THE UNIVERSITY OF HULL

Exploring experiences of Intensive Interaction used with people with learning disabilities and/or autism.

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by

Samantha Berridge, BSc (Hons) Psychology, University of Hull

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Acknowledgments

Firstly, I would like to express to my deepest gratitude to those who took part in this study, doing so despite facing other commitments and demands. I sincerely hope that through this research I have helped to make your voices heard and helped others to understand, which is the least that you deserve. This thesis is dedicated to you.

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Last, but not least, I would like to express my upmost gratitude and appreciation to my family and partner, who I adore and cherish. You have helped me in so many ways, more than you could ever imagine.

Overview

This portfolio has three parts:

Part one is a systematic literature review, that aimed to explore staff experience of the implementation of Intensive Interaction within their places of work with people with learning disabilities and/or autism. Nine research papers were analysed using thematic synthesis. Three higher-order themes were generated: 'Personal Doubt, Discordance & Discomfort,' 'A Turning Point' and 'Needing Implementation at All Levels.' The strength of the empirical evidence is evaluated, and findings are discussed in terms of their implications for future research and clinical practice.

Part two is an empirical paper, which explores mothers' experiences of Intensive Interaction. Six participants were interviewed. Results were analysed using interpretative phenomenological analysis. The findings suggest that Intensive Interaction was experienced as a beneficial approach and helped some mothers to feel connected with their child. It was also perceived to challenge assumptions and stigma related to people with learning disabilities and/or autism and it is important that the approach is accessible. Clinical and research implications are discussed.

Part 3 consists of a set of appendices relating to both the systematic literature review and the empirical paper. Also contained within these appendices are a reflective statement and an epistemological statement, which consider the researcher's experience of conducting the research and the philosophical position and assumptions underlying the research.

Total word count: 30216 (including tables, figures, appendices and references).

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PART ONE

Staff experience of the implementation of Intensive Interaction within their places of work with people with learning disabilities and/or autism

Authors: Samantha Berridge* & Dr Nick Hutchinson

University of Hull

*Corresponding author

Please send correspondence to:

Samantha Berridge, Department of Psychological Health, Wellbeing and Social Work, University of Hull, Cottingham Road, Hull, HU6 7RX

Email address: samantha.berridge@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.

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Abstract

Background: Intensive Interaction is an approach used to develop the communication and social inclusion of those who are pre-verbal. It is used in a variety of settings by healthcare and educational staff.

Method: A systematic search was conducted to identify and review the literature which explores staff experiences of Intensive Interaction being implemented within their places of work. Thematic synthesis was utilised to synthesise the findings.

Results: Nine papers were included. Three higher-order themes were generated: 'Personal Doubt, Discordance & Discomfort,' 'A Turning Point' and 'Needing Implementation at All Levels.'

Conclusions: There were consistent findings across a range of settings. Findings suggest that Intensive Interaction is rewarding for staff and beneficial to those that they work with. Implementation was sometimes perceived to be challenging and this review attempts to highlight solutions with guidance of the literature. Limitations largely relate to heterogeneity of the papers and methodological limitations are discussed.

Keywords: Intensive Interaction, learning disability, autism

Introduction

Intensive Interaction is an approach to develop the communication and social inclusion of those who are pre-verbal, such as people diagnosed with learning disabilities and/or autism. It is a way of communication that is based upon the interaction between an infant and caregiver (Ephraim, 1982). The approach consists of using pre-verbal social communication techniques (Nind & Hewett, 2005), such as mirroring body language and vocalisations (Nind, 1996). It is used in various settings, particularly as it has been recommended by government policy, 'Valuing People Now' (Department of Health, 2009).

There are variations regarding the aims of Intensive Interaction; some practitioners view it as a tool to develop communication skills (Nind & Hewett, 2005), whilst others view it as a route to social inclusion (Caldwell, 2007). Firth (2009) describes the Dual Processing Theory which gives an overview of the aims and outcomes of Intensive Interaction. The Social Inclusion Process is initial expansion of social and communicative skills and the Developmental Process suggests that, if used consistently, the individual may acquire longer-term communication skills. The Developmental Process is described to emerge at a transition point, after the Social Inclusion Process had plateaued. It is at this point where social support is crucial for acquisition of further skills.

Some of the quantitative research measures the observable effects seen in the individual to determine the effectiveness of Intensive Interaction (Argyropoulou & Papoudi, 2012; Barber, 2008; Lovell, Jones & Ephraim, 1998; Nind, 1996; Tee & Reed, 2017). Hutchinson and Bodicoat (2015) found that methodological limitations, such as small sample sizes and failing to control sources of bias, often prevented conclusions from

being made when reviewing this literature. Intensive Interaction is complex and dependent upon the individual, making generalisations from observable effects a challenge. It was also found in the review that indirect factors, such as the level of support that the staff who used Intensive Interaction perceived to have, could affect the process. It was, therefore, recommended that research needed to focus on aspects of staff training and requirements of support.

Weedle (2016) reviewed the literature that explored staff experiences of Intensive Interaction being implemented in their workplaces, but this was not exclusively focus on, so their experiences relating to this were not considered in-depth. In empirical research, Intensive Interaction has been perceived as valuable and staff wished to continue using the approach, especially due to effects observed in service users (Donnelly, Ellsworth & McKim, 2015; Firth, Poyser & Guthrie, 2013). However, organisational issues were found to be a barrier (Donnelly *et al.*, 2015). McKim (2013) stressed that developing the sustained use of Intensive Interaction requires input and influence from various levels of the organisation and that implementation success often depends on individual staff members.

To summarise, it is important to explore the experiences of staff who are involved in the implementation process as they play an important role and may be influenced by factors outside of their control. This review aims to synthesise and assess the quality of the literature exploring staff experiences of the implementation of Intensive Interaction within their places of work. Qualitative research would only be reviewed to justify the richness of experiences. This will include experiences of training programmes which usually accompany implementation (Donnelly *et al.*, 2015; Firth *et al.*, 2013; McKim, 2013). A variety of settings and programmes will be considered in attempt to compare

experiences, particularly as there is no standardised implementation process or setting whereby it is used.

Method

Search strategy

A computerized search was conducted in October 2018 on databases up to, and including, that date. Evidence of ideas relating to Intensive Interaction was apparent since the early 1980s (Ephraim, 1982), therefore 1982 was used as a cut-off date; however, the results from the searches did not extend this far. Only the English language limiter was applied as this area of research is still relatively small, therefore, further filtering was unnecessary. Databases that were included were: CINAHL, PsycInfo, Education Research Complete and Medline. The search terms used were based upon a previous systematic literature review exploring Intensive Interaction (Hutchinson & Bodicoat, 2015) and are listed below:

"menta* deficien*" OR "mental* handicap*" OR "mental* retard*" OR "mental* impair*" OR "mental* disab*" OR "mental disorder*" OR "mental* subnormal*" or "learning disab*" OR "learning difficult*" OR "intellectual difficult*" OR "intellectual* disab*" OR "intellectual* impairm*" OR "developmental disabilit*" OR autis* OR ASD OR Preverbal OR Prelingual OR "develop* dela*" OR autis* OR asd OR “autism spectrum disorder” OR asperger* OR “asperger's syndrome” OR “autistic disorder”

AND

"Intensive Interaction" OR "augmented mothering" OR "Hanging out program*" OR "imitative interaction"

Inclusion and exclusion criteria

Table 1 shows the inclusion and exclusion criteria for papers, along with the rationale for each criterion.

Table 1. Inclusion and exclusion criteria for the literature review.

Inclusion criteria	**Rationale**
Qualitative studies (may also include quantitative data which will not be included, such as papers using mixed methodology).	To include research which is likely to capture richer experiences of staff.
'Sufficient' qualitative data; this was defined as, the inclusion of papers with one or more themes, each illustrated by at least one quotation for each theme.	To include papers with rich findings to meet the aims of the review.
Grey literature (unpublished dissertations/theses).	The research for Intensive Interaction is somewhat on a small scale, therefore, it was considered beneficial to broaden the search.
Studies involving staff who worked for people with learning disabilities and/or autism. Papers were included if some staff had worked with people with alternative diagnoses (such as dementia), as long as the distinction between staff was made clear so that data related to those with alternative	There is comorbidity between diagnoses of learning disabilities and autism are they are usually lifelong.

diagnoses could be excluded. No age restrictions were applied to the people the staff worked with.	
Papers which were related to the implementation of Intensive Interaction. There were no restrictions on the nature of the implementation process (such as training method) as there is no standardised programme. There was no limit on the time between implementation and data collection, as Intensive Interaction has been found to show immediate effects (Zeedyk, Caldwell & Davies, 2009). All staff must have been involved in the same programme.	This was the research interest and it was of interest to attempt to compare programmes between studies and staff within studies if possible.
Exclusion criteria	**Rationale**
Papers which were unrelated to Intensive Interaction, if the participants were not staff in organisations where it had been implemented, if papers were unrelated to those with diagnoses of learning disabilities and/or autism or if there was no distinction between staff if some had only used Intensive Interaction with those with alternative diagnoses.	Not the area of the research interest.

Research which did not contain direct quotations or themes.	This would restrict the opportunity for interpretation of experiences.
Papers in a language other than English with no other English versions.	This was the first language of the researcher and there was no budget available for translation.
Literature reviews.	This would not include original data.
If staff within papers had not been involved in the same training programme.	This could complicate the interpretations made.
If few or none of the quality assessment criteria were met and if this was likely to compromise the conclusions made in the study.	This could affect the rigour of the current synthesis.

Quality assessment

The reliability and validity of critical appraisal tools have been questioned (Crowe & Sheppard, 2011), however, it was decided that one would be used to aid the process of analysing the rigour of papers. Rigour may be defined as the strength of the research design and the appropriateness of the method when meeting the aims of the study (Morse, Barrett, Mayan, Olson & Spiers, 2002). Regarding exclusion based upon quality assessment, Garside (2014) indicated that doing so may bias the conclusions of a review if quality was unlikely to alter its conclusions in papers. Within this review, participant experience and subsequently adequate conclusions were prioritised, therefore, studies were only planned to be excluded if they were judged to affect these components.

The UK National Institute for Health and Care Excellence (NICE, 2016) Checklist for Qualitative Studies was chosen as a critical appraisal tool, which is shown in Appendix B. Where studies employed a mixed methodological design, only the qualitative aspects were evaluated, as only these findings were included in the review. Particular attention was paid to the clarity of context bias, as was the rigor of data collection and analysis, as these could impact the experiences captured. Studies were rated into three different categories: (i) if they fulfilled all criteria or if any unfulfilled criteria were judged very unlikely to alter their conclusions or affect rigour of analysis; (ii) if they fulfilled some of the criteria and unfulfilled/inadequately described criteria were judged unlikely to alter their conclusions or affect rigour of analysis; and (iii) if few or none of the criteria were fulfilled and where the conclusions or rigour of analysis were likely to be affected. Studies in the final category were planned to be excluded.

Data synthesis

Thematic synthesis (Thomas & Harden, 2008) was used to analyse and synthesise staff experience of the implementation of Intensive Interaction. Data were extracted using a data extraction form, which is shown in Appendix C. The analysis involved line-by-line reading and coding of data presenting the experiences, which allowed for the translation of experiences between studies. These were developed into the final contributing codes, which were organised into descriptive themes that became the subthemes. These were developed by further interpretation and generated into higher-order analytical themes, which aimed to construct a conceptual account of experiences. This process was checked by the supervising researcher.

Results

The process and results of the search can be viewed in figure 1. The studies that were excluded after reading the full paper, as they had not met the inclusion criteria and/or had met the exclusion criteria, can be viewed in Appendix D. A total of 9 papers were included in the review.

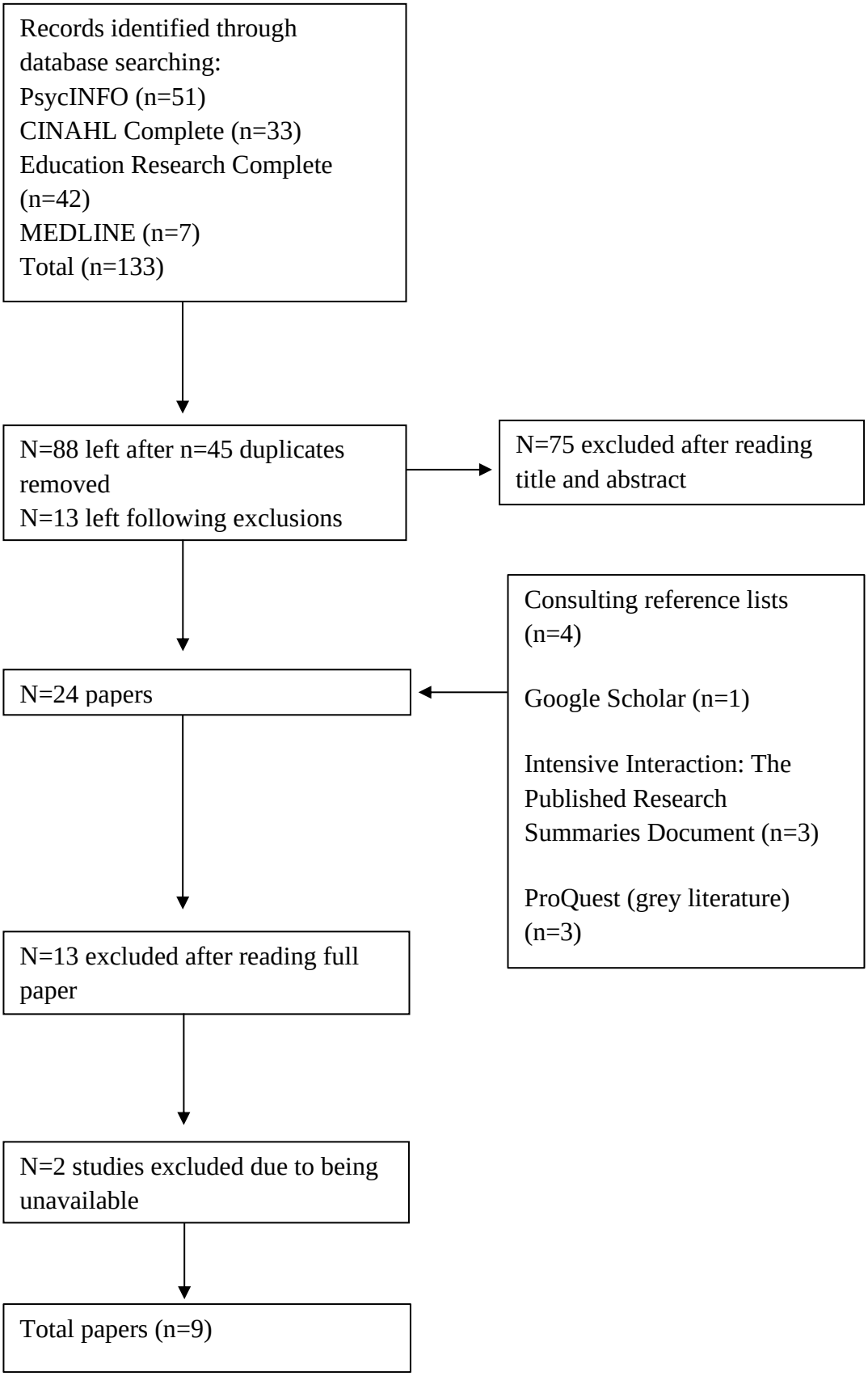

Figure 1. Preferred Reporting Items for Systematic Reviews (PRISMA) flow diagram outlining the search process and outcome.

