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interaction with people with severe-  
profound intellectual disability

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### **Declaration**

I declare that the work presented in this literature review is entirely my own personal work and is not plagiarised from other sources. Every effort has been made to appropriately reference throughout the piece.

## **Abstract**

**Background:** Intensive Interaction, is a communication technique used with people with autism and/or severe-profound intellectual disability (ID) (Berry *et al.* 2014). Practitioners have a role in ensuring that the complex health needs of people with severe-profound ID are met and their rights are upheld by actively listening and responding to unconventional communication.

**Research aim:** To explore the literature on the use of Intensive Interaction with people with severe-profound intellectual disability.

**Search Strategy:** Electronic databases were used to gather research on Intensive Interaction that was peer reviewed. Hand searches through the reference lists of retrieved studies and a search through the periodicals of Trinity College Library were also undertaken. 18 studies were selected for inclusion and were appraised. Four themes became apparent after reviewing the literature; Social engagement, impact on the person with intellectual disability, impact on the practitioner and barriers to implementing Intensive Interaction.

### **Key findings:**

- Social engagement- All of the quantitative studies, overall, found an increase in sociability when compared to baseline measurements. Three of the four qualitative studies referred to increased levels of social engagement in some manner.
- Impact on person with intellectual disability- Evidence suggests that Intensive Interaction facilitates enhanced wellbeing, may reduce distress and could help the person develop a stronger sense of self.
- Impact on practitioner- Research findings reveal that although using Intensive Interaction can be a rewarding experience and offers a number of benefits to practitioners, it can also perpetuate feelings of discomfort for some individuals.
- Barriers to implementing Intensive Interaction-. 1. Environmental constraints  
2. Resistance and uncertainty

**Conclusions:** Intensive Interaction has been proven to be beneficial for both people with severe-profound intellectual disability and practitioners implementing the intervention. However, there are a number of barriers to its implementation in practice.

**Recommendations:** A large scale longitudinal study on the effects of Intensive Interaction on people with severe-profound ID and self-injurious behaviour. Studies on the experiences of intellectual disability nurses, family members and community members using Intensive Interaction.

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## Introduction

The purpose of this review is to explore the literature on the use of Intensive Interaction with people with severe-profound intellectual disability (ID). Researching supports for people with severe impairments remains quite unusual, with interventions usually aimed at those at the higher functioning end of the spectrum (Zeedyk *et al.* 2009a). The Department of Health (DoH UK 2009) assert that people with the more severe levels of intellectual disability are among the most excluded groups in society. Thus, the author wanted to research ways of providing meaningful social engagement for, and developing therapeutic relationships with, people with severe-profound ID.

Intensive Interaction, originally developed in the 1980s, is a communication technique used with people with autism and/or severe-profound ID (Berry *et al.* 2014). While engaging in voluntary work in XXXX, the author utilised Intensive Interaction and witnessed how effective it was, validating how applicable this theory is to practice.

Anecdotally, the evidence is there but what does empirical research say about the use of Intensive Interaction?

Irish, EU and international legislation all request evidence based change in care provision for people with ID (Health Service Executive, HSE 2011). It is well documented that those with severe-profound ID frequently experience complex health needs (Mencap 2010). A high proportion of the 4,000 people with ID living in congregated settings in Ireland have a severe-profound intellectual disability, and most have little or no friend or family contact (HSE 2011). The literature abounds with higher prevalence rates of mental health problems among people with ID than the general population (Coiffait & Marshall 2011). Impaired communication skills may lead to behaviours like self-injury, screaming and stereotyped behaviours being used to express these mental health problems (Taggart 2011). Harding and Berry (2009) propound that Intensive Interaction could be used as a psychological therapeutic intervention for those who struggle with social interaction and cannot verbally articulate their emotional state. As a Registered Nurse in intellectual disability (RNID), a key element of our role in caring for people with severe-profound ID in Ireland is to be able to communicate with them and pick up on non-verbal cues, allowing any health care need to be identified promptly (Dunworth Fitzgerald & Sweeney 2013). Furthermore, Ware

(2003) states that every human being, regardless of age or ability, deserves to be afforded the respect and dignity that a responsive environment embodies.

