaps this lack of opportunities to use the approach has led to 'initiative decay', where new approaches are forgotten when they are replaced by new initiatives or replaced by more familiar old knowledge (Buchanan, Claydon, & Doyle, 1999).

Working with older adults using the techniques is a little researched area in Intensive Interaction, with only one case study in the literature so far looking at the effect of using Intensive Interaction with a lady with end stage dementia (Ellis, Astell, & Zeedyk, 2008). It seems as if, in a hospital setting, participants have more opportunity to use the techniques with those older adults.

Overall the participants felt the approaches they used helped improve the patient experience of hospital. With the difficulties people with intellectual disabilities, as well as older adults, face in hospital, this approach could be invaluable in improving the care they receive.

Barriers

Competing demands and the struggle to provide meaningful care to patients amongst a myriad of other tasks is a difficulty that has been highlighted in several cases of institutional failures such as in the Mid Staffordshire Hospitals NHS Foundation Trust (Francis, 2010) and has been pinpointed as one of the causes of burnout amongst hospital staff (McCranie, Lambert, & Lambert, 1987). It is unfortunate, yet unsurprising, that the theme of 'the pressures of a hospital environment' emerged in this study as a barrier to building relationships with patients and using approaches that staff feel would improve the patient experience.

It may be that the 'Struggle to Make a Connection' is a reflection of such a busy environment, with medicalised labels of patients potentially being used as short-hand to save time, but acting to prevent meaningful relationships being formed. Perhaps medicalising and de-individualising patients also acts as a protective way for staff to view the patients they work with, especially if there is a fear that the patients are receiving sub-standard care. Unfortunately, there is no easy answer or recommendation to be given within the limited resources available within the NHS, staff shortages will continue to be a ubiquitous issue.

The involvement of others was seen as a barrier by some, but not all participants, some felt inhibited by the presence of carers, whilst acknowledging the help they

provided as information givers. The tension and uncertainty around the role of carers in hospital was apparent and participants seemed to be struggling with issues of how much or how little to involve carers.

The theme of 'Needing Permission' highlights perceived restrictions on caring, the fact that several participants were concerned about touch mirrors the concern in the wider intellectual disability, Intensive Interaction, and nursing literature (Bush, 2001; Hewett, 2007).

Facilitators

Staff spoke about the approach being 'Simple and Instinctive,' as part of this they felt their prior personality was a part of their use of Intensive Interaction, they felt that they already had some of the skills to use Intensive Interaction. It could be that Intensive Interaction training gave the participants permission to use those skills, show their personality, and further unlocked their potential to be caring towards patients. It may also be that labelling such techniques as Intensive Interaction might give participants the space to think and talk about them, and having such a name might make those simple techniques feel more legitimate. In a way, this might have professionalised touch and compassion. This is concerning if it takes the core nursing values of touch and compassion to be professionalised in order for staff members to feel able to show them and this issue seems to fit with current concerns in the literature of societal pressures on the concept of 'care' in nursing (Herdman, 2004).

The participants highlighted 'Team-working' as a helpful factor in their use of the approach, this is in line with the literature around Intensive Interaction, suggesting sustainability of interventions and initiatives in Intensive Interaction rely upon good

team-working and support from managerial roles (Kellett, 2003). Further research would be beneficial to focus on what components of a team approach are helpful in the implementation of interventions.

Does using Intensive Interaction affect how hospital staff view the people they have used it with?

The themes 'Looking Closer' and 'Challenging Assumptions' suggest that there were differences in how the staff viewed the people that they worked with. In some ways they appeared to be seeing people more as individuals and not assuming they knew what people's abilities were, or their likes and dislikes. The theme of 'Challenging Assumptions' also seemed to sum up participants new understanding of behaviour as communicative rather than unexplained and uncontrollable. Studies have found that residential home workers seeing behaviour as communicative are more likely to meet the emotional needs of the people they are working with and suffer less stress and burnout (Rose, Horne, Rose, & Hastings, 2004). It may be that the training and subsequent re-evaluation of assumptions is an antidote to neglect and misunderstanding as highlighted in Death by Indifference Report (Mencap, 2007).

However, the theme of 'The Struggle to Make a Connection', particularly the way patients are talked about, suggests that the change in perceptions is limited somewhat. This may be as a result of institutional attitudes, which would be impossible to change with the scale of the training course considered here.

How do hospital staff feel Intensive Interaction fits in with their job role?

The tensions inherent in the themes show the struggle staff feel in fitting the approach into their job. On one hand it is an approach which is easy and simple and helps them

improve the experience of people in hospital, directly in line with what they feel their job should be, on the other hand, they don't feel the approach is directly relevant to them and they struggle to use it within the pressures of a hospital environment.

Critique

This type of study is designed to explore in-depth the concerns and lived experience of the participants interviewed. This may not reflect the concerns of other staff using Intensive Interaction, or even other staff in the same hospital. Also, research such as this makes no claims to be objective, and is highly influenced by the researcher's experiences, values and knowledge base. Therefore, any recommendations should be looked at as one possible explanation, and the analysis should be treated as a working hypothesis, which would need to be further examined through qualitative and quantitative research.

The themes that emerged were validated by discussion with other researchers, but these were also from a background of clinical psychology. It may be that the role of a clinical psychologist causes researchers to place high value on building a relationship with patients, and place lower value on 'getting the job done', which may be more important in a hospital environment. It is important to keep in mind the lens through which the data have been analysed, especially when providing a critique of hospital services and staff attitudes or behaviour. Compassionate and understanding in the analysis becomes highly important, and it is important to remember that underlying the participant's stories of the use of Intensive Interaction was a desire to care and to help patients who may be more vulnerable.

The participants were from a variety of job roles, there may have been a presumption that just because people work in a hospital they would have been a homogenous group. This could be seen to mirror the perception of people with intellectual disabilities or communication difficulties as a homogenous group. Fortunately the participants did have similar concerns from which to deduce themes.

The participants were all women, this is a reflection of the higher proportion of women in the helping profession and who had completed the training. Previous research suggests that men may have different concerns about using Intensive Interaction (Culham, 2004) and these results should not be generalised to male hospital workers.

The researcher did not attend the training course, to try and limit the impact of what the researcher felt the participants 'should' have taken away from it, and to limit the possibility of participants who may have attended the course, associating the researcher with the training and therefore giving answers they felt the researcher wanted to hear. The consequence of this may have been that there was increased distance between the understandings of the researcher and the participants.

Implications of the study and areas for future research

The themes suggest that training in intensive interaction may lead to staff recognising and catering to the needs of people who struggle to communicate, and such training aids in the building of a relationship. If one of the failings of hospital care is communication and attitudes of the staff, (Dinsmore, 2011; Mencap, 2007) then Intensive Interaction could be a way to combat this and improve patient experience, and should be considered as a possible intervention in other hospitals. Future research would benefit from gaining the perspective of people with PMID and their carers

experiencing intensive interaction in hospital perhaps through carer interviews. The theme of 'involving others' highlights the need for carers roles to be made clearer and valued by the hospital (Bradbury-Jones et al., 2013) Further research into using Intensive Interaction with older adults would also be beneficial.