Characteristics of included studies

Eight papers used a qualitative methodology and one used a mixed methodology (Clegg Black, Smith & Brumfitt, 2018). Seven studies only used interviews to collect data. Two studies combined interviews with other techniques (Jones & Howley, 2010; Sri-Amnuay, 2012) and one collected only written accounts (Zeedyk, Davies, Parry & Caldwell, 2009). Five studies used phenomenological approaches (Bodicat, 2013; Leaning, 2006; Nagra, White, Appiah & Rayner, 2017; Rayner *et al.,* 2016; Sri-Amnuay, 2012), three used thematic analysis (Clegg *et al.,* 2018; Jones & Howley, 2010; Zeedyk, Davies *et al.,* 2009) and one used grounded theory (Firth, Elford, Leeming & Crabbe, 2008). Seven studies were conducted in the UK barring two, one of which was in Romania (Zeedyk, Davies *et al.,* 2009) and the other in Thailand (Sri-Amnuay, 2012). In the papers where it was reported, ages of staff ranged from sixteen years (Zeedyk, Davies *et al.,* 2009) to sixty-four years (Nagra *et al.,* 2017). Three papers did not report age ranges of staff (Bodicoat, 2013; Clegg *et al.,* 2018; Jones & Howley, 2010). Four studies had mixed gender samples (Firth *et al.,* 2008; Leaning, 2006; Sri-Amnuay, 2012; Zeedyk, Davies *et al.,* 2009), one recruited female staff only (Bodicoat, 2013) and four studies were not explicit about gender (Clegg *et al.,* 2018; Jones & Howley; Nagra *et al.,* 2017; Rayner *et al.,* 2016). Sample sizes ranged from three (Rayner *et al.,* 2016) to twenty-nine (Firth, *et al.,* 2008).

The workplaces included were: schools (Jones & Howley, 2010; Sri-Amnuay 2012) day services (Clegg *et al.,* 2018; Leaning, 2006), an acute medical hospital (Bodicoat, 2013) and residential settings (Firth *et al.,* 2008; Nagra *et al.,* 2017; Zeedyk, Davies *et al.,* 2009). In Rayner *et al.* (2016), staff worked in a residential setting and community health team. Staff had a variety of job titles. The programmes and training varied between studies in terms of length of time to implement and what was involved. Table 2

details the main characteristics of the included studies along with the relevant findings extracted for analysis.

Table 2. Summary of the main characteristics of studies included in the review.

Authors, date and location	**Study aims**	**Participants**	**Intensive Interaction programme details**	**Methodological Approach**	**Relevant findings in the results section**
Bodicoat (2013) UK	To investigate the experience of hospital staff using Intensive Interaction, including barriers and facilitators to	N=7 female hospital staff. Only n=4 were considered in this review as they identified having had used Intensive	A day-long course conducted by a clinical psychologist and a community nurse who worked in intellectual disability services. The training covered the principles of Intensive Interaction. A mix of	Data were collected using semi structured interviews and analysed using interpretative	All the subthemes within the themes, 'Using Intensive Interaction,' 'Attempting to Improve the Patient's Experience in Hospital' and 'Working as a Team.'

	using Intensive Interaction in a hospital setting.	Interaction with people with learning disabilities and/or autism (n=1 auxiliary nurse, n=1 support worker, n=1 staff nurse, and n=1 ward housekeeper).	techniques were used, including activities, discussions and videos demonstrations.	phenomenological analysis (IPA).	
Clegg, Black, Smith and	To evaluate a city-wide implementation of intensive	N=28 social care staff (n=18 providing front line support; n=10	Staff were trained by an independent Intensive Interaction Consultant to deliver a day-long course to other staff. Ongoing	Qualitative data were collected using semi-structured	The subthemes, 'Staff Knowledge of Intensive Interaction,' 'Increased Staff Awareness' and 'Staff Perceptions of Adults with Profound

Brumfitt (2018) UK	interaction training.	in senior management roles) working in day service provision supporting adults with profound and multiple learning disability.	support in services was implemented Staff could receive further training to progress to Advanced Practitioners who were expected to support their colleagues with Intensive Interaction.	interviews (ranged in length from 6min and 5s to 32min and 23s). Data were analysed using thematic analysis.	and Multiple Learning Disability' within the overarching theme, 'The Impact of Intensive Interaction All the subthemes within the theme, 'Facilitating the Implementation of Intensive Interaction.' All the subthemes within the theme, 'Implementing Intensive Interaction: Organizational Support and Barriers.'
Firth, Elford, Leeming and	To report on the significant and influential issues for care staff	N=29 care staff (25 female, 4 males who were aged 18-58 years)	Staff attended an Intensive Interaction training course, which ran over five half-day sessions. The training was conducted by a	Data were collected using semi-structured interviews (no	All themes.

Crabbe (2008) UK	when adopting Intensive Interaction as a novel approach in the social care setting for clients with profound and multiple learning disabilities.	from 4 homes for adult clients with profound and multiple learning disabilities. Job titles were n=3 home managers, n=5 home deputy managers, n=20 support workers and n=1 regular bank staff.	Speech and Language Therapist and a former Further Education Teacher. The training was followed by a 6-month supported implementation period.	longer than 1 hour in duration), both prior to and after the initial implementation. Data were analysed using a Grounded Theory based approach.	
Jones and	To explore the effectiveness of an Intensive	The views of the n=2 staff from the local authority	The interaction programme was developed and supported by the local authority. The schools	Data were collected using questionnaires,	The themes, 'Perceptions of the System of Delivering Training' and

Howley (2010) UK	Interaction programme in schools.	which was responsible for the programme were collected for an overview of the programme. Views were collected from n=5 Special Educational Needs Coordinators, n=1 Interactionist, n=1 senior teacher with responsibility for autism, n=5	involved had completed training during a one-year period, where trainees were trained and supported by an Interactionist. At the end of this period, they can work independently and train others.	'informal discussions,' semi-structured interviews and document scrutiny. Data were analysed using thematic analysis.	'Perceptions of the Impact of Training.'

		trainees and the class teachers (unclear how many) of the n=5 children who were part of the programme. Those involved were from across n=5 schools.			
Leaning (2006) UK	To investigate the perceptions of care staff who use Intensive Interaction with	N=12 care workers (n=8 female and n=4 males, aged 27-58 years, mean age	Trained by experienced Intensive Interaction trainers who also provided weekly supervision	Data were collected using semi-structured interviews and	Subthemes, 'Fear of the Client's Behaviour,' 'Needing to be in Control' and 'Letting Clients Lead' within the theme, 'Exerting Control vs. Relinquishing'

	their clients with profound and multiple learning disabilities (PMLD).	33.8 years) from n=2 day services who had used Intensive Interaction for at least n=3 months; (range n=3 months to n=3 years).	analysed using IPA.	Subthemes, ‘Being in the Client’s Shoes,’ ‘Listening to Client’s Emotions,’ ‘Dissociating from Clients’ Feelings,’ ‘Making Sense of Emotions about Clients,’ ‘Talking About Your Feelings,’ ‘Confusing Roles and Relationships,’ ‘Security Guard vs. Friend,’ ‘Care Worker vs. Carer’ within the theme, ‘Making a Connection’ All the subthemes within the theme, ‘Thoughts about the Wider System.’

Nagra White, Appiah and Rayner (2017) UK	To explore staff perspectives to help understand the actual and perceived barriers to sustained use of Intensive Interaction after training.	N=8 paid carers (aged 27-64 years) employed in direct care roles in residential homes for people with learning disabilities.	Staff went on a 6-week training course which comprised of 6 workshops covering theory, videos demonstrations, group role-play exercises, discussion groups and live skills practice with clients in the workplace.	Data were collected using semi-structured interviews (lasted between 20 mins and 80 mins) and analysed using IPA.	All the themes.
Rayner *et al.* (2016)	To explore the lived experience of Intensive	N=3 staff (n=2 carers and n=1 home manager;	The 6-week training programme consisted of 3 workshops which utilised a combination of didactic	Data were collected using semi-structured	All the themes.

UK	Interaction training and practice of paid carers who worked with people with learning disabilities.	aged 25, 44 and 48 years) recruited from one Intensive Interaction training cohort. Staff worked in a residential care home and a community health team.	teaching, reflective group discussion, peer support and formal supervision from managers, who in turn received formal supervision from workshop facilitators.	interviews (completed within 6 months of the end of the training) and analysed using IPA.	
Sri-Amnuay (2012) Thailand	To explore how Thai teachers perceive Intensive Interaction as an	N=11 teachers (n=10 female, n=1 male, aged between 25-35 years) from n=3	The full programme lasted 6 months. A 2-day Intensive Interaction training course was provided by the researcher.	Data were collected before and over the duration of the programme via	All the subthemes within the theme, 'Becoming a Responsive Teacher- The Challenge of Transition Process.'

	approach to working with pupils with autism and severe learning difficulties in the Thai context. .	educational settings.	Following this, school visits were carried out which involved reflection and offering of solutions. The first took place after the first interview and subsequently took place monthly over the 6 months. N=3 half-day workshops were also held over the 6 months (the same strategies were used from the initial course).	n=4 semi-structured interviews. 2 focus groups were conducted after the end of the 6-month programme. Observations were carried out during school visits Phenomenological analysis was used to analyse data.	The subthemes, 'Start from the Sceptical Mind,' 'Positive Responses from the Pupils' and 'The Value of Naturalistic Approach' within the theme, 'Factors encouraging the use of Intensive Interaction in the Thai school context.' All the subthemes within the theme, 'Perceived barriers to Intensive Interaction in the Thai School Context.' All the subthemes within the 'Supporting the Sustainability of

					Intensive Interaction in the Thai School Context.'
Zeedyk, Davies, Parry and Caldwell (2009) Romania	To understand more about the staff's perceptions pertaining to the Romanian children with communication impairment they worked with and to themselves following training	N=12 staff (n=9 female, n=3 males, aged 16-19 years) who were working as volunteers for a 2-week period. All volunteers were British.	The researcher delivered 2 sessions, each lasting approximately 30 minutes. This included introduction to the background, aims and description of the practice and they were shown demonstration videos from the UK. Staff were then encouraged to try to use Intensive Interaction with the children.	Data were collected through written accounts (ranging between 250 and 750 words in length) and analysed using thematic analysis.	All the themes.

Methodological Quality Assessment

The methodological quality of the included studies was assessed by the first author and checked by the supervising researcher. A summary table containing an overview of the methodological quality is shown in Appendix E and the overall quality rating for the included papers is shown in table 3. Six papers were judged to be lacking in reflexivity. However, the unpublished theses were transparent about their reflexivity and positions as researchers (Bodicoat, 2013; Leaning, 2006; Sri-Amnuay, 2012). The aims of the studies and use of a qualitative approach were judged to be justified overall. Data collection was usually justified and clear, however, in the Jones and Howley (2010) paper, sample sizes were not presented clearly. In the Sri-Amnuay (2012) paper, the description of data collection could have been presented more concisely for clarity. Data collection in some papers was questioned but was not judged to likely affect the outcome of qualitative data (Clegg *et al.,* 2018; Zeedyk, Davies *et al.,* 2009). Methods were deemed as reliable but, often, context biases could have been further accounted for (Firth *et al.*, 2008; Jones & Howley, 2010; Rayner *et al.*, 2016; Sri-Amnuay, 2012; Zeedyk, Davies *et al.*, 2009). The studies generally took measures to ensure their data were checked, although the extent of this was somewhat unclear in Sri-Amnuay (2012). Studies demonstrated adequate conclusions from their analysed data. However, justification of the analysis could have been better described in one paper (Jones & Howley, 2010).

Table 3. Overall methodological quality rating for the included papers.

Methodological Quality Rating		
-	+	++
Few or no checklist criteria were fulfilled, and the conclusions and rigour of analysis were judged as likely to be affected.	**Some of the criteria were unfulfilled/inadequately described but this was judged as unlikely to alter conclusions or affect rigour of analysis.**	**All the criteria were fulfilled or where it was not fulfilled the conclusions were judged as very unlikely to alter conclusion or affect rigour of analysis.**
No studies were assigned to this category.	Clegg *et al.* (2018) Jones and Howley (2010) Sri-Amnuay (2012) Zeedyk, Davies *et al.* (2009)	Bodicoat (2013) Firth *et al.* (2008) Leaning (2006) Nagra *et al.* (2017) Rayner *et al* (2016)

Synthesis

The data were organised into codes which translated across studies (Appendix F). These were developed into nine descriptive subthemes that were generated into three higher-order themes. The studies that represent each theme can be viewed in Table 4.

Table 4. Organised themes and contributing papers.

Higher-order themes	**Subthemes**	**Contributing papers**
Personal discordance, doubt & discomfort	Clashes in philosophies & roles	Firth *et al.* (2008); Leaning (2006); Sri-Amnuay (2012)
	Feeling uncertain & seeking control	Clegg *et al.* (2018); Leaning (2006); Nagra *et al.* (2017); Sri-Amnuay (2012)
	Emotional discomfort	Firth *et al.* (2008); Leaning (2006); Rayner *et al* (2016); Sri-Amnuay (2012); Zeedyk, Davies *et al.* (2009)
A turning point	Seeing the light	All papers
	Gaining confidence	Clegg *et al.* (2018); Firth *et al.* (2008); Jones and Howley (2010); Leaning (2006); Nagra *et al.* (2017); Rayner *et al* (2016); Sri-Amnuay (2012); Zeedyk, Davies *et al.* (2009)
Needing implementation at all levels	The immediate workplace environment	Bodicoat (2013); Clegg *et al.* (2018); Firth *et al.*

		(2008); Jones and Howley (2010); Sri-Amnuay (2012)
	Teamwork	Bodicoat (2013); Clegg *et al.* (2018); Firth *et al.* (2008); Jones and Howley (2010); Leaning (2006); Nagra *et al.* (2017); Rayner *et al* (2016); Sri-Amnuay (2012)
	Making it official	Clegg *et al.* (2018); Firth *et al.* (2008); Jones and Howley (2010); Nagra *et al.* (2017); Sri-Amnuay (2012); Zeedyk, Davies *et al.* (2009)
	Outsider perception: needing permission	Bodicoat (2013); Clegg *et al.* (2018); Firth *et al.* (2008); Nagra *et al.* (2017); Sri-Amnuay (2012)

Personal doubt, discordance & discomfort

Some staff seemed to describe that Intensive Interaction did not fit with their previous ways of working. This sometimes led to staff feeling uncertain in their own abilities, and in the approach, and seeking control. Difficult emotions emerged when practising Intensive Interaction which, at times, contributed towards an apparent desire to 'switch-

off' these emotions. It also appeared to make them more aware of their own emotions and empathise with those they worked with.

A contrast with previous philosophies & roles

Intensive Interaction could feel contradictory to previous ways of working as views of staff relationship with clients/pupils changed; for example, they *'started to feel quite motherly'* and *'loving' (Leaning, 2006, p. 92)* towards clients after implementation. However, it was described that there were *'not supposed to feel that way about clients' (Leaning, 2006, p. 92)* and they should not get *'too close' (Firth et al., 2008, p. 64).*

Intensive Interaction contrasted with views that some staff held on *'age-appropriacy' (Firth et al., 2008, p. 64).* Discomfort was expressed within the Sri-Amnuay (2012, p. 163) study, *'It's a bit embarrassing to play a kid's trick to someone grown.'* If these concerns occurred, they sometimes later subsided, *'I feel completely different now' (Firth et al., 2008, p. 64).* Some staff discussed that the new aspect to their role, brought by Intensive Interaction, could clash with other aspects:

'I could be trying to do Intensive Interaction, but I know that I have to quickly turn into someone who knows where the boundaries are' (Leaning, 2006, p. 91).

A participant in the Sri-Amnuay (2012, p. 221) study described how duties of their role and level of force previously used clashed with their ability to effectively do Intensive Interaction with a pupil:

'I've forced her in many things… When I later approach her, it's not as fun, she doesn't enjoy it.'

Feeling uncertain & seeking control

There was a sense that some staff were uncertain of how they should "do" Intensive Interaction, for example, it was described as, *'second guessing' (Nagra et al., 2017, p.*

655). This was often apparent when staff were interviewed just as Intensive Interaction was introduced or when reflecting on the earlier stages of implementation. In the study of Clegg *et al.* (2018, p. 7), a Provider Service Worker commented on their colleagues' uncertainness when recording Intensive Interaction sessions:

'I think people don't understand that there's no right or wrong.'