There has been a welcome shift towards including the perspectives of those who were not previously seen as capable of forming a valid view. This includes those with mental health issues or dementia, as well as children or people with ID (Ware 2004). This shift can be seen in The Assisted- Decision Making Bill (2013) which has been recently enacted and will reform Irish legislation relating to those who need assistance in decision making due to reduced capacity (Kelly 2015). The portrayal of people with profound ID as helpless beings, lacking volition and intention, poses a threat to their rights and quality of life (Simmons & Watson 2014). Thus, taking cognisance of the social and political climate we live in, which promotes participation in decision making processes by people with intellectual disability, the responsibility lies with us, as practitioners, to ascertain what people's wishes and interests are (Grove *et al.* 1999). Given that Intensive Interaction is led by the person with intellectual disability, it is more likely to reflect their needs over any agenda brought by the practitioner (Leaning & Watson 2006). Therefore a literature review was conducted to explore the empirical research on intensive interaction.

## **Search Strategy and Results**

In order to source literature for the review Academic Search Complete was used and the CINAHL, PsycINFO and ERIC databases were selected to be incorporated in the search. The keywords used comprised of synonyms for 'intellectual disability' including 'intellectual\* disab\*' OR 'mental\* retard\*' OR 'mental\* handicap\*' OR 'Intellectual Development Disorder\*' OR 'mental\* impair\*' OR 'mental\* disab\*' OR 'mental\* subnormal\*' OR 'learning disab\*' OR 'learning difficult\*' OR 'intellectual difficult\*' OR 'intellectual impair\*' OR 'idiocy' OR 'mental deficien\*'. These were combined with the keywords 'severe' OR 'profound' and the words 'intensive n0 interaction' using the Boolean phrase AND. The 'n0' was used to ensure that the words 'intensive' and 'interaction' appeared together in the literature.

The search was limited to full text literature to allow for thorough analysis. Only peer reviewed literature was included in the database search to ensure the

papers found were of a reputable standard. Literature related to the use of Intensive Interaction in autism exclusively was excluded as a recent systematic literature review was published on the effectiveness of the intervention for both people with intellectual disability and/or autism, therefore this review focused specifically on the use of the intervention with people with severe-profound ID to avoid duplication of research. There were no time limits applied in order to present a comprehensive view of the literature published but the intervention was only established in the 1980s so any literature sourced is from after that date.

According to Cronin *et al.* (2008) retrieving literature from many sources is crucial to writing a good literature review. Therefore, to ensure full retrieval a hand search through the reference lists of the retrieved articles was undertaken and lead to the discovery of 2 other relevant studies. The periodicals of the Tizard Learning Disability Review in Trinity Library were accessed to source one case study that was not available in the online databases. Using Grey Net International the term “Intensive Interaction” was entered in the search engine and limited to English language papers as this is the only language known to the author. One unpublished thesis was identified as relevant and was retrieved from the University of Hull website. See Appendix 3 for a full overview of the search strategy.

Overall, this process yielded 18 relevant papers; 4 papers used qualitative methodology, 6 were quantitative, 6 used a mixed methods approach, 1 was a review of the literature and 1 was a systematic literature review. All the studies had small sample sizes ranging from a sample size of 1 to the largest sample size of 40 (which incorporated practitioners and people with intellectual disability). The largest sample of people with ID in any of the studies was 18, revealing a dearth of large scale research studies in this area. 14 of the studies were carried out in the UK, 1 study was based in Australia and 1 in Romania.

These papers were appraised and their findings were categorized into themes. The four most dominant themes were identified following a thorough reading of the literature.

## **Themes**

After a preliminary reading of the literature, the author undertook a thematic analysis by extrapolating reoccurring themes. Four main themes emerged; Social



engagement, impact on person with intellectual disability, impact on practitioner and barriers to implementing Intensive Interaction.

The definition of intensive interaction used in the literature varied, with many papers presenting a number of references. There was no agreed standardised definition apparent. Nind & Hewett (1994) are cited throughout the literature as the founders of the approach having built on the 'augmented mothering' theory propounded by Ephraim (1982) (Firth *et al.* 2008). Firth *et al.* (2008, p.58) define Intensive Interaction as "a socially interactive approach to developing the pre-verbal communication and sociability of people with severe or profound and multiple learning disabilities". It involves intently observing what your communication partner is doing and then joining in utilising the same movements, vocalisations and rhythms (Zeedyk *et al.* 2009a).

None of the studies define their classification of severe-profound ID. This reflects the absence of a universal agreement on this definition. From the Irish context, Inclusion Ireland (2016) state that a person has an intellectual disability when "general intellectual functioning is significantly below average; significant deficits exist in adaptive skills and the condition is present from childhood (eighteen years or less)" The definition utilised in the Irish National Intellectual Disability Database is based on the World Health Organisation (WHO) International Classification of Diseases (ICD) (Kelly & Kelly 2011). According to the ICD-10, a person has a severe intellectual disability if they are assessed as having an Intelligence Quotient (IQ) between 20 and 34 and a profound intellectual disability if their IQ is below 20 (WHO 1992).