The research explores struggles staff experience using Intensive Interaction, thus highlighting potential aspects to explore in training. It would be beneficial to explore quantitatively what staff learn from training and how it impacts practice, perhaps through rating scales or video-coding. Future research could also target different professional groups, or explore the experience of men in a similar situation. Further exploration of how widespread assumptions can be challenged could illuminate how best to target these, and institutionally support interventions such as Intensive Interaction.

Summary

In the face of such failings as basic care needs not being met (Francis, 2010) , or health professionals struggling to identify pain (Bradbury-Jones et al., 2013) and the possibility that such failings lead to the death of patients (Mencap, 2007), it may seem that the focus should be on more basic training rather than the more advanced Intensive Interaction techniques. However, the results of this study suggest that despite not using the techniques in their full form, being trained in the basics and introduced to the principles of Intensive Interaction had an effect on staff attitudes and behaviour. It seemed as though principles of Intensive Interaction such as close observation and attention to the patient's needs were remembered by staff, even up to two years later. The barriers and facilitators observed in this study reflect those

found in other studies, and have important implications for how training is administered and interventions are sustained.

References

- Backer, C., Chapman, M., & Mitchell, D. (2009). Access to secondary healthcare for people with intellectual disabilities: A review of the literature. *Journal of Applied Research in Intellectual Disabilities, 22*(6), 514-525.
- Barber, M. (2007). Imitation, interaction and dialogue using Intensive Interaction: Tea party rules. *Support for Learning, 22*(3), 124-130.
- Bradbury-Jones, C., Rattray, J., Jones, M., & Macgillivray, S. (2013). Promoting the health, safety and welfare of adults with intellectual disabilities in acute care settings: a structured literature review. *Journal of Clinical Nursing, 22*(11-12), 1497-1509.
- Brown, M., MacArthur, J., McKechnie, A., Mack, S., Hayes, M., & Fletcher, J. (2012). Learning Disability Liaison Nursing Services in south-east Scotland: a mixed-methods impact and outcome study. *Journal of Intellectual Disability Research, 56*(12), 1161-1174.
- Buchanan, D., Claydon, T., & Doyle, M. (1999). Organisation development and change: the legacy of the nineties. *Human Resource Management Journal, 9*(2), 20-37.
- Bush, E. (2001). The use of human touch to improve the well-being of older adults: A holistic nursing intervention. *Journal of holistic nursing, 19*(3), 256-270.
- Caldwell, P. (2007). *From isolation to intimacy: Making friends without words*. London England: Jessica Kingsley Publishers.
- Caldwell, P., & Horwood, J. (2008). *Using intensive interaction and sensory integration: A handbook for those who support people with severe autistic spectrum disorder*. London England: Jessica Kingsley Publishers.

- Culham, A. (2004). Getting in touch with our feminine sides? Men's difficulties and concerns with doing Intensive Interaction. *British Journal of Special Education*, 31(2), 81-88.
- Dinsmore, A. P. (2011). A small scale investigation of hospital experiences among people with an intellectual disability on Merseyside: speaking with patients and their carers. *British Journal of Learning Disabilities*.
- Disability Rights Commission. (2006). *Equal treatment: Closing the gap. A formal Investigation into the physical health inequalities experienced by people with learning disabilities and/or mental health problems*. London: DRC.
- Elliott, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British journal of clinical psychology*, 38(3), 215-229.
- Ellis, M. P., Astell, A. J., & Zeedyk, M. S. (2008). A new approach to communicating with people with advanced dementia: A case study of adaptive interaction. In *Promoting social interaction for individuals with communicative impairments: Making contact*. (pp. 119-136). London England: Jessica Kingsley Publishers.
- Firth, G. (2006). Intensive interaction: a research review. *Mental health and learning disabilities research and practice*(3), 53 - 63.
- Firth, G., Elford, H., Leeming, C., & Crabbe, M. (2008). Intensive interaction as a novel approach in social care: care staff's views on the practice change process. *Journal of Applied Research in Intellectual Disabilities*, 21(1), 58-69.
- Francis, R. (2010). *Independent inquiry into care provided by Mid Staffordshire NHS Foundation Trust January 2005-March 2009* (Vol. 1): Stationery Office.

Heslop, P., Blair, P., Fleming, P., Hoghton, M., Marriott, A. & Russ, L. (2013)

Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD): Final report. Norah Fry Research Centre

Herdman, E. A. (2004). Nursing in a postemotional society. *Nursing Philosophy*, 5(2), 95-103.

Hewett, D. (2007). Do touch: physical contact and people who have severe, profound and multiple learning difficulties. *Support for Learning*, 22(3), 116-123.

Kellett, M. (2003). Jacob's journey: developing sociability and communication in a young boy with severe and complex learning difficulties using the Intensive Interaction teaching approach. *Journal of Research in Special Educational Needs*, 3(1), 1-16.

Kellett, M. (2005). Catherine's legacy: social communication development for individuals with profound learning difficulties and fragile life expectancies. *British Journal of Special Education*, 32(3), 116-121.

Krahn, G. L., Hammond, L., & Turner, A. (2006). A cascade of disparities: Health and health care access for people with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews*, 12(1), 70-82.

McCranie, E. W., Lambert, V. A., & Lambert, C. E., Jr. (1987). Work stress, hardiness, and burnout among hospital staff nurses. *Nursing Research*, 36(6), 374-378.

Mencap. (2007). *Death by Indifference*. London.

National Institute for Health and Care Excellence. (2012). *Methods for the development of NICE public health guidance (third edition)*. London: National Institute for Health and Care Excellence.

- Nind, M., & Hewett, D. (2001). *A practical guide to Intensive Interaction*: BILD Publications.
- Patja, K., Iivanainen, M., Vesala, H., Oksanen, H., & Ruoppila, I. (2000). Life expectancy of people with intellectual disability: a 35-year follow-up study. *Journal of Intellectual Disability Research*, 44(5), 591-599.
- Rose, D., Horne, S., Rose, J. L., & Hastings, R. P. (2004). Negative emotional reactions to challenging behaviour and staff burnout: Two replication studies. *Journal of Applied Research in Intellectual Disabilities*, 17(3), 219-223.
- Samuel, J., Beinart, H., Kennedy, P., & Llewelyn, S. (2009). Intensive interaction for people with profound and complex learning disabilities. In *Clinical psychology in practice*. (pp. 175-185). Leicester Malden England: British Psychological Society Blackwell Publishing.
- Sharma, V., & Firth, G. (2012). Effective engagement through intensive interaction. *Learning Disability Practice*, 15(9), 20-23.
- Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research*: SAGE Publications Limited.
- Smith, J. A., Larkin, M., & Flowers, P. (2009). *Interpretative phenomenological analysis*. Sage.
- van Schrojenstein Lantman-de Valk, H. M. J., van den Akker, M., Maaskant, M. A., Haveman, M. J., Urlings, H. F. J., Kessels, A. G., et al. (1997). Prevalence and incidence of health problems in people with intellectual disability. *Journal of Intellectual Disability Research*, 41(1), 42-51.
- Williams, P. (2005). Intensive interaction -- entering someone's inner world. *Community Living*, 18(4), 28-28.