In Sri-Amnuay (2012, p. 186), it was reported, *'I don't see the clear steps of what I should do…'* This appeared to contrast to usual teaching methods, *'It feels like we didn't have any objectives at all' (p. 189).*

Sometimes, within Leaning (2006) and Sri-Amnuay (2012), this uncertainty seemed to transition to feeling out of control of their clients/pupils during the initial phases: *'You make yourself vulnerable by giving up control and letting them lead and take the initiative' (Leaning, 2006, p. 84).* By allowing the client more control, the care worker felt they would lose theirs. Staff sometimes were concerned that Intensive Interaction would cause the individual to not view them as being in a position of authority: *'he wouldn't see me as someone that he needed to be respectful of' (Leaning, 2006, p. 84).*

In the Sri-Amnuay (2012) paper, one participant was concerned that her pupils would no longer fear her, meaning she would lose control: *'We have to make them afraid of us as we are their teacher. Otherwise we will be unable to control them for discipline and cannot teach' (p. 166).*

Emotional discomfort

Certain staff found the implementation experience emotional: *'The training at times it (..) it made it I think it makes you feel quite emotional' (Rayner et al., 2016, p. 66).* In this account, the participant found it difficult to explain why this was, but the account suggests that it had an impact upon them. Self-harm that occurred when interacting with

the clients was emotionally difficult for some staff: *'I had found being around Anton extremely hard... I even cried while attempting to interact with him' (Zeedyk, Davies et al., 2009, p. 192).*

Some staff in Leaning (2006, p. 88) seemed to become more in touch with their clients' emotions: *'Intensive Interaction means you switch that around and take other people's emotions again, it's hard, sometimes you think more about it after work.'* Because of this, it was expressed that, *'sometimes I don't want to work like that' (p. 89)* and their old ways of working were emotionally easier: *'it was easier to just help people with their personal care and eating and moving and handling' (p. 89).*

One participant in the study of Sri-Amnuay (2012, p. 181) also seemed become more conscientious of their pupils, which could be stressful: *'Sometimes, it's hard and I feel stressed. I think, think and think hard. Sometimes my head hurts as we cannot interpret what the children mean.... It seems like the children felt guilty when they cannot do what they were told by us....'*

Due to the emotional challenges which accompanied Intensive Interaction for some staff, this increased their need for someone to empathise with their feelings: *'you need someone who understands to listen to your emotions, just like you listen to the clients' emotions… and to share these feelings of success or failure with others' (Leaning, 2006, p. 90).*

Occasionally, it appeared that some staff had denied acknowledgment of the client's level of communication. This may demonstrate a distancing from the client and possibly their emotions. For example, in Firth *et al.* (2008, p. 63), one Support Worker commented, *'I know they (clients) understand what I'm saying to them anyway… so, I tend to revert back into just normal conversation…'* during Intensive Interaction.

However, the authors noted that *'some alleged "client knowledge" claimed by staff was not supported by the field researcher's own observations' (p. 63).*

A turning point

Despite the challenges described in the previous theme, there appeared to be a turning point whereby staff felt more positive about the approach. One turning point appeared to be when staff saw the effects of Intensive Interaction. This seemed to contribute to them becoming aware of, and challenging, their assumptions. Another turning point related to staff themselves, as they gained confidence and, therefore, enjoyment in the approach.

Seeing the light

Staff described the profound impact of seeing the effects of Intensive Interaction and describing this in a way which suggested that light was shed on their assumptions. There appeared to be an assumption that some clients/pupils were incapable of communication, sometimes leaving staff feeling that Intensive Interaction *'would not work' (Sri-Amnuay, 2012, p. 200).* Staff expressed feelings of, *'surprise' (Zeedyk, Davies et al., 2009, p. 190)* or were *'amazed' (Sri-Amnuay, 2012, p. 201)* when they found that it did benefit their clients/pupils. There was a suggestion that some staff thought it was seemingly impossible- *'I just couldn't believe what I was seeing' (Rayner et al., 2016, p. 68)*- and had to see it to believe it:

'I feel like I've been witness' (Zeedyk, Davies et al., 2009, p. 193)

'They [the staff] have seen clients do things that they didn't think they would…' (Firth et al., 2008, p. 63).

This led to some staff explaining that their views had *'changed in a positive way' (Sri-Amnuay, 2012, p. 200).* Staff reconsidered that their client's/pupil's behaviour may have

been communicative attempts: *'made me realise she's not just doing that cos it's her you know, that's her way of telling ya' (Bodicoat, 2013, p. 58)* and that, previously, they did *'already respond' (Sri Amnuay, 2012, p. 195)* but staff, , may have been *'ignoring them' (Firth et al., 2008, p. 63)* or were *'ignorant' (Nagra et al., 2017, p. 652).* Therefore, Intensive Interaction led to them developing awareness of previous assumptions: *'I didn't think that she would have any way of communicating but she does'* (*Clegg et al., 2018, p. 6).*

This shift helped staff view clients as equals *'Intensive Interaction made me realise that everybody is the same… whether you have a profound learning disability or if you're a doctor...' (Leaning, 2006, p. 87).* Staff appeared to think more about clients/pupils as individuals and, therefore, as one participant described, *'treat them as an individual' (Bodicoat, 2013, p. 60).* This was demonstrated in various ways, such as offering *'choice' (Rayner et al., 2016, p. 67) and* acknowledging that what they *'do with one child will be miles apart from another' (Jones & Howley, 2010, p. 120)*.

Gaining confidence

Staff also described feeling more *'confident'* following training *(Jones & Howley, 2010, p. 119; Nagra et al., 2017, p. 652)* and one described that they, *'probably wouldn't have got this far without the training' (Firth et al., 2008, p. 61).* Confidence appeared to improve as the training programme progressed: *'the more of the sessions I went on the more fluid it became, the more easier, the less inhibited I felt' (Rayner et al., 2016, p. 66).* In one instance, this was described to lead to *'no more feelings we had when we started' (Sri-Amnuay, 2012, p. 194)* in relation to uncertainty. As confidence developed so did a desire to carry the approach forward. Sometimes this was on a personal level: *'I certainly continue to use Intensive Interaction as I was inspired by it…' (Sri-Amnuay, 2012, p. 228)* or by *'passing it on to somebody else' (Nagra et al., 2017, p. 656)* via

training, *'go ahead and train other people... because I think the impact… has been so positive….' (Jones & Howley, 2010, p. 119).*

Staff described the new way of working *'satisfying' (Zeedyk, Davies et al., 2009, p. 192).* Some examples of this were: *'it gives you drive' (Rayner et al., 2016, p. 67),* in reference to feeling supported by other staff, *'it felt like I had made a real contribution' (Zeedyk, Davies et al., 2009, p. 192), 'I feel like I've learnt something' (Nagra et al., 2017, p. 656), 'more meaningful' (Leaning, 2006, p. 94)* and *'it makes a happier environment … for staff and people you care for' (Clegg et al., 2018, p. 8).* This was sometimes directly contrasted with previous ways of working, *'we were stressed and the children were unhappy' (Sri-Amnuay, 2012, p. 179).*

Needing implementation at all levels

The success of the implementation seemed to be affected at different levels, for example, the workplace environment, staff dynamic within the workplace and assumptions held by those beyond the workplace.

The immediate workplace environment

Staff described practical barriers within the workplace environment:

'there was a difficulty sometimes . . . I had to make sure that there was somebody to watch him for five, ten, fifteen minutes while I set out the room.'

The quotation is taken from the study of Jones and Howley (2010, p. 119), whereby a staff member described needing a *'distraction free room'* but that this depended upon the availability of other staff. In Sri-Amnuay (2012, p. 218), a similar issue relating to acquiring a distraction free environment was described:

'I keep playing with the consented pupils but not for long because there are twenty of them. And I have to take turn taking care of all of them.'

Within this setting, consent from the pupils' parents were required for Intensive Interaction, meaning that the approach could only be used selectively.

Distractions also occurred within adult settings due to the other duties of staff:

'You're having to show them [the new staff] around and you're having to guide them… so you're then pulled away from doing the Intensive Interaction' (Clegg et al., 2018, p. 8).

A similar issue of being distracted by the need to tend to others besides the clients was described in Bodicoat (2013, p. 63) by the author: *'lots of visitors and health professionals coming onto a ward…'* Low staff levels were also an issue, *'you've got two qualified and one auxiliary on and you've got thirty patients on a ward, you don't have time' (Bodicoat, 2013, p. 63).* This was similar in Sri-Amnuay (2012, p. 218): *'we have a large number of pupils, but a small number of teachers.'*

There was a sense that *'personal care' (Clegg et al., 2018, p. 8)* tasks were felt to be prioritised over Intensive Interaction. Sometimes the amount of duties required by staff appeared to be overwhelming for them: *'I've got quite a heavy workload anyway, and… (it's) getting bigger (lists individual roles and responsibilities)… so sometimes you just think 'no, no I can't do anymore' (Firth et al., 2008, p. 65).*

Ultimately these issues contributed to reduction in the amount of *'time' (Bodicoat, 2013, p. 63; Clegg et al., 2018, p. 8; Firth et al., 2008, p. 65; Sri-Amnuay, 2012, p. 218)* that could be dedicated to Intensive Interaction. Because of these issues, some staff described that Intensive Interaction had, *'fallen down the wayside' (Firth et al., 2008, p. 66)* and *'probably got lost' (Clegg et al., 2018, p. 8).*

Teamwork

For successful implementation, it was described that, *'really good team work' (Bodicoat, 2013, p. 65)* was an important factor. Specifically, the importance of consistency within the team was emphasised in relation to the adoption of the approach:

'If all the staff team were on board and all the staff team were trained… then I think we're laughing, we've cracked it' (Rayner et al., 2016, p. 68).

In Jones and Howley (2010, p. 120), collaborative communication was described as a facilitator of implementation and it was perceived that this was done successfully: *'we are all very aware of what each other are doing now and it is mainly done through everyone giving each other lots of copies of various things . . . but a lot of verbal communication as well.'*

In some cases, collaborative communication was viewed as important between staff and those external to the organisation. For example, in other schools, where staff could *'observe'* Intensive Interaction to gain, *'good ideas' (Jones & Howley, 2010, p. 120)* and with the *'families and the friends' (Bodicoat, 2013, p. 65)* of the individuals. In Sri-Amnuay (2012, p. 229), it was explained that, *'parents should also be trained in Intensive Interaction as they can continue to use it with their child at home. … This will be easier to allow us to continue.'*

Collaborative communication with those who delivered the course was important so trainers could *'get an insight in to what they're actually dealing with' (Nagra, et al., 2017, p. 654)*. The authors in Clegg *et al.,* (2018, p. 7) described that, Advanced Practitioners, who were trained to support colleagues with Intensive Interaction, *'were viewed by managers as not only "vital"… but also "instrumental"… in feeding back to the management team the barriers staff experienced in using Intensive Interaction.'*

Top-down support from managers was viewed as important: *'if they've not got the support from the management then it's just gonna be a lost cause' (Nagra et al., 2017, p. 654).* In the study of Clegg *et al.* (2018, p. 8), top-down support was sometimes perceived as ineffective: *'I've sat in meetings with (managers) and staff team and it's all "oh yeah, we'll promise this and make sure this happens" and it all sounds good but then it doesn't happen.'* A possible reason for this was that there was *'idealism on the manager's side and the quite negative realism from the staff team'* and that there needed to be a way to *'keep that ideal spirit but within the reality of how it can work.'*

While in Clegg *et al.* (2018) it appeared that staff perceived that managers had good intentions, a participant within Leaning (2006, p. 93) explained, *'management just make that time smaller and smaller'* when using Intensive Interaction. One participant felt *'skeptical'* after implementation: *'they want to impose control because they are scared of challenging behaviour, scared of trying to interact with people who don't give you feedback, so they try to put these emotions in a box and take control over the environment' (p. 93).*

Making it official

Often, the need to be reminded to do the approach was an important factor (Clegg *et al.*, 2018; Nagra *et al.*, 2017; Zeedyk, Davies *et al.*, 2009) so that it did not *'get lost' (Nagra et al., 2017, p. 656)* and to keep *'the whole aspect of Intensive Interaction going' (Clegg et al., 2018, p. 7).* Sometimes it was described that something which assisted with this was making the approach official. For example, it was described that, *'if it's not officially pinned down…. I think Intensive Interaction will disappear…' (Sri-Amnuay, 2012, p. 226)* and that it was more likely that *'something would have come along' (Jones & Howley, 2010, p. 119)* to disrupt Intensive Interaction. Within the school setting, it was suggested that *'It will be easy if Intensive Interaction is implemented as a*

part of the pupil's IEP' and that *'The curriculum should be rearranged' (Sri-Amnuay, 2012, p. 228).*

Other solutions to make it official were described. The authors in of Firth *et al.* (2008, p. 66) described that, *'A proactive solution to circumvent this problem was to "make time" in the face of competing demands, either through setting a specific time for "sessional" Intensive Interaction, or by integrating it into care tasks.'* However, this was also viewed as an issue due to, *'not allowing for client choice about the time or circumstances of the interactive session.'*

Within Clegg *et al.* (2018, p. 7), a solution to make it official was to record Intensive Interaction on a sessional basis. However, it was reported that, *'Using video to record sessions "rarely happened"... as it is too time consuming.'*

Outsider perception: needing permission

Some staff described feeling *'self-conscious' (Firth et al., 2008, p. 65)* when using the approach in front of those who were external to the organisation and one individual *'felt afraid some people who don't know about it will have a negative attitude' (Sri-Amnuay, 2012, p. 222).* One participant felt inhibited during Intensive Interaction: *'Well I wouldn't overly touch him cos he's got a carer with him' (Bodicoat, 2013, p. 65).* Staff described issues in relation to how they thought that others viewed them: *'people tend to stare very oddly at me' (Nagra et al., 2017, p. 655).* One staff member thought that others viewed them as *'taking the mick' (Nagra et al., 2017, p. 655)* during the mirroring technique.

Besides mental concerns of others' perceptions, there appeared to be genuine risks which staff had experienced when using Intensive Interaction in the presence of those externally, such as receiving *'complaints' (Sri-Amnuay, 2012, p. 77)* or having a *'report*

that went to safeguarding' due to being perceived to be *'speaking to a service user in a patronizing way' (Nagra et al., 2017, p. 656).*

On the other hand, one individual felt that implementation and training caused them to have less concern of *'political correctness' (Bodicoat, 2013, p. 58)* and it gave them permission to work in the ways they wanted under certain conditions: *'permitting that the circumstances are right and if it puts them more at ease' (Bodicoat, 2013, p. 59).* There was a sense that some no longer had to hide these ways of working as they became accepted:

'So whereas before (Intensive Interaction training programme) we were sort of doing it and someone from outside would walk in and we'd sort of jump up quickly and start to look busy' (Clegg et al., 2018, p. 7).

'Now I was not blamed anymore as everyone is doing the same thing. I just felt relieved... I felt very good that Intensive Interaction was known in this place' (Sri-Amnuay, 2012, p. 172).

Discussion

This review aimed to explore the experiences of the implementation of Intensive Interaction. Staff described practical issues in the workplace environment when implementing Intensive Interaction. A risk of this being unresolved could be 'initiative decay,' a situation where novel working practices and procedures are abandoned over time (Buchanan Claydon & Doyle, 1999). To prevent this from happening, it was suggested that Intensive Interaction could be made "official," for example, by incorporating it into curriculums or scheduling it into the day. An issue relating to this was that scheduled sessions are not spontaneous so may not be on the individual's terms; a key part of Intensive Interaction (Leaning & Watson, 2006).

At times, Intensive Interaction contrasted with previous ways of working, those of which appeared to reflect a 'normalization' philosophy of social care (Wolfensberger, 1972). This included age-appropriateness, which has previously been viewed as a barrier (Nind & Hewett, 1998). Intensive Interaction is alternatively developmentally focussed, as it is based upon the communication between an infant and caregiver (Ephraim, 1982).