## **1. Social Engagement**

When discussing social engagement, the studies in this review were referring to the individual's social engagement with the person implementing the intervention. Kellett (2004, p. 181) defines engagement as "a state of absorbed intellectual or emotional arousal and connectedness with another person or with an activity". A large proportion of the literature on intensive interaction highlights that the intervention is most suitable and effective for using with people who are in some way socially isolated or withdrawn (Barber 2008; Berry *et al.* 2014; Elgie & Maguire 2001; Firth *et al.* 2008; Kellett 2000, 2003, 2004, 2005; Leaning & Watson 2006; Samuel *et al.* 2008; Zeedyk *et al.* 2009a; Zeedyk *et al.* 2009b). Thus a large

proportion of the research studies focus on how intensive interaction enhances social engagement in some manner. This is mirrored in the thematic analysis carried out by Hutchinson and Bodicoat (2015) in their systematic review where 'Social interaction' featured as a key theme.

### **1.1 Increased Sociability**

A number of studies focus specifically on measuring the indicators of increased sociability. Some did this through quantitative analysis of video observations (Barber 2008; Elgie & Maguire 2001; Kellett 2000, 2003, 2004, 2005; Zeedyk *et al.* 2009a), while others undertook a thematic analysis of qualitative reports from those utilising the intervention (Berry *et al.* 2014; Firth *et al.* 2008; Rayner & Bradley *et al.* 2016). In contrast to this, Leaning and Watson (2006), Samuel *et al.* (2008) and Zeedyk *et al.* (2009b) used a mixed method approach incorporating quantitative and qualitative elements when analysing the increase in sociability among participants.

The use of observation in the quantitative studies was an appropriate data collection method as it is suited to the study of non-verbal behaviour (Parahoo 2006). The behavioural indicators used in the quantitative studies to demonstrate increased social engagement varied. These indicators included measuring eye gaze/contact, engagement in a mutual activity, physical contact, contingent vocalisation, engagement in social interaction, emotional valence, body orientation, proximity to partner and reduction in self-stimulation. All of these quantitative studies, overall, found an increase in sociability when compared to baseline measurements. For example, Barber (2008) reported that all participants displayed increased social engagement. Similarly, Zeedyk *et al.* (2009a) found that all participants increased on at least one of the behavioural indicators used in the study, while 70% of their sample showed increases in all four behavioural measures of social engagement.

Many of the studies were quasi-experimental, lacking randomization and a control group (Polit & Tatano Beck 2014). This approach, although lower down on the hierarchy of evidence strength than a randomized control trial (Polit & Tatano Beck 2014), is more ethical, as it is unethical to withhold an intervention known to be beneficial. Equally, a 'reversal phase' adopt approach was ruled out as to introduce and subsequently withdraw a potentially beneficial intervention would

again be unethical (Kellett 2003). The absence of control groups in these studies means that attributing any changes in behaviour to the specific intervention in question is not as definitive as one might hope. This is particularly pertinent when it comes to child participants as Firth (2006) proffers that any development could be attributed to general maturation rather than the intervention being studied. Nonetheless, Zeedyk *et al.* (2009a) propound that the absence of a control group does not undermine the validity of findings, especially considering that in their study there was a clear correlation between the introduction of the intervention and increased social engagement. Watson and Fisher (1997) further contest the need for a control group stating that the heterogeneity of people with ID and the individuality of their abilities invalidates the use of a control. Firth (2006) also highlights that one study in his review propounded that where no significant events occurred at the same time as Intensive Interaction was introduced there is no alternative explanation for any developments that occurred.

In the qualitative studies, participants noted “increased awareness of the social environment and increased client-initiated...social activity” and “more sustained toleration of social proximity” (Firth *et al.* 2008, p.61). Similarly, the most popular theme to emerge in the study by Zeedyk *et al.* (2009b) was an increase in social engagement. Although, Rayner & Bradley *et al.* (2016) didn’t mention the term ‘sociability’ exclusively, they did refer to clients becoming more proactive in demonstrating their needs through engaging with staff.