Zeedyk, S., Caldwell, P., & Davies, C. E. (2009). How rapidly does Intensive Interaction promote social engagement for adults with profound learning disabilities?

European Journal of Special Needs Education, 24(2), 119-137.

Zeedyk, S., Davies, C., Parry, S., & Caldwell, P. (2009). Fostering social engagement in Romanian children with communicative impairments: the experiences of newly trained practitioners of Intensive Interaction. *British Journal of Learning Disabilities, 37(3)*, 186-196.

PART THREE

Appendices

Appendix A

Journal of Applied Research in Intellectual Disabilities: Guidelines for Authors

Crosscheck

The journal to which you are submitting your manuscript employs a plagiarism detection system. By submitting your manuscript to this journal you accept that your manuscript may be screened for plagiarism against previously published works.

1. GENERAL

The *Journal of Applied Research in Intellectual Disabilities* is an international, peer-reviewed journal which draws together findings derived from original applied research in intellectual disabilities. The journal is an important forum for the dissemination of ideas to promote valued lifestyles for people with intellectual disabilities. It reports on research from the UK and overseas by authors from all relevant professional disciplines. It is aimed at an international, multi-disciplinary readership.

The topics it covers include community living, quality of life, challenging behaviour, communication, sexuality, medication, ageing, supported employment, family issues, mental health, physical health, autism, economic issues, social networks, staff stress, staff training, epidemiology and service provision. Theoretical papers are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. All original and review articles continue to undergo a rigorous, peer-refereeing process.

Please read the instructions below carefully for details on submission of manuscripts, the journal's requirements and standards as well as information concerning the procedure after a manuscript has been accepted for publication. Authors are encouraged to visit <http://authorservices.wiley.com/bauthor/> for further information on the preparation and submission of articles.

2. ETHICAL GUIDELINES

Acceptance of papers is based on the understanding that authors have treated research participants with respect and dignity throughout. Please see Section 2.2 below.

2.1 Authorship and Acknowledgements

Authorship: Authors submitting a paper do so on the understanding that the manuscript has been read and approved by all authors and that all authors agree to the submission of the manuscript to the journal. ALL named authors must have made an active contribution to the conception and design and/or analysis and interpretation of the data and/or the drafting of the paper and ALL authors must have critically reviewed its content and have approved the final version submitted for publication. Participation solely in the acquisition of funding or the collection of data does not justify authorship.

It is a requirement that all authors have been accredited as appropriate under submission of the manuscript. Contributors who do not qualify as authors should be mentioned under Acknowledgements.

Acknowledgements: Under Acknowledgements please specify contributors to the article other than the authors accredited. Please also include specifications of the source of funding for the study and any potential conflict of interest if appropriate. Suppliers of materials should be named and their location (town, state/county, country) included.

2.2 Ethical Approvals

Research involving human participants will only be published if such research has been conducted in full accordance with ethical principles, including the World Medical Association Declaration of Helsinki (version, 2002 www.wma.net) and the additional requirements, if any, of the country where the research has been carried out. Manuscripts must be accompanied by a statement that the research was undertaken with the understanding and written consent of each participant (or the participant's representative, if they lack capacity), and according to the above mentioned principles. A statement regarding the fact that the study has been independently reviewed and approved by an ethical board should also be included. All studies using human participants should include an explicit statement in the Material and Methods section identifying the review and ethics committee approval for each study, if applicable. Editors reserve the right to reject papers if there is doubt as to whether appropriate procedures have been used.

Ethics of investigation: Papers not in agreement with the guidelines of the Helsinki Declaration as revised in 1975 will not be accepted for publication.

2.3 Clinical Trials

Clinical trials should be reported using the CONSORT guidelines available at www.consort-statement.org. A CONSORT checklist should also be included in the submission material (www.consort-statement.org). The *Journal of Applied Research in Intellectual Disabilities* encourages authors submitting manuscripts reporting from a clinical trial to register the trials in any of the following free, public trials registries: www.clinicaltrials.org, www.isrctn.org. The clinical trial registration number and name of the trial register will then be published with the paper.

2.4 Conflict of Interest and Source of Funding

Conflict of Interest: Authors are required to disclose any possible conflict of interest. These include financial (for example patent ownership, stock ownership, consultancies, speaker's fee). Author's conflict of interest (or information specifying the absence of conflict of interest) will be published under a separate heading.

The *Journal of Applied Research in Intellectual Disabilities* requires that sources of institutional, private and corporate financial support for the work within the manuscript must be fully acknowledged, and any potential conflict of interest noted. As of 1st March 2007, this information is a requirement for all manuscripts submitted to the journal and will be published in a highlighted box on the title page of the article. Please include this information under the separate headings of 'Source of Funding' and 'Conflict of Interest' at the end of the manuscript.

If the author does not include a conflict of interest statement in the manuscript, then the following statement will be included by default: 'No conflict of interest has been declared'.

Source of Funding: Authors are required to specify the source of funding for their research when submitting a paper. Suppliers of materials should be named and their location (town, state/county, country) included. The information will be disclosed in the published article.

2.5 Permissions

If all or parts of previously published illustrations are used, permission must be obtained from the copyright holder concerned. It is the author's responsibility to obtain these in writing and provide copies to the Publishers.

2.6 Copyright Assignment

If your paper is accepted, the author identified as the formal corresponding author for the paper will receive an email prompting them to login into Author Services; where via the Wiley Author Licensing Service (WALS) they will be able to complete the license agreement on behalf of all authors on the paper.

For authors signing the copyright transfer agreement

If the OnlineOpen option is not selected the corresponding author will be presented with the copyright transfer agreement (CTA) to sign. The terms and conditions of the CTA can be previewed in the samples associated with the Copyright FAQs below:

CTA Terms and Conditions http://authorservices.wiley.com/bauthor/faqs_copyright.asp

3. ONLINEOPEN

For authors choosing OnlineOpen

If the OnlineOpen option is selected the corresponding author will have a choice of the following Creative Commons License Open Access Agreements (OAA): Creative Commons Attribution License OAA, Creative Commons Attribution Non-Commercial License OAA, Creative Commons Attribution Non-Commercial -NoDerivs License OAA

To preview the terms and conditions of these open access agreements please visit the Copyright FAQs hosted on Wiley Author Services http://authorservices.wiley.com/bauthor/faqs_copyright.asp and visit <http://www.wileyopenaccess.com/details/content/12f25db4c87/Copyright--License.html>.