As suggested in this review, the relationship between staff and people with learning disabilities has been found to be, at times, at risk of being exclusively procedural, task related, controlling and ritualised (Dobson, Upadhyaya, Conyers & Raghavan, 2002). However, these factors do not fit with the ethos of Intensive Interaction as it is intended to be 'done with' the person (Irvine, Firth & Berry, 2010, p.21). The review demonstrated that these issues were sometimes consciously considered during implementation and were directly challenged by Intensive Interaction.

The subtheme, 'Outsider Perception: Needing Permission*'* suggested that cultural discourses sometimes contribute towards barriers to implementation, however, the papers within the subtheme did not always explicitly specify this. It was most explicit in Sri-Amnuay (2012) and Bodicoat (2013). In Sri-Amnuay (2012), it was described that Thai culture is 'hierarchical' and there was an expectation that 'Thai teachers require respect' (p.225) from their pupils and it was suggested that Intensive Interaction may not be thought to comply with this. Bodicoat (2013) described that cultural discourses could link to concerns related to physical touch and referenced Hewett (2007), which describes that this can be 'explicitly' or 'implicitly forbidden' in workplaces (p. 120) for

reasons such as fear of allegations of abuse. Staff may have internalised rules regarding closeness within their role, which can be influenced by culture (Estabrooks & Morse, 1992). This review found that through training, and when everyone in the system used the approach, staff felt permission to be closer. The likelihood of misperceiving allegations being made may have been reduced.

Seeing changes in the individual tended to overcome initial doubt, which was supported by Donnelly *et al.* (2015) and Firth *et al.* (2013). This echoes the description by Nind (2000); that Intensive Interaction is transformative for staff. Staff began to view the people they worked with as individuals. This is important because otherwise there is a risk that social constructions of the person can be formed by the functions of tasks rather than by the person themselves (Statham & Timluck, 2001).

Staff were found to experience growing confidence in their own ability as time progressed. Ager and O' May (2001) found that perceived support from management and colleagues determined perceptions of self-competence, which highlights the importance of teamwork, as reflected in the review. As Clegg *et al.* (2018, p. 9) suggested, 'there needs to be a core team of consistent, enthusiastic staff who are trained in and committed to intensive interaction.' This appeared to be embodied well in Jones and Howley (2010), whereby staff perceived that they were supported and benefitted from ongoing support in the programme.

Staff described discomfort when getting close to the individuals they worked with via Intensive Interaction in a psychological sense as they were confronted with difficult feelings. Emotional overload has been found to lead to staff emotionally distancing from clients as a way of coping (Payne & Firth-Cozens, 1987). Some staff appeared to

become more understanding of their clients/pupils and acknowledged their feelings, which may be defined as empathy (Halpern, 2003). Empathy is an important part of Intensive Interaction and is one dimension of attuning with the individual (Griffiths & Smith, 2015). This is important to prevent the distancing effect. It is important that staff feel emotionally supported, otherwise this may risk them feeling burnout (Ager and O' May, 2001). Due to the stronger emotional connection that can take place during Intensive Interaction, proper supervision is recommended (Nind and Hewett, 2005).

Limitations

This review did not collect original data, so transparency of the processes is important due to the further interpretations made (Bearman & Dawson, 2013). It is important that researcher bias is acknowledged. Measures were taken to attempt to reduce bias, such as themes being checked by the supervising researcher, however, some biases may relate to both the primary and supervising researcher having a background in clinical psychology.

Findings in this review are partly dependent upon the quality of the papers reviewed, specific detail of this can be viewed in 'methodological quality assessment.' Sometimes there was a lack of clarity in the presentation of the methodology and design. There were also inconsistencies between papers in the amount of information provided about samples and methodology. Some papers did not explicitly consider context biases, such as participant demographic, job role, setting and cultural differences. Researcher bias was not always transparent, which may have been an issue when researchers also took an active role in training delivery. Accounts of reflexivity were inadequate, bedsides in the unpublished theses. Publishing research in this field ought to give more consideration to this, as failing to do so may influence the trustworthiness of findings

(Lincoln & Guba, 1985).

Despite this, data appeared to be rich, therefore, the depth of the synthesis was not deemed to be affected (NHS Centre for Reviews and Dissemination., 2001) and the designs and methodologies of the papers overall were considered to be appropriate. There was generally enough information regarding context, allowing for the reader to acknowledge this in the interpretation of data.

Due to there being no standardised implementation programme, and to attempt to further compare papers, studies were not excluded based upon factors such as job role, setting or training programme. This demonstrated the sheer variety of Intensive Interaction programmes and settings where it is used. However, this also meant that papers were heterogenous. This made it difficult to identify and compare experiences across papers while always considering how these factors had an impact. However, the Sri-Amnuay (2012) paper suggested that the cultural salience of hierarchy could contribute to a unique challenge. There appeared to still be similarities captured in the themes within the review. This demonstrates that despite the vast heterogeneity, the experiences of the implementation of Intensive Interaction may be relatively consistent, meaning that the following implications may be applicable to a variety of settings and roles.

Implications for research and practice

This review considered a range of workplaces and staff who were involved in the implementation of Intensive Interaction so provided a broad overview of experiences. This is a starting point for comparison of experiences between settings. Due to

heterogeneity of the papers, as the research area grows it may be beneficial for future reviews to include more homogeneous papers to allow for further comparison. This may allow for better understanding into what specific barriers certain workplaces face, especially as aims of the approach can vary between settings (Firth 2009). This review also concluded that, at times, there were lack of clarity and consistency in what was reported between papers and context bias could have been further accounted for.

The implementation of Intensive Interaction led to staff having greater expectations of the communicative ability of those they worked with and further acknowledging individuality. A significant turning point appeared to be when staff could see the effects that Intensive Interaction had on the individuals they worked with. Training courses/programmes could involve demonstrations of Intensive Interaction being used with the individuals the staff work with or provide direct support for staff while they engage in Intensive Interaction with those individuals. Staff appeared to gain confidence in the approach over time, therefore, it is important that there is time and space for this to happen.

An ongoing, whole-organisational approach could be taken during implementation, involving support from management and colleagues and space to reflect upon experiences and practices. Other job demands are a barrier so it may be beneficial if staff were appointed to specifically be involved in the initiation/maintenance of Intensive Interaction. Training could be adapted to the workplace to consider specific barriers.

Finally, it is important for implementers to consider the potential issue of concern about others' perceptions. A full system approach may reduce the likelihood of this due to less

discrepancies in ways of working. It may be useful to inform and educate those involved who are external to the workplace, such as family, friends or carers. As the review demonstrated that concern of perception could be influenced by cultural discourses, future research could specifically investigate the boarder influences and reasons of concern of outsider perceptions, such as media, culture or faith.

Conclusions

Overall, there were relatively consist experiences of Intensive Interaction implementation across a variety of settings. The implementation of Intensive Interaction has been found to be experienced as a positive transformation for many staff. Implementation can involve challenges, and these may be dealt with by taking a consistent approach throughout and by ensuring that the staff receive ongoing support. It would be beneficial if future research consistently gives greater detail of methodology and context bias and if barriers related to specific settings were further considered. Further research could also consider the connection between Intensive Interaction and cultural discourses.

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PART TWO

Mothers' experience of Intensive Interaction

Authors: Samantha Berridge* & Dr Nick Hutchinson

University of Hull

*Corresponding author: Samantha Berridge

Please send correspondence to:

Samantha Berridge, Department of Psychological Health, Wellbeing and Social Work, University of Hull, Cottingham Road, Hull, HU6 7RX

Email address: samantha.berridge@nhs.net

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Abstract

Background: There is limited research into parents' experience of Intensive Interaction. Despite this, there are parents who use it and may hold unique experiences. Exploring this may provide insight into how to support parents with Intensive Interaction.

Method: Six mothers with children with learning disabilities and/or autism who used Intensive Interaction with them were interviewed. Results were analysed using interpretative phenomenological analysis.

Results: The analysis yielded ten subordinate themes which were organised into four superordinate themes: 'The Connection,' 'Bittersweet,' 'Fighting for Support' and 'Challenging Underlying Low Expectations & Stigma.'

Conclusions: Intensive Interaction was found to help some mothers feel connected with their child. It was also perceived to challenge external assumptions and stigma. It is important that it is accessible to parents. It may be beneficial for those who support and provide services for children with social and communicative needs to be aware of, or trained in, Intensive Interaction.

Keywords: Intensive Interaction, learning disability, autism

Introduction

Individuals with a diagnosis of a learning disability and/or autism can often face communication and inclusion barriers (Health Service Executive, 2011; Taggart, 2011). Intensive Interaction is a social communication approach which may help to overcome these issues (Nind & Hewett, 2005). A key aspect is that it is led by the person with the communication needs (Leaning & Watson, 2006). Techniques often involve mirroring body language, responding to behaviours 'as if they have significance,' and joint activities (Nind, 1996).

Intensive Interaction is derived from the Augmented Mothering theory (Ephraim, 1982). This theory suggests that an individual who is preverbal, due to learning disabilities and/or autism, could benefit from the social communication style that takes place between an infant and caregiver, usually described as the mother. It links to Attachment Theory (Bowlby, 1969), which suggests that the infant operates from a secure base. The secure base is created by the mother attending to the child's communication in a synchronous fashion and letting them take the lead, for example, by imitating the infant's vocalisations (Pawlby, 1977). A less synchronous interaction may be if the mother persists with an interaction while the infant wishes to divert their attention away (Brazelton, Kowslowski & Main, 1974). Ephraim (1982) described how successful communication can increase the field of security and that unsuccessful attempts may recede the boundaries of security. The Augmented Mothering theory was designed to increase the success of interaction for those with learning disabilities and/or autism.

Much of the research about Intensive Interaction has explored the experiences of staff who are in healthcare and educational settings (Clegg *et al.*, 2018; Jones & Howley, 2010; Nagra *et al.*, 2017; Rayner *et al.*, 2016). These studies suggest that staff experienced improvements in their own ability to build better relationships with the individuals they worked with. However, this research also highlights barriers, such as finding the time for meaningful interaction in busy working environments (Clegg *et al.*, 2018).

There has been minimal research in relation to parental experience of involvement in Intensive Interaction. In the study of Sri-Amnuay (2012), the potential benefits of introducing Intensive Interaction training for parents were considered. For example, it may have allowed collaboration between parents and teachers at the school whereby Intensive Interaction was implemented. For many people with communication needs, their parents may be their largest support system so would play an important role in their social and communicative development. Lack of research regarding their unique experiences may deny this group acknowledgment or support in being involved with Intensive Interaction. Therefore, this research was designed to explore their lived experiences of Intensive Interaction.

Method

Design

The research employed a qualitative design to capture the experience of participants. Data were gathered via semi-structured interviews. The interview schedule can be viewed in Appendix G; this included open questions to allow exploration but also discussion around more structured points to allow for consistency (Smith, Flowers & Larkin, 2009). Care was taken to avoid closed questions to ensure that questions did not

jeopardise meaning and sense making of the participants' experiences (Smith *et al.,* 2009).

Participants

A purposive sampling strategy was adopted to recruit a homogenous participant group as this can assist with accessing particular experiences (Smith *et al.,* 2009). Participants were included if they had a child with a diagnosis of learning disability and/or autism and their child must have received Intensive Interaction. They must have parental responsibility of their child, as defined by the Children Act (1989), to increase the likeliness that they would have a consistent and long-term relationship with their child. They must have learned about Intensive Interaction, such as via a training or from a healthcare professional and they must have been able to consent to take part in the study. They could also have taken part if they had only observed others using it with their child after they had learned about it. Participants would be excluded if they had not learned about Intensive Interaction, if their child did not have a diagnosis of a learning disability and/or autism or their child had not received Intensive Interaction. The length of time participants had used Intensive Interaction was not within the exclusion criteria, as research has shown that effects can occur within minutes (Zeedyk, Caldwell & Davies, 2009). Six participants took part in the study; see table 1 for their characteristics. Despite that it was intended to recruit parents of any gender, only female participants were recruited who identified themselves as their child's mother, therefore, this study explored specifically mothers' experiences.

Table 1. Participant characteristics.

Participant pseudonym	**Age of their**	**Gender of their**	**How they first learned**	**How long they had used Intensive**

	child/children (years)	**child/children**	**about Intensive Interaction**	**Interaction with their child/children after learning about it.**
Lynn	7 & 10	Males	Formal training	1 year with younger child & 5 years with older child
Sophie	4	Female	Supported by portage, later had formal training	2-3 years
Rebecca	5	Male	Supported by portage, later had formal training	5 months
Heather	11	Male	Self-taught by reading, later had formal training	7 years
Amanda	6 & 14	Males	Formal training	11 years with older child, used it for all younger child's life
Rachel	11	Female	Formal training	11 months

Procedure

Please see specific details of information for participants and recruitment advertisement in Appendices H & I. Staff in special educational needs schools, where Intensive Interaction was used, were asked to circulate the recruitment information to parents. Three participants were recruited via this method. Three participants were recruited via a local Intensive Interaction workshop for parents, which was run by a Speech and Language Therapist. The researcher allowed time for parents to practise what they had learned if it was the first time they had learned about Intensive Interaction. The researcher attempted to recruit via a social media group for parents who used or were interested in Intensive Interaction. However, no participants were successfully recruited via this method.

All participants signed a consent form (see Appendix J) before interviews commenced. Interviews were one-to-one and were between 45 minutes - 1.5 hours. The interviews took place in the homes of the participants (n=5) and at a University site (n=1). Following the interviews, participants were given a copy of their signed consent form and information about further sources of support (see Appendix K). Interviews were audio recorded onto an encrypted laptop and transcribed for data analysis.

Ethical considerations

This research was approved by the University of Hull Research Ethics Committee (Appendix L). Identifiable information was kept in the supervising researcher's locked cabinet at the university. Recorded interviews were destroyed after transcription. Participants were reminded that they could withdraw from taking part at any point up until data analysis and were given a time period of when this would be. The primary

researcher met with an expert by experience (a mother who used Intensive Interaction who was not recruited) who helped to develop the interview schedule and information sheets.

Data analysis

Appendix M shows the epistemological position of the researcher. Data were analysed using Interpretative Phenomenological Analyses (IPA) based on the guidelines of Smith *et al.* (2009). This method was chosen to allow insight into the participants' experiences and the double hermeneutic process meant the researcher could interpret and present the complexity of experiences. Data analysis ran alongside data collection. Transcripts were read and re-read line by line and were developed into codes. The codes developed into more abstract themes but stayed grounded to the accounts of participants by the re-reading of transcripts. Please see appendix N for a worked example of this process. The secondary researcher assisted with and checked the development of this process.

Reflexive statement

Due to the interpretative nature of the analysis, the researcher's preconceptions are worked with rather than eradicated (Schleiermacher, 1998). Therefore, researchers need to be aware of the personal, social and cultural contexts in which they live and work and to understand how these impact on the ways they interpret their world (Etherington, 2004). The researcher had the personal experience of having a sibling who appeared to thrive from Intensive Interaction. This experience shaped the researcher's preconceptions as the views of the researcher were that family/systemic role was crucial for the person's inclusion, communication and wellbeing, which is reflected throughout the paper. The researcher developed awareness of their own preconceptions throughout the research process by keeping a reflective diary (please see appendix O for a reflective

statement that resulted from this). Measures were taken to ensure rigour in analysis and credibility of findings, such as discussing transcripts and corresponding themes at different stages in supervision and at qualitative research groups.

Results

The analysis yielded three superordinate themes, which consisted of ten subordinate themes that conceptualise mothers' experience of Intensive Interaction. See table 2 for an overview of the themes and the participants included in them.

Table 2. Overview of themes and participants included within the themes.

Superordinate themes	**Subordinate themes**	**Participants included**
The connection	Already having a connection: it's what we've always done	Rebecca Rachel
	Finally feeling connected	Lynn Sophie Heather Amanda
Bittersweet	Looking back	Rachel Lynn Sophie Heather Amanda
	It works like any loving relationship	All participants
Fighting for support	Getting support in the first	All participants

	place: taking it into your own hands	
	Maintaining a dialogue with school	All participants
	Pressures of parenting a disabled child: why we cannot always take it into our own hands	Lynn Sophie Heather Amanda Rachel
	What was, or could have been, a missed opportunity	Sophie Rebecca Heather
Challenging underlying low expectations & stigma	'Setting up to fail'	Sophie Amanda Rachel
	Proving everybody wrong	Sophie Rebecca Heather Amanda Rachel

The connection

This relates to the mother-child relationship and how this was impacted by Intensive Interaction. Mothers differed regarding how Intensive Interaction affected the connection and closeness felt with their child. On one end of the continuum it seemed that Intensive Interaction itself did not have a large impact as it was felt that the

connection and reciprocity was present in the relationship. On the other end, Intensive Interaction had a powerful impact and seemed to bring a feeling of connectedness with their child and lessen a feeling of psychological distance.

Already having the connection: it's what we've always done

Despite learning about Intensive Interaction, Rachel described that Intensive Interaction seemed to be already naturally part of her relationship with her daughter: *'When I learnt about it, I kind of thought… it seemed fairly… obvious… we're just naturally doing that because that is our way of communicating.'* The techniques of Intensive Interaction were already often used: *'...we've always, done a lot of turn taking and waiting for her to respond ...we've always been, you know, very close up.'*

Rebecca suggested that they were not seeking to change their child and were accepting of them*: 'We've got the mother-son bond, and you know so it's you know it, unconditional love anyway… I'd be proud of him no matter what.'*

Rachel experienced that her child characteristically reciprocated love*: 'she is very responsive and very, you know she loves us and she loves people and you get a lot from her.'*

Finally feeling connected

In contrast to the previous subtheme, Heather was actively seeking to develop her relationship with her son: *'I was hoping that it would be a way to build up a relationship with him cos we didn't have that, none of us had that.'*

Learning about Intensive Interaction and using it had a more profound impact and was described as a way to connect with her child who appeared to be unreachable: *'we had to get him... we couldn't, we couldn't reach him.'*

Lynn and Sophie used language which suggested that there was a barrier in between them, and their children and that Intensive Interaction was a way to get past this:

'a way in, we can see little chinks in his armour' (Lynn).

'she's just in this massive bubble, and couldn't see what was going on… but there was, just that glimpse of her' (Sophie).

Sophie and Amanda used metaphors relating to their child being on a different planet demonstrating the extent of the distance and disconnection they previously felt and how Intensive Interaction helped:

'I think.. that that Intensive Interaction, brought her, into the world' (Sophie).

'just give us that time to be sort of… bit on the same planet for a little while… it's the only time where you feel that you've actually made that like connection' (Amanda).

The impact of the first point of connection that Sophie could recall was powerful, *'she did a glance over it was the first time she… she'd looked at me since eleven months of age.'* Sophie, Rachel and Heather also noted the greater *'eye contact'* their child gave them.

A sense of panic seemed apparent in Sophie due to the need to keep the connection, *'for that split sort of moment she's in your world and I sort of panicked, thinking, don't go don't go as in don't leave, you know, come and stay with me.'*

Bittersweet

The experience of Intensive Interaction itself was described positively and connotations of love were used to attempt to describe the lived experience. Yet there was a noticeable sadness alongside this when mothers thought about what their relationship with their child, and what their child's experiences, could have been like prior to the introduction of Intensive Interaction in the relationship. The latter was apparent in mothers who felt

that Intensive Interaction brought a feeling of connection as opposed to it already feeling present.

Looking back

The introduction of Intensive Interaction appeared to bring up difficult feelings when looking retrospectively. While Rachel had described that she had already felt connected to her child, she imagined that her child's reciprocity was influential over her perception of her competence as a parent: *'if she, didn't respond as much… I think as a parent you would feel… like you, like you were doing it wrong.'*

Sophie appeared to embody the imagination of Rachel, as her perception of her competence as a mother seemed influenced by lack of responsiveness.

'she just wasn't responding at all so I did feel like a bit of a failure as a mother, cos I couldn't respond to my own child' (Sophie).

Sophie noted that Intensive Interaction had somewhat reversed this:

'by doing that Intensive Interaction for me, personally… I felt.. better as a parent, I felt more equipped to be able to look after her.'

A reversal effect was mirrored by Lynn, who reflected on the time just after she had adopted one of her sons:

'he'd just been quite badly neglected. And, just used to babble… what he'd heard, as a way of regulating himself really. And we were able to turn that around.'

Heather appeared to realise during Intensive Interaction training what she had missed in terms of her child's development: *'realising that I'd missed out on a lot of.. pointers.'* She empathised with her child by imagining how life could have been without Intensive Interaction: *'he'd still be… locked in his own world.'* The term, *'locked'* suggests that this would be the case even against his will and that it was her responsibility to 'unlock.'

Amanda reflected on how her son felt prior to Intensive Interaction: *'he was just really erm… grumpy and sad, probably bored, you know, not, not motivated, you know he'll have been a little boy trying…'* She suggested that this was despite him trying, which suggests that she may have felt responsible to change this.

It works like any loving relationship

Participants talked about Intensive Interaction in ways that could be used to describe any loving relationship. An array of positive adjectives, many which had connotations of love, were used. Lynn emphasised the *'warmth'* involved in the experience. Both Sophie and Rebecca described it as *'lovely'* and Rebecca emphasised the *'affection*' which accompanied the experience. Amanda described how she would *'catch him glancing at me,'* something which may take place in a loving relationship.

Lynn found excitement from the experience, describing it as *'absolutely thrilling'* and *'hysterical and beautiful at the same time.'* She commented, *'It's sort of magic isn't it?'* This suggests that she found it to be subjective and mysterious regarding how it works.

Like any loving relationship, Rachel described Intensive Interaction as *'in essence… it's kind of natural,'* which could indicate that she found it was already part of their relationship. Heather found that it introduced a *'bit of normality.'*

For Rebecca it seemed to develop into a way of being and had a sense of ease, *'you do it without, even realising you're doing it, most of the time… it's just au, automatic.'* Amanda reiterated this: *'it is so simple but yet you don't think about it.'*

However, like any loving relationship, Lynn described that *'you really have to work at it'* as it needed to be *'On their terms. Totally on their terms…if you don't have the child with you, it… not necessarily meaningful.'*

Fighting for support

Finding information and support for Intensive Interaction was often a challenge. This appeared to be a parallel process in that it was not the ideal two-way interaction, like with Intensive Interaction. At times this extended beyond Intensive Interaction, as mothers described difficulty when gaining support generally for their child. Mothers sometimes found it challenging to gain support in relation to connecting with their child and when specifically accessing information and support with Intensive Interaction. It was suggested that mothers had to be proactive when finding information and getting support as it was not readily available. Delay in support seemed to result in difficult consequences.

Getting support in the first place: taking it into your own hands

Rachel appeared to describe an unsupportive climate: *'I feel as a parent, you don't get really supported with anything (laughs).. to be perfectly honest. Whatever you want to do in terms of, learning anything, you have to find out for yourself. Nobody offers, you know, there's not much on offer in terms of, not for a child with profound disabilities anyway.'* Rachel explains that *'you have to find out yourself,'* suggesting that she felt that there was no other option as this was factual. Amanda appears to suggest that the lack of support is a result of her son's disability as it is disinteresting or off-putting in some way to others: *'We don't get any support with (older son) really with his communication whatsoever, with any of that side of things… he's got PMLD (profound and multiple learning disabilities).. people don't want to know.'*

The fight for support often started early, prior to introduction to Intensive Interaction, as the introduction came after the need for it was identified. Sophie described an unsupportive encounter with a health visitor after acknowledging she needed help to communicate with her child: *'well she ignored me to begin with then she called me an*

era, an erratic parent and said.... take my nursing hat off and put the mum hat on… I said, I, I am which is why I'm emotionally involved, and I'm saying please do something… that's what I did, in the early, years assessment I put… please help me, to play with my child.' This demonstrated desperation and willingness to depend on advice and support. She perceived the response as suggestive that they were over-reactive. However, Sophie appeared to persist through this. When Rebecca expressed concerns to a health visitor, who passed this to a Speech and Language Therapist, she also had a response which suggested that she was over-reacting. She still persisted which enabled support: *'I think we've pushed an awful lot for it… the Speech and Language Therapist said… he's too young… to see if there's anything, erm developmentally delayed with him… come back when he's five. My husband was like, oh right ok that's fine we'll we'll come back when he's five, and I said to, I said, we are not coming back when he's five!'* Rebecca used the term *'pushed'* suggesting an element of force was needed and the contrast of her husband's response indicates how support could have been delayed if they were less forceful.

Lynn commented that support was determined by funding and political decisions: *'social service's support is negligible… health support is, is.. you know is.. it's a real challenge now to get the right health support… It's political, it's all to do with funding, because it, just not enough.'*

Lack of support seemed to transfer to Intensive Interaction as Heather emphasised the sparsity of information about Intensive Interaction: *'there wasn't a lot on the internet at the time… there wasn't a lot…'* Rachel had experienced the inaccessibility of information and training: *'it's not as accessible as you would hope, to be able to, find out about it.'* Amanda described training courses as being infrequent with no opportunity for a review of their progress: *'I've had nobody suggest it to me with*

(younger son), you know I've had.. nobody mention it since I've been on the training really.' The regular use of the words, *'no-one'* and *'nobody'* may suggest that participants feel alone in the process.

Heather and Sophie used their educational and work resources independently to gain information:

'I had to look myself… it's a good job that I was starting my masters, and so I had access to the university library and that's where I found out (about Intensive Interaction)' (Heather).

'I just google searched, did all the research papers and if I couldn't get one then I got one of the consultants to get it' (Sophie).

Maintaining a dialogue with school

School was often another setting whereby Intensive Interaction was used and could provide information and support. Dialogue between mothers and school staff was a salient factor. Rebecca had a positive experience: *'the beauty of.. having (son) in a specialist school is you get invited to a lot more training, and, and also you get a lot more support… communication is a lot better than than erm we could have ever have imagined.'* This appeared to contrast the encounter they had when trying to gain initial support, hence why it may have been better than imagined. Amanda also had a positive experience with the school her younger son attended: *'they're really good with him he uses, erm they use Intensive Interaction and they do get a lot of support.'*

Lynn emphasised the need to be proactive to ensure to maintain dialogue and the consistency of Intensive Interaction: *'there's got to be a partnership parents and the child, er the child's school really. Because if you don't have that it becomes like two*

separate places…. parents are part of that team, you know.' Amanda described having to take a more forceful approach in the school her older son attended, similarly to the previous subtheme, to maintain an adequate environment for Intensive Interaction: *'a lot of pushing the head mistress, erm, let me move him... so now he's with other pupils who interact with him, and he can interact with them.'*

Other participants did not have a sense of strong dialogue with school, meaning that they were uncertain as to how and whether Intensive Interaction was used:

'I don't know what they do at school...' (Sophie).

'I don't get a breakdown of what he's doing in those sessions, from school, I just know what he can do with me at home.' (Heather).

'I don't know if, I think they kind of do it (Intensive Interaction)… I don't know, I'm not entirely sure.' (Rachel).

A lack of awareness of school involvement may be related to participants not viewing this as important. However, Rachel expressed that is may be important to ensure consistent knowledge of progress: *'it would be nice if there was more communication about what school, actually does. Erm, especially with Intensive Interaction because then you're all on the same page.'* Sophie suggested it would be important, as her child *'benefits'* from Intensive Interaction. Possible reasons for lack of dialogue were as follows:

'I think that's cos they don't have time' (Amanda).

'I think as children get older in a special school… there's a tendency among the staff to think that actually that's the sort of things for little ones' (Lynn).

'because they've got her attention now' (Sophie).

Pressures of parenting a disabled child: why we cannot always take it into own hands

Barriers were identified that could compromise capability of taking independent action when accessing support or information, despite this being apparently essential. Lynn and Heather appear to transition to their role as a teacher when considering that parents may not seek support and dialogue with school due to daily struggles and lack of support. There is suggestion that when this is the case, greater support is needed:

'Some (parents) that want to do everything they can for their child and some that just want to get them off to school to give them a break... it's reaching the ones that just want to get rid of them because, they're the ones that struggle with them at home and they're the ones that really need to use these types of strategies' (Heather).

'child goes off to school and probably the last thing that parents want to do is go to school after them and be trained in something. Because actually, just coping with the day to day life is enough… lack of support in other areas of their life' (Lynn).

Other mothers within the study appear have experienced some challenges, particularly those exemplified by Lynn:

*'I had two really young children and I was a single mother… I got a really small package of care.. horrendous hospital appointments physio to do, other speech and language that was expected, portage... but then I still have three children to then find individual time with them, and it's, you know difficult…' (Amanda).*This difficulty appears to be ongoing, as her language changes from past to present tense. Rachel describes similar issues and uses the words *'draining'* and *'tiring'* when describing the physical care, which compromised their ability to invest in Intensive Interaction.

Sophie recalled experiencing doubt when initially hearing about Intensive Interaction:

'I was doubtful it was gonna work, not much had worked, we were going through the diagnosis of autism at the time so we were sort of on a low anyway with what to expect... coming to terms with a child.. that was, erm, gonna have some disabilities, and y, you know you feel lost and, you feel guilty.' The language used in this account suggests an element of grief during the identification of disability and diagnosis process. This led to them feeling *'lost'* and *'guilty,'* suggesting confusion and self-blame which may contribute to the participant feeling challenged to seek support externally, especially as they are internally focused on their difficult state of well-being.

What was, or could have been, a missed opportunity

There appeared to be an actual or potential, impact of less than helpful or delayed support and information about Intensive Interaction and that this contributed to opportunities being missed: *'there's big, big gaps where I could have been doing something' (Sophie).* The use of first person suggested that this may transfer to self-blame when looking retrospectively and the word *'big'* is repeated for emphasis suggesting the perceive enormity of this.

Heather emphasised the importance of early intervention: *'if you get told as a parent that, to have a look at Intensive Interaction and what it can do, I think… the earlier that you can do that the more sane you'll stay.'* Use of the word *'sane'* suggests that time taken to find out about Intensive Interaction may affect mental health somewhat. Rebecca had a contradictory experience, as she felt well supported quickly but she suggested that her mental wellbeing may have suffered if they had waited as recommended: *'everyone within six months was all coordinating to help (son). I think if we'd have gone with the first… recommendation… I think we would have been pulling*

our hair out and I don't think we would know what to do. The early intervention, like I say, it's worked significantly.'

Challenging underlying low expectations and stigma

Mothers experienced others having low expectations of their child which often extended beyond Intensive Interaction. They perceived that the effects of this contributed towards a self-fulfilling prophecy. There was a sense that Intensive Interaction proved those with low expectations wrong and that it showed that there was more to their child by demonstrating qualities and human desires they held.

'Setting them up to fail'

Sophie explained how her child was not expected to progress with her communication. This may have been somewhat responsible for the doubt which Sophie discussed previously: *'I got told she'd never do PECS (Picture Exchange Communication) until she'd learned sign language and she probably wouldn't be doing sign language, and.. it was all negative.'* Rachel emphasised how a staff member at school had seemed to not make effort to get to know her child: *'it kept saying in her book, oh, oh (daughter) was not very cooperative today or, I thought, yeah cos she doesn't know you! She doesn't know who you are. And I thought well that just shows how much you don't know her.'* It appeared that the opportunity for assumptions of the staff member to be proven otherwise were diminished as they had not taken time to understand her child, so the child seemed unresponsive, demonstrating a detrimental cycle of self-fulfilling prophecy.