If you select the OnlineOpen option and your research is funded by The Wellcome Trust and members of the Research Councils UK (RCUK) you will be given the opportunity to publish your article under a CC-BY license supporting you in complying with Wellcome Trust and Research Councils UK requirements. For more information on this policy and the Journal's compliant self-archiving policy please visit: <http://www.wiley.com/go/funderstatement>.

4. SUBMISSION OF MANUSCRIPTS

Submissions are now made online using ScholarOne Manuscripts (formerly Manuscript Central). To submit to the journal go to <http://mc.manuscriptcentral.com/jarid>. If this is the first time you have used the system you will be asked to register by clicking on 'create an account'. Full instructions on making your submission are provided. You should receive an acknowledgement within a few minutes. Thereafter, the system will keep you informed of the process of your submission through refereeing, any revisions that are required and a final decision.

4.1 Manuscript Files Accepted

Manuscripts should be uploaded as Word (.doc) or Rich Text Format (.rtf) files (not write-protected) plus separate figure files. GIF, JPEG, PICT or Bitmap files are acceptable for submission, but only high-resolution TIF or EPS files are suitable for printing.

To allow double-blinded review, please upload your manuscript and title page as **separate** files.

Please upload:

1. Your manuscript without title page under the file designation 'main document'.
2. Figure files under the file designation 'figures'.
3. Title page which should include title, authors (including corresponding author contact details), acknowledgements and conflict of interest statement where applicable, should be uploaded under the file

designation 'title page'.

All documents uploaded under the file designation 'title page' will not be viewable in the HTML and PDF format you are asked to review at the end of the submission process. The files viewable in the HTML and PDF format are the files available to the reviewer in the review process.

Please note that any manuscripts uploaded as Word 2007 (.docx) will be automatically rejected. Please save any .docx files as .doc before uploading.

4.2 Blinded Review

All articles submitted to the journal are assessed by at least two anonymous reviewers with expertise in that field. The Editors reserve the right to edit any contribution to ensure that it conforms with the requirements of the journal.

5. MANUSCRIPT TYPES ACCEPTED

Original Articles, Review Articles, Brief Reports, Book Reviews and **Letters to the Editor** are accepted. **Theoretical Papers** are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. Articles are accepted for publication only at the discretion of the Editor. Articles should not exceed 7000 words. Brief Reports should not normally exceed 2000 words. Submissions for the Letters to the Editor section should be no more than 750 words in length.

6. MANUSCRIPT FORMAT AND STRUCTURE

6.1 Format

Language: The language of publication is English. Authors for whom English is a second language must have their manuscript professionally edited by an English speaking person before submission to make sure the English is of high quality. It is preferred that manuscripts are professionally edited. A list of independent suppliers of editing services can be found at http://authorservices.wiley.com/bauthor/english_language.asp. All services are paid for and arranged by the author, and use of one of these services does not guarantee acceptance or preference for publication.

6.2 Structure

All manuscripts submitted to the *Journal of Applied Research in Intellectual Disabilities* should include:

Cover Page: A cover page should contain only the title, thereby facilitating anonymous reviewing. The authors' details should be supplied on a separate page and the author for correspondence should be identified clearly, along with full contact details, including e-mail address.

Running Title: A short title of not more than fifty characters, including spaces, should be provided.

Keywords: Up to six key words to aid indexing should also be provided.

Main Text: All papers should be divided into a structured abstract (150 words) and the main text with appropriate sub headings. A structured abstract should be given at the beginning of each article, incorporating the following headings: Background, Materials and Methods, Results, Conclusions. These should outline the questions investigated, the design, essential findings and main conclusions of the study. The text should then proceed through sections of Introduction, Materials and Methods, Results and Discussion, and finally Tables. Figures should be submitted as a separate file.

Style: Manuscripts should be formatted with a wide margin and double spaced. Include all parts of the text of the paper in a single file, but do not embed figures. Please note the following points which will help us to process your manuscript successfully:

-Include all figure legends, and tables with their legends if available.

- Do not use the carriage return (enter) at the end of lines within a paragraph.
- Turn the hyphenation option off.
- In the cover email, specify any special characters used to represent non-keyboard characters.
- Take care not to use l (ell) for 1 (one), O (capital o) for 0 (zero) or ß (German esszett) for (beta).
- Use a tab, not spaces, to separate data points in tables.
- If you use a table editor function, ensure that each data point is contained within a unique cell, i.e. do not use carriage returns within cells.

Spelling should conform to *The Concise Oxford Dictionary of Current English* and units of measurements, symbols and abbreviations with those in *Units, Symbols and Abbreviations*(1977) published and supplied by the Royal Society of Medicine, 1 Wimpole Street, London W1M 8AE. This specifies the use of S.I. units.

6.3 References

The reference list should be in alphabetic order thus:

- Emerson E. (1995) *Challenging Behaviour: Analysis and Intervention in People with Learning Disabilities*. Cambridge University Press, Cambridge.
- McGill P. & Toogood A. (1993) Organising community placements. In: *Severe Learning Disabilities and Challenging Behaviours: Designing High Quality Services* (Eds E. Emerson, P. McGill & J. Mansell), pp. 232-259. Chapman and Hall, London.
- Qureshi H. & Alborz A. (1992) Epidemiology of challenging behaviour. *Mental Handicap Research*5, 130-145

Journal titles should be in full. References in text with more than two authors should be abbreviated to (Brown *et al.* 1977). Authors are responsible for the accuracy of their references.

We recommend the use of a tool such as EndNote or Reference Manager for reference management and formatting.

EndNote reference styles can be searched for here:

<http://www.endnote.com/support/enstyles.asp>

Reference Manager reference styles can be searched for here:

<http://www.refman.com/support/rmstyles.asp>

The Editor and Publisher recommend that citation of online published papers and other material should be done via a DOI (digital object identifier), which all reputable online published material should have - see www.doi.org/ for more information. If an author cites anything which does not have a DOI they run the risk of the cited material not being traceable.

6.4 Tables, Figures and Figure Legends

Tables should include only essential data. Each table must be typewritten on a separate sheet and should be numbered consecutively with Arabic numerals, e.g. Table 1, and given a short caption.

Figures should be referred to in the text as Figures using Arabic numbers, e.g. Fig.1, Fig.2 etc, in order of appearance. Figures should be clearly labelled with the name of the first author, and the appropriate number. Each figure should have a separate legend; these should be grouped on a separate page at the end of the manuscript. All symbols and abbreviations should be clearly explained. In the full-text online edition of the journal, figure legends may be truncated in abbreviated links to the full screen version. Therefore, the first 100 characters of any legend should inform the reader of key aspects of the figure.