Amanda seemed to talk about a self-fulfilling prophecy which resulted from low expectations: *'their expectations of (older son) were so low… they never put that sort of input in to him because they didn't expect him to do anything so… they didn't give him*

that opportunity to progress… he was just expected to lay on a beanbag… and just be fed and watered, his nappy changed and that was it… if you look at somebody and only expect a certain thing from them then, actually you're setting them up to fail.' This also transferred to Intensive Interaction: *'they don't think he's capable of engaging in Intensive Interaction.'*

Amanda also discusses how during the introduction to Intensive Interaction she may have succumbed to having low expectations of their child's capabilities: *'...people had sort of dismissed and tried to make me dismiss which, I wasn't very dismissive of but, maybe I must have been to a certain degree cos I was quite shocked how it worked.'* It appears that she developed an awareness of her own expectations when reflecting retrospectively after using Intensive Interaction.

Amanda described that low expectations and stigma were a *'mind-set,'* suggesting that they are established. This is likened to *'racism'* which may suggest that they may be ideological: *'it's like disabilities some people get it some people don't... It's the mind-set… it's almost a bit like racism's a mind-set.'*

Proving everybody wrong

Despite low expectations and stigma, participants expressed that use of Intensive Interaction had contradicted these. There appeared to be a sense of 'us against them,' as indicated by the word *'they,'* which conflicted *'we'* and *'us:'*

'She's on stage four of PECS now and they told us she would wouldn't get.. up, the stages.' Sophie explained how Intensive Interaction had made her child more aware of others and so was more easily able to learn new things, such as how to use picture exchange communication.

Rachel demonstrated the contradiction between her perceived reality of her child and how perception of her child could be shaped by assumptions, which she emphasises by listing her disabilities: *'if you said on paper.. well she can't really see very well, she can't hear, she can't walk, she can't talk, she doesn't really eat much bla bla.. it sounds like she's just sat in a corner (laughs) you know what I mean? But actually she is very responsive and very, you know she loves us and she loves people and you get a lot from her.'*

Amanda describes how Intensive Interaction has proven wrong misconceptions, which she felt had empowered her son: *'Intensive Interaction, that showed them that he could progress… it's give him that opportunity to show that actually, he understand what's being said to him, so then that's given him a voice.'* Amanda also felt that she had proved others wrong and was given confidence regarding her opinions: *'I felt like I'd proved everybody… wrong, I always said that he had more about him than what everybody was telling me… there was somebody in there that, you know he wasn't… just a little boy who couldn't, I don't know… was just profoundly disabled and his brain didn't work and you know wasn't, you know, he was just going to lay there looking at starry lights like his diagnosis.'*

Heather explained that Intensive Interaction challenged the stigma relating to her child as her experience of Intensive Interaction was normalising: *'if it's a shared experience between the two of us, we don't tend to get that, that response of what's he doing in here, he's a bit strange... they just accept that that's the way we communicate.'* Rebecca narrates the progression of social inclusion and emphasis the need for awareness of Intensive Interaction to further the progression and challenge negative

stigma: *'they used to be institutionalised didn't they (disabled people)... It needs to be out in the public more.. and the awareness more, and, everybody needs to understand that, the the benefits of it (Intensive Interaction) will help these children be part of society.. and not, you know considered weird and disruptive.'* Amanda also expresses the need for inclusion and emphasises that this is important in meeting her son's desires and human rights: *'...it was that, you know.. he deserved to be, part of school life and part of society and that he wanted to be.'*

Discussion

This research investigated mothers' experiences of Intensive Interaction. It was also intended to explore what it was like for mothers when others use Intensive Interaction with their child, however, experiences of themselves using it took the focus. Intensive Interaction appeared to be experienced as natural and normalising. The natural aspect may reflect its implications in the Augmented Mothering theory (Ephraim, 1982) as it is an interaction based on the caregiver-child relationship. The normalising aspect likens to Positive Psychology due to emphasis of positive subjective experience and traits as opposed to a focus on pathology (Seligman & Csikszentmihalyi, 2014).

This study suggests that mothers experienced a two-way aspect to Intensive Interaction as, while they got enjoyment from it, it needed to be on their child's terms. This may explain why it was described in a way that any loving relationship could be as, arguably, a healthy relationship has a two-way process. However, the power imbalance may be greater due to the child having additional needs, which may be why it was explicitly emphasised that a conscious effort was needed for it to be on their child's terms. This is in line with it being an approach that is 'done with' the person (Irvine, Firth & Berry, 2010, p.21), otherwise, the interaction pattern can fall into action-

response, whereby the response is focused upon rather than the communication itself (Barber, 2007).

For some mothers, an effect of Intensive Interaction was a way of feeling connected to their child. Some ways in which this was described, such as increased eye contact and psychological and physical proximity, appeared to relate to bonding necessary for a secure attachment between an infant and caregiver (Perry, 2001). For these mothers, learning about the approach appeared to link to reflecting retrospectively, which could be challenging. This may be due to them feeling responsible for their child' previous responsiveness which, at times, impacted their perception of their competence as a mother. Some mothers seemed to experience a connection prior to the introduction to Intensive Interaction, which was largely related to them perceiving that their child was reciprocatively affectionate, therefore, the approach did not have such an effect.

Intensive Interaction seemed to challenge assumptions and societal stigma. This appeared to be through demonstration of communicative progression, normalisation and that their child held their own hopes and desires. Research involving staff experience had also suggested that Intensive Interaction challenged their assumptions of the individual's communicative ability (Bodicoat, 2013; Clegg *et al.*, 2018; Firth, Elford, Leeming, & Crabbe 2008). This seemed to apply to mothers to some extent, but they usually perceived that Intensive Interaction proved those outside of the mother-child relationship wrong and confirmed their own internal views.

This research showed that there was a need for, but lack of, external support and information about Intensive Interaction. This research supports the view that Intensive Interaction should not be exclusive (Irvine *et al.*, 2010). Prior to knowing about

Intensive Interaction or being at a point where they could access it, mothers described that they required support for their child's additional needs generally or for finding ways to help them to interact. This was often a challenge and mothers described instances where healthcare professionals were unhelpful and could have delayed early intervention. This required mothers to be persistent, proactive and, at times, forceful. This research suggests that when mothers face challenges in other areas of their life, this makes persistence a challenge. This was supported by Catherall and Iphofen (2006), who found that caregivers were left feeling tired and stressed at the amount of energy needed to access support. This finding was concerning, especially in consideration of the subtheme, 'What Was, or Could Have Been, a Missed Opportunity,' as this highlights the consequences of not introducing support or knowledge of Intensive Interaction earlier.

School was the main setting where there were ongoing opportunities to learn about Intensive Interaction and receive support, although this was variable. This study uncovered the importance of mothers having a good dialogue with school in relation to Intensive Interaction. This was supported by teachers' perspectives in the study of Sri-Amnuay (2012, p. 229), as they explained that consistency of the approach between home and school is important.

While low expectations and stigma appeared to be challenged by Intensive Interaction, this also appeared to be a barrier, as it seemed to contribute towards others expecting little of the individual, potentially reducing opportunities for social inclusion and communication. This was suggested in, 'Setting Up to Fail.' Low expectations and stigma reflected the Triad of Impairments (Caldwell & Horwood, 2008), which sums up

negative assumptions of those with autism: a failure to relate, a failure to think flexibly and a failure to understand speech.

Limitations

As participants had different experiences of learning about Intensive Interaction, this may have meant they had varying concepts of what it is. Nonetheless, one of the interview questions was, 'In your own words, how would you describe Intensive Interaction?' These accounts appeared to be in line with the literature, as were the answers throughout, which reflected that participants held a reasonable understanding.

All participants were female; therefore, it is unclear if males, or those with different gender identities, would have different perceptions. Despite that age was not part of the exclusion criteria, only mothers of young children were recruited, therefore, experiences may have resulted from factors relating to a particular cohort. This may have been due to the recruitment process, however, attempts were made to recruit parents of children in adulthood, by recruiting via social media and seeking advice from those who worked in the field. Most of the participants had worked in education or healthcare sectors therefore; this may have affected their experiences and ability to access support. Despite lack of representation due to homogeneity and small sample size, the aim of IPA is to explore in detail the perceptions and understandings of people. (Smith *et al.*, 2009).

Implications and further research

Intensive Interaction was found to be a normalising and positive approach and it seems to have the biggest impact for mothers who find it difficult to connect with their child or do not feel like their relationship with them is reciprocal. The potentially challenging emotional consequences of learning about Intensive Interaction should be considered in

training courses as it can contribute to mothers questioning their competence. As this research only recruited mothers, further research could consider father's experiences of Intensive Interaction.

The study demonstrated that mothers are not always capable of fighting for support and information due to life stressors, therefore, it is important that Intensive Interaction is accessible and there ought to be more learning opportunities. Greater education about Intensive Interaction may be beneficial for those who provide external support and advice to families with children with special educational needs, such as those bodies who 'have regard to' the SEND Code of Practice (Department for Education and Department of Health, 2015). This may be especially important within early years settings and schools, which was found to be a significant provider and informer of Intensive Interaction. This may help to reduce the likelihood in delay of mothers learning about the approach. A good dialogue between home and school is essential. Ideally, this will contribute towards the reduction of burden on mothers when accessing support.

Further understanding of parental experience of collaboration with other contexts in relation to Intensive Interaction may be beneficial, so research may need to consider the experiences of parents with children in adulthood, as they will access different services. It was more challenging to recruit these parents in the study. Besides the limitations of the study, this may be due to barriers specific to this group, such as having less involvement or even less information available. Further research could therefore consider this and recruit parents from broader populations.

This study indicated that underlying attitudes and stigma were salient factors and while mothers perceived that Intensive Interaction challenged these, they also appeared to cause barriers. Further research could explore the impact of low expectations and stigma of people with diagnoses of learning disabilities and/or autism, including ways to address these.

Conclusions

Overall, for some mothers, Intensive Interaction was found to be a way to connect with their child through developing reciprocity, suggesting that it may be a beneficial approach in a relational and emotional sense for mothers and possibly their children. These benefits will be maximised if mothers are supported quickly with their child's needs and provided with opportunities to learn about Intensive Interaction, or its principles. For some mothers, particularly those who already perceived that their child reciprocated affection, learning about Intensive Interaction had less of an impact on their relationship. Despite this, Intensive Interaction was found to challenge negative discourses relating to people with diagnoses of learning disabilities and/or autism.

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Appendices

Appendix A: Author guidelines for contributions to the Journal of Applied Research in Intellectual Disabilities.

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.

All manuscripts must be submitted solely to this journal and not published, in press, or submitted elsewhere.

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.

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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'.

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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 (.rft) 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.

By submitting a manuscript to or reviewing for this publication, your name, email address, and affiliation, and other contact details the publication might require, will be used for the regular operations of the publication, including, when necessary, sharing with the publisher (Wiley) and partners for production and publication. The publication and the publisher recognize the importance of protecting the personal information collected from users in the operation of these services, and have practices in place to ensure that steps are taken to maintain the security, integrity, and privacy of the personal data collected and processed. You can learn more at https://authorservices.wiley.com/statements/data-protection-policy.html.

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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. Words in Tables, Table captions/legends, Figures and Figure captions/legends are excluded in the limit.

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 have a structured abstract (maximum 150 words) as follows: Background, Method, Results, and Conclusions. The abstract should provide an outline of the research questions, the design, essential findings and main conclusions of the study. Authors should make use of headings within the main paper as follows: Introduction, Method, Results and Discussion. Subheadings can be used as appropriate. All authors must clearly state their research questions, aims or hypotheses clearly at the end of the Introduction. Figures and Tables 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

APA - American Psychological Association

References should be prepared according to the Publication Manual of the American Psychological Association (6th edition). This means in text citations should follow the author-date method whereby the author's last name and the year of publication for the source should appear in the text, for example, (Jones, 1998). The complete reference list should appear alphabetically by name at the end of the paper.

A sample of the most common entries in reference lists appears below. Please note that a DOI should be provided for all references where available. For more information about APA referencing style, please refer to the APA FAQ. Please note that for journal articles, issue numbers are not included unless each issue in the volume begins with page one.

Journal article

Example of reference with 2 to 7 authors

Beers, S. R. , & De Bellis, M. D. (2002). Neuropsychological function in children with maltreatment-related posttraumatic stress disorder. The American Journal of Psychiatry, 159, 483–486. doi:10.1176/appi.ajp.159.3.483

Ramus, F., Rosen, S., Dakin, S. C., Day, B. L., Castellote, J. M., White, S., & Frith, U. (2003). Theories of developmental dyslexia: Insights from a multiple case study of dyslexic adults. *Brain, 126*(4), 841-865. doi: 10.1093/brain/awg076

Example of reference with more than 7 authors

Rutter, M., Caspi, A., Fergusson, D., Horwood, L. J., Goodman, R., Maughan, B., ... Carroll, J. (2004). Sec differences in developmental reading disability: New findings from 4 epidomiological studies. *Journal of the American Medical Association, 291*(16), 2007-2012. doi 10.1001/jama.291.16.2007

Book Edition
Bradley-Johnson, S. (1994). Psychoeducational assessment of students who are visually impaired or blind: Infancy through high school (2nd ed.). Austin, TX: Pro-ed.

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.

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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.

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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.

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Appendix B: The National Institute for Health and Care Excellence Checklist for Qualitative Studies

Study identification Include author, title, reference, year of publication	
Guidance topic:	**Key research question/aim:** .
Checklist completed by:	

	Circle or highlight 1 option for each question	
Section 1: theoretical approach		
1.1 **Is a qualitative approach appropriate?** *For example:* Does the research question seek to understand processes or structures, or illuminate subjective experiences or meanings (in social care this would apply to how care and support is organised and service user or carer experience)? Or could a quantitative approach better have addressed the research question?	Appropriate Inappropriate Not sure	Comments:

1.2 **Is the study clear in what it seeks to do?** *For example:* Is the purpose of the study discussed – aims/objectives/research question(s)? Are the values/assumptions/theory underpinning the purpose of the study discussed?	Clear Unclear Mixed	Comments:
Section 2: study design		
2.1 **How defensible/rigorous is the research design/methodology?** *For example:* Are there clear accounts of the rationale/justification for the sampling, data collection and data analysis techniques used?	Defensible Not defensible Not sure	Comments:
Section 3: data collection		
3.1 **How well was the data collection carried out?** *For example:* Are the data collection methods clearly described? Were the data collected appropriate to address the research question?	Appropriate Inappropriate Not sure/ inadequately reported	Comments:
Section 4: validity		

4.1 **Is the context clearly described?** *For example:* Are the characteristics of the participants and settings clearly defined? Were observations made in a variety of circumstances and from a range of respondents? Was context bias considered (that is, did the authors consider the influence of the setting where the study took place)?	Clear Unclear Not sure	Comments:
4.2 **Were the methods reliable?** *For example:* Were data collected by more than 1 method? Were other studies considered with discussion about similar/different results?	Reliable Unreliable Not sure	Comments:
Section 5: analysis		
5.1 **Are the data 'rich'?** *For example:* How well are the contexts of the data described? Has the diversity of perspective and content been explored? Has the detail of the data that were collected been demonstrated? Are responses compared and contrasted across groups/sites?	Rich Poor Not sure/not reported	Comments:

5.2 **Is the analysis reliable?** *For example:* Did more than 1 researcher theme and code transcripts/data? If so, how were differences resolved? Were negative/discrepant results addressed or ignored? Is it clear how the themes and concepts were derived from the data?	Reliable Unreliable Not sure/not reported	Comments:
5.3 **Are the findings convincing?** *For example:* Are the findings clearly presented? Are the findings internally coherent (that is, are the results credible in relation to the study question)? Are extracts from the original data included (for example, direct quotes from participants)? Are the data appropriately referenced so that the sources of the extracts can be identified? Is the reporting clear and coherent?	Convincing Not convincing Not sure	Comments:

5.4 **Are the conclusions adequate?** *For example:* How clear are the links between data, interpretation and conclusions? Are the conclusions plausible and coherent? Have alternative explanations been explored and discounted? Are the implications of the research clearly defined? Is there adequate discussion of any limitations encountered?	Adequate Inadequate Not sure	Comments:
Section 6: ethics		
6.1 **Was the study approved by an ethics committee?**	Yes No Not sure/not reported/not applicable	Comments:
6.2 **Is the role of the researcher clearly described?** *For example:* Has the relationship between the researcher and the participants been adequately described? Is how the research was explained and presented to the participants described?	Clear Not clear Not sure/not reported	Comments:
Section 7: Overall assessment		

As far as can be ascertained from the paper, how well was the study conducted (see guidance notes)	++ + –	Comments

Appendix C: Data extraction form.

Authors, date and location of study	
Study population (age, gender, job role and characteristics of work setting)	
Study aims	
Intensive Interaction programme details	
Study design, data collection and analysis	
Examples of relevant findings in the results section	

Appendix D: Papers rejected after the whole paper was read.

Alloway, M. P. (2004). *A qualitative survey into the introduction of intensive interaction techniques by ten teachers in special needs schools.* University of Birmingham, United Kingdom.

Cameron, L., & Bell, D. (2001). Enhanced interaction training: a method of multi-disciplinary staff training in intensive interaction to reduce challenging behaviour in adults who have learning disabilities and who also have a severe communication disorder. *Working with People Who Have a Learning Disability 18*(3), 8-15.

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.

Donnelly, C. M., Elsworth, J., & McKim, J. (2015). An audit of an Intensive Interaction service. *Tizard Learning Disability Review*, *20*(3), 111-116.

Firth, G., Poyser, C., & Guthrie, N. (2013). Training care staff in Intensive Interactions. *Learning Disability Practice*, *16* (10).

Forster, S., & Taylor, M. (2006). Using Intensive Interaction - A case study. *Acquiring Knowledge in Speech, Language & Hearing*, *8*(1), 12-15.

Harding, C., & Berry, R. (2009). Intensive interaction as a psychological therapy. *The Psychologist, 22*(9), 758-759.

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.

Lloyd, E. M. (2015). Intensive Interaction in the mainstream classroom: evaluating staff attitudes towards an inclusive socio-communicative intervention. *Good Autism Practice*, *16*(2), 49-68.

McKim, J. (2013). Developing the use of intensive interaction in the Oxfordshire Learning Disability NHS Trust (Ridgeway Partnership). *Clinical Psychology & People with Learning Disabilities, 11*, 12-18.

Nind, M. (1999). Intensive Interaction and autism: a useful approach?. *British Journal of Special Education*, *26*(2), 96-102.

Walter, C. (2008). Intensive Interaction with Autistic Children. *Relational Child & Youth Care Practice*, *21*(2), 60-70.

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), 310-25.

Appendix E: Methodological quality assessment

Study	Theoretical approach	Study design	Data collection	Validity and reliability	Analysis	Ethics	Overall assessment
Bodicoat (2013)	A qualitative approach was appropriate, and the study was clear in what it sought to do.	Clear rationale for the design and defensible.	Data collected was appropriate to address the research question and data collection methods were clearly described.	Context clearly described and context bias accounted for. Methods were judged to be reliable.	Findings were clearly organised, and contradictions were accounted for. Measures taken to ensure reliability. The context of the data is considered. Conclusions from findings were adequate.	Ethical approval stated. Reflexivity thoroughly considered: statement of position section and reflective statement included.	++
Clegg, Black, Smith and Brumfitt (2018)	A qualitative approach was appropriate, and the study was clear in what it sought to do.	Clear rationale for the design and defensible.	Clearly described and appropriate, interview lengths were somewhat short. This may have been due to the larger sample size.	Context is clearly described, and context bias accounted for. Methods judged to be reliable.	Analysis deemed reliable. Richness may have been compromised due to interview length but may not be the case as findings and conclusions	Ethical approval stated. There was inadequate reflexivity in the paper.	+

					were judged to be adequate.		
Firth, Elford, Leeming and Crabbe (2008)	A qualitative approach was appropriate, and the study was clear in what it sought to do.	Clear rationale for the design and defensible.	Data collected was appropriate to address the research question and data collection methods were clearly described.	Context described but participant bias could have been further accounted for. Methods judged to be reliable.	Measures to ensure reliability were taken. Findings were convincing, well organised and conclusions were adequate.	A statement of ethical approval was not included; however, the authors' ethical considerations of the study were. Reflexivity was inadequate.	++
Jones and Howley (2010)	A qualitative approach was appropriate, and the study was clear in what it sought to do.	Defensible but the design could have been presented more clearly.	Rationale for mixed methods of data collection included. The numbers of participants were not clearly presented.	Context clearly described, although context bias was not well accounted for. Methods deemed reliable.	Measures were taken to ensure reliability. Findings were convincing and conclusions were adequate. The research approach was described but further justification of the method of analysis could have been provided.	Ethical statement not included. Lack of clear ethical consideration and reflexivity.	+

Leaning (2006)	A qualitative approach was appropriate, and the study was clear in what it sought to do.	Clear rationale for the design and defensible.	Data collected was appropriate to address the research question and data collection methods were clearly described.	Context is clearly described, and context bias accounted for. Methods judged to be reliable.	Findings were clearly organised, and contradictions were accounted for. Measures taken to ensure reliability. The context of the data is considered. Conclusions from findings were adequate.	A statement of ethical approval was included. Authors' ethical considerations of the study were included. A section of the researcher's perspective was included. A reflective statement was included.	++
Nagra White, Appiah and Rayner (2017)	A qualitative approach was appropriate, and the study was clear in what it sought to do.	Clear rationale for the design and defensible.	Data collected was appropriate to address the research question and data collection methods were clearly described.	Methods judged to be reliable. Context is clearly described, and context bias accounted for.	Findings were clearly organised, and contradictions were accounted for. Measures taken to ensure reliability. The context of the data is considered. Conclusions from findings were adequate.	Statement of ethical approval not included. Information provided on basic ethical procedures. Lack of reflexivity.	++

Rayner, Bradley, Johnson, Mrozik, Appiah and Nagra (2016)	A qualitative approach was appropriate, and the study was clear in what it sought to do.	Clear rationale for the design and defensible.	Data collected was appropriate to address the research question and data collection methods were clearly described.	Context is clearly described; however potential context bias could have been further discussed. Methods were deemed reliable.	Measures taken to ensure reliability. Findings were convincing well organised and conclusions were adequate.	Information provided on basic ethical procedures. Lack of reflexivity.	++
Sri-Amnuay (2012)	A qualitative approach was appropriate, and the study was clear in what it sought to do.	The design was defensible. The presentation of the design could have been made clearer by being more structured.	Data collected was appropriate to address the research question. The presentation of the methods for data collection could have been made clearer by being more structured.	Methods deemed reliable. Context is clearly described, however, potential context biased of the findings themselves was not well considered within the discussion.	Measures were taken to ensure reliability, but it was unclear if a peer researcher checked the consistency of findings. Findings were convincing and organised, conclusion were adequate.	A statement of ethical approval was included. Reflexivity was well considered throughout.	+
Zeedyk, Davies, Parry and Caldwell , (2009)	A qualitative approach was appropriate, and the study was clear in what it sought to do.	Clear rationale for the design and defensible.	Clear, however, interviewing may also have gained additional information of experiences.	Methods deemed reliable. Context was clearly described, and biasness was accounted for, but this could have been taken further.	Measures were taken to ensure reliability. Findings were convincing and organised. Conclusions were adequate.	A statement of ethical approval was included. Reflexivity inadequate.	+

Appendix F: Codes contributing to descriptive and analytic themes

Higher-order themes	Subthemes	Contributing codes
Personal discordance, doubt & discomfort	A contrast with previous philosophies	It's not age-appropriate
		Shouldn't get too close
	Feeling uncertain and needing control	Concerns of losing control over those they work with
		Lacking clarity and direction
	Emotional discomfort	Emotionally heightened way of working
		Needing emotional support
		Switching off
A turning point	Seeing the light	Needing to see it to believe it
		Awareness of previous assumptions/ignorance
	Gaining confidence	

		More personally satisfying
		Practice and confidence
		Desire to carry it forward
Needing consistent implementation at all levels	The immediate workplace environment	Time and environment
		Lower priority
	Teamwork	A need for consistent collaboration
		Top down support
	Making it official: a reminder	A need for reminders
		A need to make it official
	Outsider perception: needing permission	Concern of others' perceptions
		Training as permission

Appendix G: Interview Schedule

Demographic information

Gender ……

Age……

Age of your child…….

Have you learnt about Intensive Interaction and use/used to use it with your child?.....

Have you learnt about Intensive Interaction and not used it with your child?.....

Has someone else used Intensive Interaction with your child which you observed?.....

How long has Intensive Interaction been used with your child?.....

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. Where did you hear about Intensive Interaction?

Prompt a: Have you been on a training course?

Prompt b: Where else did you get the information from?

Prompt c: Who gave you the information?

Prompt d: What were your initial thoughts/presumptions about it?

2. What is your experience of using or being involved with Intensive Interaction?

Prompt a: Can you think of a recent example?

Prompt b: What did it feel like?

Prompt c: If someone else was using Intensive Interaction with your child, what was that like?

Prompt d: If you used it, what did you do?

Prompt e: Why did you use it/be involved?

Prompt f: If you chose to not use it/stop using it, could you tell me more about this?

3. In your own words, how would you describe Intensive Interaction?

Prompt a: How do you feel about it?

Prompt b: How does it differ from other forms of communication?

4. Did you feel supported to use/be involved with Intensive Interaction?

Prompt a: If you were the primary person using Intensive Interaction, did you receive support from any family member, friend, school, or other organisation?

Prompt b: If a staff were mainly using it, did you feel that you were supported by them to be involved in anyway?

Prompt c: What could be done differently?

Prompt d: Were people/organisations encouraging?

5. What effect have you noticed from Intensive Interaction, if any?

Prompt a: Have you felt that your relationship has changed with your son/daughter in anyway?

Prompt b: Has your child changed in any way since using it?

Prompt c: How long lasting were these changes?

Prompt d: Has it changed your perception of them in anyway?

Prompt: Have there been changes in their other relationships?

6. What barriers have you faced in relation to Intensive Interaction?

Prompt a: In the environment?- Did you feel comfortable?

Prompt b: Practical issues?- Were you able to use it/was it used regularly? Were staff willing to include you?

Prompt c: Your personality?- What was is like letting the person take the lead?

Appendix H: Participant Information Sheet

Parents' experience of Intensive Interaction.

We would like to invite you to take part in a research study whereby we would listen to your experiences of Intensive Interaction. Before you decide if you want to take part, we would like to make the purpose of the research clear in terms of what it would involve for you. This information sheet will explain this in more detail. If, after reading through the form, you have any questions then you can contact the researcher (please see the contact details at the end of the form).

What is the research about?

While there are many parents/guardians who use Intensive Interaction with their child or have children who receive Intensive Interaction from staff at school or in residential settings, there is no research considering parent/guardian experiences of this. As you will likely have a unique and close relationship with your child, we think it is important to hear your views on this topic. We would like to know: how you would describe Intensive Interaction, where/how you learnt about it, your experience of using/being involved with it and how supported you have felt, any effects of Intensive Interaction you may have noticed and barriers that you may have faced.

Why have I been invited to take part in the research study?

<u>You have been asked to take part because:</u>

- You have a son/daughter who has a learning disability (they may or may not have another diagnosis) and is receiving/has received Intensive Interaction. Your child can be of any age, this includes adulthood.
- You either have learnt about Intensive Interaction and use/used to use it with your child
- Or you have learnt about Intensive Interaction and have not used it with your child
- Or you have observed others (such as school/residential staff) use Intensive Interaction with your child

Do I have to take part?

No. It is up to you whether you want to take part. If you agree to take part, we will then ask you to sign a consent form. You will be given a copy of the information sheet and the signed consent form.

What will happen if I decide to take part?

If you are interested in sharing your experience, please contact the researcher via the contact details below. The researcher will ask you a few questions to check if you are able to take part. You will be invited by the researcher to take part in a one-to-one interview which will last 1-2 hours. If your partner/another parent or guardian of your child also wishes to take part you can choose to attend the same interview together, as long as they meet the criteria too- please inform the researcher of this prior to the interview. The interview will be arranged at a time and place that is convenient for you and will be in private. If preferred, interviews can take place online via Skype or telephone. You will need

to sign a consent form before the interview commences (the researcher will provide this). The researcher will ask you about your experiences of Intensive Interaction. The interview will be audio recorded.

What are the possible benefits of taking part?

Your contribution will give insight into the support and information about Intensive Interaction that is currently available to parents/guardians. You may have noticed that Intensive Interaction has positively or negatively affected you, your child or family in some way and this information may be useful to other parents/guardians. If there are barriers you have faced when trying to learn about Intensive Interaction or when using Intensive Interaction, this is an opportunity to speak about those experiences to work towards these issues being addressed.

What if there is a problem?

If you feel that you need further support following on from the interview, the researcher may signpost you to a relevant organisation where you can get support if appropriate. You can also choose to leave the interview at any time if an issue arises during the interview.

Will my taking part in this study be kept confidential?

Everything you speak about in the interview will remain anonymous and confidential. Non-anonymised information (information which could identify you e.g. your signature, name and contact details) will only be accessible to the researcher and their supervisor. The information will be securely stored at the University and will be destroyed after the research is complete. As this research is being carried out as part of a University course, it will be written up as a thesis that will be submitted for marking at the University. The research will also be submitted for publication in an academic journal. This means that other people who would be interested in the research will be able to read about it. Some direct quotes from your interview may be used in the write-up of the research, but information which could identify you will NOT be included.

Some information about you will be included in the research to help give context to your experiences. This will include your gender and the age of you and your child.

Confidentiality would only be broken if you tell the researcher something which gives them immediate concern for your own or someone else's safety. In these cases, they would discuss this with you before any action was taken where possible.

What will happen if I decide I no longer wish to take part?

You can choose to opt out of the research even after you have agreed to take part, and you do not have to give a reason for this. However, you would need to

let the researcher know before the researcher analyses the interview content so any information that you give can be removed from the research, as once analysis has begun, you cannot opt out. Therefore, if you wish to no longer take part, please let us know as soon as possible.

Who is organising and reviewing the research?

The researcher is a Trainee Clinical Psychologist. They are an employee of the NHS and undertaking a Doctorate Degree in Clinical Psychology at the University of Hull. The research is being carried out as part of the requirements of the Clinical Psychology Doctorate programme.
All research at the University of Hull is reviewed by a Research Ethics Committee.

Expenses and Payments

Your participation in this study is voluntary; therefore, there will be no payment for taking part. However, you will be reimbursed for any travel expenses should you need to travel to the research interview.

Further information and contact details

If you would like to take part or want any further information about this research, please contact me:

Samantha Berridge
Clinical Psychology Doctorate Programme

Faculty of Health Sciences

Aire Building, University of Hull

Cottingham Road

Hull

HU6 7RX

Telephone: 07592734008

E-mail: samantha.berridge@nhs.net

This research project is being supervised by:

Dr Nick Hutchinson

Clinical Psychology Doctorate Programme

Faculty of Health Sciences

Aire Building, University of Hull

Cottingham Road

Hull

HU6 7RX

E-mail: N.Hutchinson@hull.ac.uk

Thank you very much for your interest!

Appendix I: Recruitment Sheet

Parents' experience of Intensive Interaction: A research project

Participants needed

We are interested in hearing from:

- **Parents/guardians who have learnt about Intensive Interaction and use/used to use it with their child**
- **Parents/guardians who have learnt about Intensive Interaction and chose not to use it with their child**
- **Or, parents/guardians whose child receives/has received Intensive Interaction from staff at school/other settings and the parent/guardian has observed this.**

About the researcher: I am a Trainee Clinical Psychologist and I am undertaking this research as part of my doctorate in Clinical Psychology at the University of Hull. I have had personal experience with Intensive Interaction as it has been used as a form of communication with my

younger sibling. There are parents/guardians who are involved in using Intensive Interaction or have children who receive Intensive Interaction from others yet there is no research on their experience of this. I would like to hear about parent's/guardian's experiences of Intensive Interaction. Listening to parent's/guardian's views is important and can inform the way Intensive Interaction is implemented in training, schools and residential settings.