Preparation of Electronic Figures for Publication

Although low quality images are adequate for review purposes, print publication requires high quality

images to prevent the final product being blurred or fuzzy. Submit EPS (line art) or TIFF (halftone/photographs) files only. MS PowerPoint and Word Graphics are unsuitable for printed pictures. Do not use pixel-oriented programmes. Scans (TIFF only) should have a resolution of at least 300 dpi (halftone) or 600 to 1200 dpi (line drawings) in relation to the reproduction size. Please submit the data for figures in black and white or submit a Colour Work Agreement Form. EPS files should be saved with fonts embedded (and with a TIFF preview if possible).

Further information can be obtained at Wiley-Blackwell's guidelines for figures:<http://authorservices.wiley.com/bauthor/illustration.asp>.

Check your electronic artwork before submitting it:<http://authorservices.wiley.com/bauthor/eachecklist.asp>.

Permissions: If all or parts of previously published illustrations are used, permission must be obtained from the copyright holder concerned. It is the author's responsibility to obtain these in writing and provide copies to the Publisher.

Colour Charges: It is the policy of the *Journal of Applied Research in Intellectual Disabilities* for authors to pay the full cost for the reproduction of their colour artworkhttp://www.blackwellpublishing.com/pdf/SN_Sub2000_X_CoW.pdf

7. AFTER ACCEPTANCE

Upon acceptance of a paper for publication, the manuscript will be forwarded to the Production Editor who is responsible for the production of the journal.

7.1 Proof Corrections

The corresponding author will receive an e-mail alert containing a link to a website. A working e-mail address must therefore be provided for the corresponding author. The proof can be downloaded as a PDF file from this site.

Acrobat Reader will be required in order to read this file. This software can be downloaded (free of charge) from the following website:

www.adobe.com/products/acrobat/readstep2.html

This will enable the file to be opened, read on screen, and printed out in order for any corrections to be added. Further instructions will be sent with the proof. Proofs will be posted if no e-mail address is available; in your absence, please arrange for a colleague to access your e-mail to retrieve the proofs.

Proofs must be returned to the Production Editor within 3 days of receipt.

As changes to proofs are costly, we ask that you only correct typesetting errors. Excessive changes made by the author in the proofs, excluding typesetting errors, will be charged separately. Other than in exceptional circumstances, all illustrations are retained by the Publisher. Please note that the author is responsible for all statements made in their work, including changes made by the copy editor.

7.2 Early View (Publication Prior to Print)

The *Journal of Applied Research in Intellectual Disabilities* is covered by Wiley-Blackwell's Early View service. Early View articles are complete full-text articles published online in advance of their publication in a printed issue. Early View articles are complete and final. They have been fully reviewed, revised and edited for publication, and the authors' final corrections have been incorporated. Because they are in final form, no changes can be made after online publication. The nature of Early View articles means that they do not yet have a volume, issue or page number, so Early View articles cannot be cited in the traditional way. They are therefore given a DOI (digital object identifier) which allows the article to be cited

and tracked before it is allocated to an issue. After print publication, the DOI remains valid and can continue to be used to cite and access the article.

7.3 Author Services

Online production tracking is available for your article through Wiley-Blackwell's Author Services. Author Services enables authors to track their article - once it has been accepted - through the production process to publication online and in print. Authors can check the status of their articles online and choose to receive automated e-mails at key stages of production. The author will receive an e-mail with a unique link that enables them to register and have their article automatically added to the system. Please ensure that a complete e-mail address is provided when submitting the manuscript.

Visit <http://authorservices.wiley.com/bauthor/> for more details on online production tracking and for a wealth of resources include FAQs and tips on article preparation, submission and more.

For more substantial information on the services provided for authors, please see Wiley-Blackwell's Author Services.

7.4 Author Material Archive Policy

Please note that unless specifically requested, Wiley-Blackwell will dispose of all hardcopy or electronic material submitted two issues after publication. If you require the return of any material submitted, please inform the editorial office or Production Editor as soon as possible.

7.5 Offprints and Extra Copies

Free access to the final PDF offprint of the article will be available via Author Services only. Additional paper offprints may be ordered online. Please click on the following link, fill in the necessary details and ensure that you type information in all of the required fields: <http://offprint.cosprinters.com/blackwell>

If you have queries about offprints please email offprint@cosprinters.com

Appendix B

Quality Rating Scale for Single Case Experimental Design (SCED), Tate et al. (2008)

(Removed for hard-binding)

Appendix C: Quality Rating Scale for Qualitative Studies (National Institute for Health and Care Excellence, 2012)

Study identification Include author, title, reference, year of publication		
Guidance topic:	Key research question/aim:	
Checklist completed by:		
	<i>Circle or highlight one option for each question</i>	Comments & Rating 0 =inadequate or absent 1 = poor 2= good
Section 1: Aims of the Research		
1.1 Are the aims and objectives of the research clearly stated?	Clearly described Unclear Not reported	Comments:
1.2. Is a qualitative approach appropriate?	Appropriate Unclear Not Appropriate	Comments:
Section 2: Study design		
2.1 Is/are the research question(s) clearly defined and focused?	Clearly defined and focused Unclear Not focused Not defined	Comments:
2.2 Are the methods used appropriate to the research question?	Appropriate Unclear Not Appropriate	Comments:
Section 3: Recruitment and data collection		
<u>3.1</u> Is the recruitment or sampling strategy appropriate to the aims of the	Appropriate	Comments:

research.	Unclear Not Appropriate	
3.2 Are the methods of data collection adequate to answer the research question?	Adequate Not Adequate Not reported	Comments:
3.3 Are the roles of the researchers clearly described?	Clear Unclear Not reported	Comments:
3.14 Have ethical issues been addressed adequately?	Adequate Unclear Not adequate	Comments:
4. Data Analysis		
4.1 Is the data analysis sufficiently rigorous?	Rigorous Not Rigorous	Comments:
5. Findings/interpretations		
5.1 Are the findings internally coherent, credible (valid)?	Valid Unclear Potential bias	Comments:
5.2 Are the findings relevant?	Relevant Unclear Limited relevance	Comments:
6. Implications of Research		
6.1 Are the implications of the study clearly reported?	Clearly Reported Unclear	Comments:
6.2 Is there adequate discussion of study limitations?	Adequate Inadequate Not Reported	Comments:

Appendix D - Data Extraction Form (computerised database used)

Title	Author	Date	Journal/ page & issue	Aims of the study	Other Research Questions	Country	Study sites	Target Population	Characteristics of participants	Sampling/recruitment procedures and any info (age, gender, ethnicity)	Theory referred to or conceptual models used

Study Design	Control group (if any)	Methods of data collection	Definition/ measurement of 'social behaviour'	Research tools/ outcome measures used	Analysis used	Details of intervention (number of sessions, length, how was it delivered)	Training in intensive interaction	Who provided intervention (SALT, residential worker, parent)	Details of outcomes

Strengths of the study	Weaknesses of study	Authors conclusions	Components of approach proposed to be helpful	Suggestions for further research

Appendix E: Papers rejected after the whole paper was read

Cameron, L. & Bell, D. (2001) Enhanced Interaction Training. *Working with People who have an intellectual disability*, 18 (3), 8 -15.