How do I get involved?

I would like to meet with parents/guardians individually to talk about their experiences. If you would like to know more about the research and are interested in taking part, please contact me:

Samantha Berridge

Via telephone: * or via email: s.berridge@2013.hull.ac.uk.**

Appendix J: Consent Form

Title of Project: Parents' experience of Intensive Interaction

Name of Researcher: Samantha Berridge

Please initial boxes

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information. If I had any questions, they have been answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason up to the point of data analysis and transcription. ☐

3. I confirm that direct quotes from the interview may be used in future publications or conference presentations and understand that they will be anonymised. Any quotes that risk breaching confidentiality will not be used in publications. ☐

4. I agree to take part in the interview part of the study and understand that my interview will be audio recorded. ☐

Name of participant	Date	Signature
_____	_____	_____

Name of person taking consent	Date	Signature
_____	_____	_____

When completed: 1 for participant; 1 for researcher

Version 1

Date 28/3/18

Appendix K: Sources of support

Thank you for taking part in the study. If following the interview today you feel you need further support, then below is a list that might help.

If you have any specific problems or questions that taking part in the research has raised, you can contact the following:

If you are worried about your own health or well-being: You could contact your GP.

Online support and general information available

Mencap

Website: https://www.mencap.org.uk

Telephone: 0808 808 1111

Foundation for People with Learning Disabilities

Website: http://www.learningdisabilities.org.uk/

The Challenging Behaviour Foundation

Website: www.challengingbehaviour.org.uk/

Telephone: 01634 838739

The Intensive Interaction Institute

Website: https://www.intensiveinteraction.org/

A Facebook support group for family members who use/are interested in Intensive Interaction

Website: https://www.facebook.com/groups/IntensiveInteractionForParents/about/

Local Help

Let's Talk… Depression and Anxiety Services Hull

Website: http://www.letstalkhull.co.uk/

Telephone: 01482 247 111

Text: TALK to 61825

Yorkshire & The Humber Befriending Service (emotional support service for parents who have recently discovered their child has a disability or they are facing a particularly challenging time in their disabled child's life)

Website: https://www.kids.org.uk/yorkshire-the-humber-befriending

Telephone: 01482 467540

Appendix L: Ethical approval form

Page removed for hard binding.

Appendix M: Epistemological statement

Epistemology is the means and conditions for knowledge. This is determined by ontology, which is what can exist. This is important in qualitative research as it can affect how the research is conducted in terms of its methodology, what can be assumed to be an outcome of the research and how the researcher communicates and presents themselves to the audience (Carter & Little, 2007). Epistemology can either be explicitly or implicitly considered. Ultimately it is useful for the researcher to be aware of their epistemological position, as it can constrain other possibilities (Carter & Little, 2007). Furthermore, identifying and understanding philosophical stance helps the reader to evaluate the work and assess if the research strategy is valid for the research (Aveyard, 2014).

In relation to this research, before becoming explicitly aware of my epistemological adoption, I was aware that I was interested the subjective experience from the perspective of participants themselves. I also believed that there was some correspondence between what a person said and their subjective experience.

A constructivist epistemological standpoint was adopted, which suggests that truth and meaning are constructed by experience and are subjective. Therefore, it refutes that there is an objective truth to be discovered (Crotty, 1997). This stance ties into Husserl's transcendental phenomenology, a concept which arose in the early twentieth century, which focusses on the world as it presents itself to humans and takes that position that the world of objects and subjects are not separate from our experience. The way in which the world's objects are perceived creates a phenomenon relative to the perceiver's psychological state, such as desires, wishes, emotions. This depends upon the context in which one is in. Ultimately, this means that the self and the world are

inseparable in the process of making meaning (Moustakas, 1994). I believed that experience would be influenced by the participant's context, such as age, gender, societal expectations of them as a mother and other discourses they were surrounded by. Therefore, this stance made sense to me, given my interests and own standpoint of the subjectivity of human experience. Interpretative Phenomenological Analysis (IPA) was chosen as the method to analyse the qualitative data to allow for interpretation of experiences.

IPA acknowledges that interpretations cannot be made without preconceptions of the experience that is being interpreted, which introduces the hermeneutic cycle (Schleiermacher, 1998). This was an aspect of interpretative phenomenology I particularly liked, as it allowed me to work with the inevitable preconceptions by acknowledging them, unlike descriptive phenomenology, which is traditionally more closely linked to Husserl's (1931) phenomenological purity. The purpose of IPA is to investigate the experiences of the participant, so stays true to Husserl's argument that we should 'go back to the things themselves' (Smith, Flowers & Larkin, 2009). IPA takes an idiographic approach because of the focus on individuals and their contexts. Therefore, a small homogenous sample is often recommended (Smith *et al.,* 2009). This fitted with my interests, as I wanted to look in depth at subjective meaning for the participants and did not seek to generalise to a wider context or population, especially as the research scope did not apply to the general population.

Grounded theory (Glaser & Strauss, 1967) was also considered, and possibly could have been applied to develop theoretical understanding of Intensive Interaction from a parental perspective. This was tempting, as previous research has suggested that further

research may be necessary to clarify the theoretical implications of Intensive Interaction, especially from a psychological perspective (Berry, Firth, Leeming & Sharma, 2014). However, there is a principle in grounded theory that the data 'speaks for itself' and aims to minimise the imposition of the researcher's role within the construction of the findings. As I have personal experience in relation to the research topic, it appeared detrimental to overlook this. As emphasised by Dey (1999): 'what we discover will depend on some degree on what we are looking for.'

References

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Appendix N: A worked example of the data extract with interpretative commentary and descriptive codes.

Descriptive code	Transcript	Interpretative commentary
Confusion: a need for direction from external source	**Where there other barriers to accessing information and support? If so what was that like?** Oh yeah. Oh yeah definitely, I knew at four months there was something, she's my fifth child… So I had the experience of children and babies and I'd been a nurse for twenty-two years, but the… I knew at four months that she was not developing like.. she was developing as in, interacting eye contact and giggling and, as, as the time's going on.. she never did the babbling which I thought… slightly strange, but I didn't, it's only til I look back that I thought well actually you didn't do the cooing or.. anything like that, erm… Yeah and, health visitors could do with erm, a lot of education cos my health visitor, was the main one who.. well she ignored me to begin with then she called me an era, an erratic	Thrown off-guard Did she hope to have spotted it sooner? Looking retrospectively Changes from focus on self- they could do better Felt ignored- needed to be persistent

A need to do something quickly: an unshared feeling Taking it into own hands	parent and said, come off the.. take my nursing hat off and put the mum hat on which I found quite insulting and I said, I, I am which is why I'm emotionally involved, and I'm saying please do something, in the end I just went to one of my consultants at work and said.. please refer me to, well I took her in and said.. so she was about twelve months by the time… somethings started to be done, but when, and the health visitor did apologise and, erm, she was lovely bless her, but ah, she even admitted I don't know what to do, ah, it would have been nicer that she was my core person, erm, luckily, erm… I did my own referral to the early assessment team, and it was my portage worker who came to be the core person she had a wealth of knowledge, of what to do, how to play, how to get her to interact so that was the Intensive Interaction, so I learnt from her coming to the house, but the health visitor didn't have a clue and I think from.. that professional body I think they, they could do a lot really, with that, I mean they could get that parent off to a	Felt misunderstood/lack of empathy to her confusion/anxiousness to do something. Hopefulness challenged but justifies own emotions. Concerned of lost time? Had to take into own hands They could do more

Sense of failure Lost time: looking retrospectively	very.. they wouldn't need a diagnosis just… you know like some parents, they could go to the health visitor and say… I don't, I don't actually know how to play with my.. that's what I did, in the early, years assessment I put… please help me, to play with my child because I can't get her to play, I can't get her to do anything, erm, cos it said something in the box like how can we help you and I said anything and everything I just can't do that, I don't understand, everything I'm doing, she doesn't play with toys I can't get her to interact, erm… so it would have been nice, if I had the health visitor to say, right this is what you need to do, this is Intensive Interaction, try to do these things while we do a referral to portage and get them working alongside you, there's big, big gaps where I could have been doing something.	Health visitor in prime position Hopelessness and failure within the relationship from perspective of herself (first person) - needing to look externally Guilt or regret or agitation- lost time. Would help if felt that action was being taken

Appendix O: Reflective statement

As I have gone through the process of explicitly reflecting upon the whole research process, what has become increasingly striking to me is how much I have been driven by personal experiences and preconceptions. This will, therefore, be a common theme throughout my reflective statement. To a large extent I did know that my choice of topic had been chosen because of personal experience but I have noticed that experience has likely governed many of my choices throughout the research process, which I have found interesting to discover as I may have taken this for granted somewhat initially. This has led me to wonder if this is a common revelation for most researchers who take on a large project. Because of this, I have certainly learned about the importance of and influences on the journey itself, not just the product; it may have been the explicit element of reflection that has helped me to learn this.

My personal experience in relation to this research consists of me having a younger sister with autism, who seemed to thrive from communication which mirrored that of Intensive Interaction. I say mirrored as I was, for the most part, unfamiliar with Intensive Interaction myself besides hearsay, up until the beginning of this thesis. Nonetheless, it appeared to me that this was how I had always naturally communicated with her. For me, this research was an exciting opportunity to pursue my curiosity of how others perceived this form of interaction with those who seemed to me to not have prominent voice in mainstream society. Despite my own experiences and assumptions, I was pleased that I had maintained a genuine curiosity of others' views.

Alongside this genuine feeling of interest and curiosity was a worry that my research would somehow be less credible because of my experiences. I remember firmly

thinking that I should not let my assumptions carry me too much and tried to go back to basics - to a position of unknowing, which was probably not entirely possible. I discussed the impact upon personal experience in supervision and it was suggested that I investigate papers that had considered this. I came across the paper of Etherington (2016), which I found particularly useful. Within it, I found a quote that I felt I could relate to, "I was being encouraged to use myself as a powerful tool in my research, but on the other hand, I was still concerned that others would not consider my personal experience to be a legitimate source of knowledge…I believed that even though it might be acceptable to use myself in research in the field of counselling, in the wider world of academia using myself would almost certainly be seen as self-indulgent or solipsistic" (p. 4).

I was glad to learn about IPA, as it accepts that not only can experience be looked at through the person's interpretations of it but that the researcher is also responsible for the presentation of the findings due to their own interpretations, which can be worked with and made explicit and that made sense to me. Because of this, attempts ought to be made by the researcher to at least acknowledge, their own assumptions and preconceptions. I liked how it acknowledged that I would be influenced by my own preconceptions but emphasised that the focus remained on the participant's experience. Throughout the process I took various measures to put aside my own biases to help me to fully consider and appreciate the experiences of the participants. I used supervision to create an interview schedule which consisted of open-ended questions to reduce restraint on what participants expressed. I met with an expert by experience - a mother who used Intensive Interaction with their child who was not included in the study - to assist with my interview schedule and the wording of my recruitment information in a way that was likely accessible to them; I did not wish to rely on my own assumptions of

how it should look. It was the expert by experience who encouraged me to mention my own experience in the recruitment flyer - something which I was hesitant about but, on a deeper level, completely agreed with – in the interest of developing an initial trust which would, in turn, help prospective to talk more openly about their experiences. However, care was taken to not include my opinions about Intensive Interaction or discuss my experience by any other means prior or during interviews with participants in case this further affected their accounts. I was aware that due to the constant care the participants' children would likely need, the participants may have been unable to be interviewed outside of their home, therefore I wanted them to feel as comfortable, trusting and metaphorically 'at home' as possible.

By far one of the most enjoyable aspects of the research process was meeting with and interviewing the participants; I am incredibly grateful to them that they took the time to take part in my research, especially given their busy days of being a parent. The only time I felt uncomfortable was when prompting participantss to get in touch with me if they told me they were interested but had not been in contact for some time. This was because I assumed that they had busy, and occasionally stressful, lives caring for their children. It was of utmost importance to me that they perceived my study as beneficial and not as an inconvenience.

I also enjoyed networking with the staff in the local schools and workshop, who assisted with my research and who also held an interest in Intensive Interaction. The initial networking phase is exceptionally important and, as I did this early, I believe that this allowed me the psychological space to enjoy this process and would therefore recommend to anyone undertaking a large project to start early.

Furthermore, I really enjoyed re-reading transcripts and discussing them with my supervisor and colleagues in reflective groups as it felt like I could relive the shared experiences of the participants and it was both enjoyable and constructive when others also shared interest in what the participants had to say. While this process was enjoyable and, in many ways, 'the easy part,' I found further analysis, particularly regarding my own contribution, daunting and I was cautious about doing 'the right thing' and ultimately not misinterpreting. This was where I greatly appreciated the assistance of my supervisor, other staff within the department and those involved in the reflective groups. I certainly came to learn that it is not necessarily a case of right or wrong in this type of analysis but rather dedication to time and thoughtfulness. I remember being told that analysis can be a long, and not a particularly clear-cut, process before even starting the research but I now feel understand the gravity of this statement. I recall having typed and cut out endless possible themes taken from transcripts and spreading these across my living room floor and feeling backed into a corner, metaphorically and literally! It took a long time, with a lot of re-shifting and discussions with myself and others for it to begin to feel like I was getting somewhere. Ultimately, constantly revisiting the original data really helped with this and, again, as did allowing myself a lot of time to go through this process, as I do not think it would have been possible to get to a place where things felt right otherwise, even though I probably wanted it to be quick and easy to ease my own anxiety. I chose to submit my papers to the Journal of Applied Research in Intellectual Disabilities as it is widely disseminates research of people with disabilities. I also considered the British Journal for Learning Disabilities; however, this journal held a lower word count limit and I was cautious that this would affect the representation of an IPA study.

The data which came out of the interviews demonstrated to me how much the mothers were invested in their children, which I found inspiring. I was amazed at the intensity of their experiences which, shine throughout the process, and they had a lot to say, which made me grateful for my interview schedule!

I'll now use this opportunity to be more explicit about my own preconceptions from experience. Interestingly, I did, in many ways, identify with what they were saying: from my own experience, I feel that I get so much out of my relationship with my sibling. Considering that, I am also sensitive to the fact that I view her as a strong and interesting character, which is how I happen to perceive many people who I have met who have disabilities; it seems that society does not always readily view disability in the same way. Therefore, my assumptions are that the appreciation of the individual does not always seem to extend too far beyond those who are within the person's close circle, instead beginning and ending with their limitations. To an extent, I remember thinking this during analysing the findings from the studies within the systematic literature review, as prior to Intensive Interaction findings suggested that staff did not view communication attempts as meaningful. Yet, I was aware that this data was still a useful contribution in understanding experiences of Intensive Interaction and how its implementation is perceived.

While inspiring, this brought me back to my initial worry of my research somehow being less credible or self-indulgent. Nonetheless, I was reminded by Etherington's (2016) quote, "personal experience is at the heart of what we do" (p. 3) and is something which all researcher's need to be aware of. I feel assured that I put measures in place to help to counteract this and reduce bias, such as sticking closely to participants' accounts, having transcripts and themes checked by others and including

open ended questions, which I was careful to include in my interview schedule (Smith & Noble, 2014). I recall being back at the beginning when I was tasked with deciding on a research topic; a choice which ultimately came down to this and something I was less familiar with. With the clarity of hindsight, I would recommend going with what the researcher finds they are passionate about, which I chose to ensure I produced not only a thought-provoking and contributory product, but to ensure that I also had a fulfilling, inspiring, arguably more self-reflective, and moreover, enjoyable journey.

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