Heimann, M., Laberg, K. E., & Nordøen, B. (2006). Imitative interaction increases social interest and elicited imitation in non-verbal children with autism. *Infant and Child Development*, 15(3), 297-309.

Nind, M., Kellett, M., & Hopkins, V. (2001). Teachers' talk styles: communicating with learners with severe and complex learning difficulties. *Child Language teaching and therapy*, 17(2), 143-159.

Watson, J., & Fisher, A. (1997). Research Section: Evaluating the Effectiveness of Intensive Interactive Teaching with Pupils with Profound and Complex Learning Difficulties. *British Journal of Special Education*, 24(2), 80-87.

Watson, J., & Knight, C. (1991). An evaluation of intensive interactive teaching with pupils with very severe learning difficulties. *Child Language Teaching and Therapy*, 7(3), 310-325

Appendix F – Quality Ratings of Quantitative Studies

Table 1: Quality Ratings of Quantitative Studies using the SCED (Tate et al. 2008). 1 = yes, 0 = no

Study	Clinical history specified	Target Behaviours	Design	Baseline	Treatment phase	Data Record	Observer bias	Independence of assessors	Statistical analysis	Replication	Evidence for generalisation	Sum
Argyropoulou, & Papoudi, 2012	1	1	1	1	1	1	1	0	0	0	1	8
Barber, 2008	0	1	1	1	0	0	0	1	0	1	1	6
Elgie, & Maguire, 2001	1	1	0	0	0	0	1	0	0	0	0	3
Jones, R. & Williams, 1998	1	1	1	1	1	0	1	1	0	0	0	7
Kellett, 2000	1	1	0	1	1	0	1	1	0	0	1	7
Kellett, 2003	1	1	0	1	1	0	1	1	0	1	1	8
Kellett, 2004	1	1	0	1	1	0	1	1	0	0	0	6
Kellett, 2005	1	1	0	1	0	0	1	1	0	1	1	7
Kellett, & Nind, 2002	0	1	1	0	1	0	1	0	0	1	1	6
Leaning B; Watson T, 2006	1	1	0	0	1	1	0	1	0	1	0	6
Lovell, Jones, & Ephraim, 1998	1	1	1	1	1	0	1	0	0	0	0	6
Nind, 1996	1	1	1	1	1	0	1	?	0	1	?	7
Nind, 1999	1	1	1	1	1	0	0	0	0	1	0	6
Samuel J et al., 2008	1	1	1	1	1	0	1	1	0	1	1	9
Zeedyk et al., 2009	1	1	0	0	0	0	1	1	1	1	0	6

Appendix G – Quality Ratings of Qualitative Studies

Table 2: Quality Ratings of Qualitative Studies using the NICE framework (2012) 0 = unacceptable or not reported, 1=poor, 2= good

	Aims stated	Approach	Research questions	Methods	Sampling	Data Collection	Researcher roles	Ethical issues	Rigorous analysis	Valid findings	Relevant findings	Implications	Limitations	Sum
Forster & Taylor 2006	2	1	1	1	0	0	1	0	0	1	1	1	1	10
Jones & Howley, 2010	2	2	2	1	1	0	0	0	0	1	2	2	2	15
Zeedyk et al. 2009	2	2	2	1	2	1	0	2	2	2	2	2	1	21

Appendix H – Epistemological Statement

The research was developed from a constructivist epistemological standpoint, which holds that truth and meaning is subjective and constructed in a process of engagement of our minds with the world, rather than there being an objective truth to be discovered (Crotty, 1997). This anti-positivist or interpretivist approach sees positivist scientific investigation as incomplete, partly because it fails to take into account the historical, cultural and situation-specific influences upon research and findings (Habermas, 1967).

This stance enables reflection upon cultural discourses of our time, and how these might influence findings. Both long-held cultural discourses, (e.g. nursing staff are inherently caring) and discourses more recently developed (e.g. patients suffer because the NHS is under strain) will influence this research, as it looks into hospital staff experience. It was important to the researcher to be able to take these into account, so qualitative research was undertaken, and Interpretative Phenomenological Analysis (IPA) used.

IPA recognises the importance of ‘meaning-making’ or hermeneutics and encourages recognition of influences such as cultural discourses on such hermeneutics. The researcher becomes involved in a ‘double-hermeneutic’ as they seek to make sense of the participant’s making sense of the experience. The importance of acknowledging the processes behind this hermeneutic is apparent when considering the different professional background the researcher and the staff members are from. The other two principles of IPA of phenomenology and idiography (Smith, Flowers & Larkin, 2009) also fitted well with the research area. Phenomenology is the study of experience, and

the research was concerned with how the hospital staff experienced using a new approach and their perspectives regarding the people they used it with. Idiography is the focus on individuals and their contexts, the research wanted to look in depth at subjective meaning for the participants, and did not seek to generalise to a wider context or population.

Grounded Theory (GT) was also considered as an approach before selecting IPA. GT aims to generate theory and goes through series of analyses until 'saturation point' is reached (Charmaz, 2003). As such, a large amount of data is often utilised. With the population to be researched limited to those who had done a specific training course, in a specific hospital, this may not have been possible. Also, the generation of theory was not a key aim, the researcher instead wanting to understand in-depth the experiences of the hospital staff.

In summary, the anti-positivist stance and viewing truth and meaning as subjective enabled a detailed exploration of hospital staffs' views of the use of Intensive Interaction, and could take into account the variety of definitions of the approach that staff had. IPA helped the researcher take into account the personal and cultural influences on the double-hermeneutic, which is essential for such issues as working with people with learning disabilities and hospital care.

References for Appendix H - Epistemological statement

- Charmaz, K. (2003). Grounded theory. *Strategies of qualitative inquiry*, 2, 249.
- Crotty, M. (1998). *The foundations of social research: Meaning and perspective in the research process*. London: Sage Publications.
- Habermas, J. (1988). *On the logic of the social sciences* (p. xv). Cambridge, MA: MIT Press.
- Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory Method and Research*. London: Sage.
- Smith, J. A. & Osborn, M. (2008). Interpretative Phenomenological Analysis. In J. A. Smith (Eds.), *Qualitative Psychology: A practical guide to research* (2nd ed). London: Sage Publications.

Appendix I – Post Graduate Medical Institute Ethical Approval

(Removed for hard-binding)

Appendix J – Site Specific Approval from Research & Development

(Removed for hard-binding)

Appendix K – Invitation letter

Dept. of Clinical Psychology and Psychological Therapies
Hertford Building
University of Hull
Cottingham Road
Hull
HU6 7RX

Dear

You are invited to take part in a research study about the experience of hospital staff using intensive interaction. You have been invited because you have attended the 'Intensive Interaction Awareness Day.' The research will consist of an interview about your experiences of using intensive interaction. If you are interested in taking part, please take some time to read the information sheet and decide whether or not you would be interested in being interviewed.

If you have any questions please contact Anna Bodicoat on 07871 915282 or A.L.Bodicoat@2010.hull.ac.uk.

Thank you.

Anna Bodicoat

Appendix L – Semi-Structured Interview Schedule

Interview Schedule: Version 2

Demographic Information

Job Role

Gender

When attended the course

From 1- 10, where 10 is very knowledgeable and 1 is not at all knowledgeable, how knowledgeable are you about intensive interaction?.....

From 1-10, where 10 is very experienced and 1 is not at all experienced, how experienced are you in using intensive interaction?.....

The following questions are to find out about your experience of using intensive interaction. Please give as much detail as you can in answer to the questions.

1. First of all, could you please tell me about the training course you went on?
 - a. *Prompts: Why did you go on it? What did you do? What was it like? How did you feel about it?*
 - b. *What skills do you feel you have learnt from it? What skills have you used?*

2. Could you please tell me about a time when you have used intensive interaction?
 - a. *Why did you use it?*
 - b. *What did you do?*
 - c. *What was it like?*
 - d. *How did you feel about it?*
 - e. *Can you imagine using it again?*
 - f. *How many times have you used it?*

3. Could you describe the person you used intensive interaction with?
 - a. *What information did you get about them (e.g. patient passport, feedback from carers)?*
 - b. *How do you imagine the person felt?*
 - c. *How did you feel about them whilst doing intensive interaction?*

4. What things helped/allowed/enabled you to use intensive interaction?
 - a. *Practical*
 - b. *Personal – is there anything about you personally which enabled you to use it*
 - i. *Past experience, type of person you are,*

Appendix M – Consent form



Consent Form

The experience of hospital staff using intensive interaction

- I confirm that I have read and understood the information sheet for the above study on the experience of hospital staff using intensive interaction. I have had the opportunity to consider the information, ask questions and have had any questions answered.

- I understand that I do not have to participate in this study if I don't want to, and that I am free to withdraw at any point, without giving any reason for withdrawing.

- I understand that my participation and personal details will be kept confidential.

- I am willing to take part in the above study.

Name

Signed

Date

Appendix N – Information Sheet



The experience of hospital staff using intensive interaction

You are being invited to take part in a research study. Before you decide whether or not you want to take part in the study, it is important that you know what the study is about and what it will involve. Please take some time to read the following information.

The research is being carried out by Anna Bodicoat, Trainee Clinical Psychologist at the University of Hull, as part of a Doctorate in Clinical Psychology, supervised by Nick Hutchinson, Clinical Psychologist.

If you have any questions, please contact the researcher, Anna Bodicoat, on 07871 915282 or A.L.Bodicoat@2010.hull.ac.uk.

What is the purpose of the study?

The study is to explore the experience of hospital staff using intensive interaction. Previous research has found that intensive interaction has positive effects on people with learning disabilities. However, there has not been very much research on how staff feel about using intensive interaction, and there has not been any research on using intensive interaction in hospital settings. This study aims to explore how hospital staff feel about using intensive interaction, what the barriers and facilitators are to using it, and how it fits with job roles in a hospital setting.

Why have I been chosen?

The research requires around 10 participants who have attended the 'Intensive Interaction Awareness Day,' and who have subsequently used intensive interaction with a person with an intellectual disability in their work at the hospital. It doesn't matter if you have only used it a little bit, or if you have used it a lot, the questions are likely to be relevant no matter how much you have done.

What will I be asked to do?

You will be asked to take part in one interview that will last between 30 and 60 minutes, during the interview the main researcher will ask you questions about your experience of intensive interaction, what you thought of the course, what things helped or hindered you to use it, how you feel about the person you used it with, and how it fits with your job role. The interview will just be you and the main researcher, and it will be audio-recorded to make sure no important bits of information are missed.

The interview will be arranged at a time convenient for you and the researcher, and will happen in a venue convenient for you and the researcher.

In the interview it is important to be as open and honest as you can, and not to worry about what you should or shouldn't say. There is no right way to answer the questions and your experience is important, no matter what that is.

Do I have to take part?

You do not have to take part, and if you decide at any point during the interview that you do not wish to continue, the interview will be stopped.

Will it be kept confidential?

The answers you give will be kept confidential and only those people who have a need or right to know will be able to see it. Upon transcription your responses will be anonymised, and any identifiable information taken out. The interviews will be kept where only those doing the research access them. After the research is completed, your information will be kept locked at the University of Hull for 5 years, after this time it will be destroyed.

The exception to this is if, during the interview, it becomes clear that there is any risk of harm to yourself or anybody else. If there is a risk of harm the researcher will have a duty to discuss such issues with research supervisor, Nick Hutchinson, and line manager, Peter Oakes, and follow the correct safeguarding procedures if necessary. If the researcher has any concerns of this sort, and wishes follow the safeguarding procedures, this will be discussed with you during the interview.

What are the potential 'costs' of taking part?

The interviews are semi-structured, and you can talk about what you like in them. This may mean that you discuss topics that are upsetting or distressing. If you become upset by anything you discuss in the interview and require further support, you can contact the occupational health team at the hospital on 01482 674773.

What are the potential benefits of taking part?

This research could help develop services in hospitals for people who do not use words to communicate, such as those with learning disabilities or autism. Your answers could help identify potential difficulties in implementing intensive interaction techniques, as well as potential benefits, both to people you are communicating with, and yourselves.

What will happen to the research?

The results will be written up as part of clinical psychology doctoral thesis at the University of Hull, and will be submitted for publication in an appropriate journal. Hopefully, the research will prove to be of benefit to people with learning disabilities who go into hospital, and the staff who work with them. After the research has been written up you will be invited to attend a presentation at Hull Royal Infirmary outlining the findings. You will also be offered a written summary of the results.

Who has reviewed the study to ensure it is safe to carry out?

The study has been reviewed by the University of Hull Post Graduate Medical Institute ethics committee.

Who can I contact for further information?

You can contact Anna Bodicoat, Trainee Clinical Psychologist, on 07871 915282 or A.L.Bodicoat@2010.hull.ac.uk. Thank you for your time.

Appendix O – Worked Example of Interpretative Phenomenological Analysis

These steps followed the stages from Smith, Flowers & Larkin (2008). Stage one (right hand column): reading and re-reading, initial notes of descriptive, linguistic (*italicised*) and conceptual (underlined) comments. Stage two (Left hand column): Emergent themes identified from transcript and initial notes. Stage three was conducted by noting down the themes on post-its and grouping them according to overarching themes. Once all transcripts had been analysed like this, post-its were again used to identify common themes across participants. These were discussed with a peer-researcher group in order to validate them.

Stage two Emergent Themes	Transcript extract	Stage one Initial notes
Uncertainty Personal experience Outside work Opens your eyes/look at things differently It works	I thought mmm will I be able to use it as much but I've a brother that's disabled who's in a nursing home so there is a lot of people with learning disabilities or different disabilities there. So I knew I could use it maybe in that context um but yeah, I've, it, it just makes you, opens your eyes to different ways of dealing with people that you wouldn't have maybe thought of, you know, sort of the, the mirroring mirroring people and things um and it really works. <i>I: What skills do you feel you have learnt from it, from the course?</i>	Uncertainty but personal experience. Out there but not in here? <u>Distance from 'us', 'they' are out there</u> Using it outside work. <i>'I knew' = confident</i> Opens your eyes <i>metaphor</i> <u>what couldn't</u> <u>you 'see' before? Why did your eyes need</u> <u>opening?</u> Mirroring – direct technique Works to do what? And how? <i>Hesitations – required prompts –</i> <i>uncertainty</i>

<p>Uncertainty about skills</p> <p>Watching attentively and carefully/paying attention</p> <p>Making assumptions that are challenged</p> <p>?mismatch between busyness and reflection</p> <p>Skills already there/prior personality</p>	<p>P: um I think um,</p> <p><i>I: You mentioned the mirroring</i></p> <p>P: The mirroring and um just observing somebody really well, you know, you tell, you tend to take a first glance sort of decision of somebody but if you watch enough you can see when somebody is upset about something or, I mean maybe the slightest um, you know, the slightest reaction um but yeah it just makes you more observant I think, yeah I think I learnt that and and I already have to be really patient with my job anyway, so the patience was sort of there anyway but yeah just really observant and the mirroring I think is um.</p>	<p>Mirroring & observing – direct techniques</p> <p>‘first glance decision’ making assumptions based on looks/ initial impressions.*</p> <p><u>Perhaps I.I. challenges that? Have to be attentive to challenge it.</u></p> <p><u>‘watch enough’ makes me think of image of quiet, careful waiting, stillness and time out that does not match with busy ward and many appts.</u></p> <p>‘Slightest reaction’ – careful attention to the person.</p> <p>Skills already there</p> <p><i>‘the patience was there’ not I was/am patient -?distancing?</i></p> <p><u>*parallel process - I have to be attentive and mindful to challenge 1st assumptions of data</u></p>
---	---	--

Appendix P - Reflective Statement

Motivation for the project

Before starting this research process I had used Intensive Interaction with just one young man, but that was enough to convince me of the opportunities to build meaningful relationships with people with profound and multiple learning disabilities and its potential to change people's lives. The work I did with him and his staff team was a highlight of the year I spent as an assistant psychologist, and through it I learnt about the possibilities of getting to know and have fun with someone who does not use words. I therefore valued the opportunity of examining Intensive Interaction in a research capacity.

It was also important to me that the research opportunity was in a hospital setting. I had found the Death By Indifference report and the scandal at Winterbourne View highly distressing. I felt it was important that clinicians and researchers investigate areas around hospital care and staff training, in order to help ensure incidents such as those are not repeated.

These two aspects mean that I have felt very passionate about my topic throughout the research process, something that kept me going during the less interesting aspects of research, such as waiting for Research and Development approval, hours of transcribing, or combing through yet another study. Being so passionate, however, meant that there was a greater emotional impact when frustrations occurred. It was hard to accept that many of the studies I was critically evaluating had methodological flaws, or only found minimal positive effects. It was also

difficult not to feel frustration that participants lacked a clear understanding of the approach I believed so strongly in!

Qualitative Methodology

I feel the reflective stance required in qualitative research helped to acknowledge and contain the difficulties in the research, and I found this invaluable throughout. The anti-positivist stance I had to come from whilst conducting IPA helped to crystallise the difficulties I saw in purely positivist research. This gave me the courage to include 'anecdotal evidence' as part of my systematic review, despite not having seen any other papers using such a theme, and I feel the paper is richer for it.

When faced with interviewees who I felt did not understand Intensive Interaction and therefore the questions asked of them, I had to remind myself of the tenets of IPA. I needed to be reminded that what I saw as a disparity was instead their subjective experience and just as valid a data set from which to develop themes. At this point I really valued the support of more experienced qualitative researchers.

Having completed my undergraduate degree at York University where the research teaching focused solely on quantitative methodology, I came to the doctorate knowing very little about qualitative research, or quasi-experimental research. Indeed, there was a sense during the undergraduate teaching that these were vastly inferior methodologies. I had to adjust my thinking to accept that they could be significant in adding to a literature base.

I have since come to recognise the incredible richness and value of qualitative methods. I have always had a love of words and language and I found much pleasure in reading IPA papers, interviewing participants and immersing myself in the data. I will definitely be drawn back to IPA when considering any future research. I have already seen the impact on my work in clinical settings, as I now always consider qualitative approaches when evaluating group-work

Research with people with learning disabilities

The papers I have examined in my SLR highlighted many ethical challenges of working with people with learning disabilities. The critical approach I had to take made me re-evaluate my assumption that single case designs do not add meaningfully to the literature, and I now see them as a good way to tackle the challenges of including people with profound and multiple learning disabilities (PMID) in the research base, if they are done well. In any further research I do I will consider more thoroughly how to engage and involve people with PMID and their supporters. Involving service users, especially those who struggle to be heard, has become more important to me over the course of my training, I now feel that I did not think about this enough at the start of my project.

Challenges in the research

Much of the research process had been relatively smooth until I was met with delays obtaining site-specific approval. This meant I could not start data collection until the end of April. After much deliberation I took the decision to ask for a week-long extension to allow more space to consider the emerging themes. I have always

worked best and produced more focused work when deadlines are approaching, so the short time-span I had in which to write-up did feel helpful in some ways.

Choice of Journal

I decided to submit to the Journal of Applied Research in Intellectual Disabilities, as this is widely read so the research can be disseminated effectively. It also has one of the higher allowed word-counts of journals for research involving people with learning disabilities, which is important in order to do justice to a study using IPA.

When the participants spoke about working with people with communication difficulties, or older adults, I considered submitting instead to a multi-disciplinary, acute care, or nursing journal. However, the starting point of my research was working with people with an intellectual disability and so I felt this should remain the focus.

Implications for practice

I originally came to this research with a viewpoint of hospital staff behaviour needing to change. I have since come to see those staff members as struggling to do their best in a difficult environment, with patients that might challenge their ways of working. It has made me realise that psychologists have a comparatively luxurious amount of time and reflective space to work with client's difficulties. The research challenged my assumptions about the ease with which staff members can take on-board new ideas, and will impact upon how I think about training and implementing interventions.