## **1.2 Communication Development**

When referring to social engagement, some studies focused more closely on communication development (Kellett 2000, 2003, 2004, 2005; Samuel *et al.* 2008; Watson & Fisher 1997). Four of these studies collected data within the framework of the Pre-Verbal Communication Schedule (PVCS) (Kiernan & Reid 1987). The PVCS uses descriptors of communication attainment to measure progress in communication development (Kellett 2000). These studies all found that participants initiated communications more effectively when compared to baseline measures. In the study by Kellett (2000) the participant’s PVCS score rose from 0 to nearly 90. This focus on communication development is echoed by Berry *et al.* (2014, p. 405) who referred to a participant stating that “Intensive Interaction is, first and foremost, about finding a way to communicate with

somebody". Furthermore, Culham (2004) found that 20% of participants expressed that the development of 'communication opportunities' was the most rewarding element of using Intensive Interaction.

Many studies also highlighted an increase in vocalisations during sessions (Elgie & Maguire 2001; Kellett 2000; Samuel *et al.* 2008; Watson & Fisher 1997), which could potentially be viewed as increased attempts at communication (depending on the intentionality behind these vocalisations).

### **1.3 Reduction in Stereotypy**

Stereotyped behaviours, e.g. ritualistic finger play, hand biting, rocking and head banging, are viewed as potential barriers to social interaction (Kellett 2003). Thus evaluating the effectiveness of Intensive Interaction at reducing these behaviours was perceived by some of the studies as significant to the measurement of social engagement.

Kellett (2003) in the case study on Jacob, found that he replaced many stereotypical behaviours with ones of a more socially communicative nature following his involvement in Intensive Interaction, with an overall average percentage decrease from 66.7% at baseline to 3.8% during intervention. Similarly, Leaning and Watson (2006) note a reduction in self-stimulation and active avoidant behaviours after engagement in Intensive Interaction. However, Hutchinson and Bodicoat (2015) conclude that evidence on whether Intensive Interaction reduces or changes the quality of stereotyped behaviours remains quite limited.

Overall, there was a strong focus on social engagement throughout the literature. The increase in sociability, the development of communication and the decrease in ritualistic behaviours displayed by the participants of these studies has had a notable influence on their sociability.

## **2. Impact on Person with Intellectual Disability**

As well as increased social engagement, a common theme among the literature was the impact the use of Intensive Interaction had on the person with intellectual disability.

### **2.1 Enhanced Wellbeing**

Research showed that Intensive Interaction was seen as a means of improving the experiences of people with ID in hospitals (Bodicoat 2013). Firth *et al.* (2008) spoke of how participants believed that people with ID found the experience of partaking in Intensive Interaction to be a pleasurable one. Watson and Fisher (1997) also state that Intensive Interaction was an enjoyable and satisfying experience for the pupils in their study. Similarly, Rayner and Bradley *et al.* (2016) refer to the transformation in the clients and how they came to life during Intensive Interaction sessions and were viewed as more proactive and empowered.

The reports of increased incidence of smiling during Intensive Interaction sessions recorded in the literature (Barber 2008; Kellett 2000; Leaning & Watson 2006; Zeedyk *et al.* 2009b), as well as the increased emotional valence reported by Zeedyk *et al.* (2009a), could also be indicative of a greater sense of wellbeing.

## **2.2 Decrease in Distress**

Zeedyk *et al.* (2009b) reported decreased evidence of distress and self-harm among the children in their study. Eight of the twelve volunteers interviewed noted these decreases among the children they were working with. Overall, 39% of the children were reported to have a decrease in distress following the introduction of Intensive Interaction.

Contrary to this Elgie and Maguire (2001) found no appreciable change in the levels of self-injurious behaviour displayed by the participant in their study. However, these behaviours were long standing and their intervention period only lasted 16 weeks. The authors propound that long term intervention may reveal different outcomes, highlighting the need for more longitudinal studies on the effects of this intervention on self-injurious behaviour over time. Overall, the paucity of data on its effects on levels of distress means that conclusions remain tentative at present.

## **2.3 Personal Development**

Participants of the study by Berry *et al.* (2014) believed that Intensive Interaction helps the person to develop a greater sense of self and to develop a sense of agency by learning that they can impact their environment. One participant stated that “It enables people to realise that they’ll be listened to [...] and [that] what they’re saying is meaningful...” (Berry *et al.* 2014, p. 406). This is

mirrored in the study by Firth *et al.* (2008) who speaks about an increase in client-initiated (or contingently sustained) social activity.

These studies demonstrate that engaging in Intensive Interaction appears to have had a positive impact on the person with intellectual disability. Evidence suggests that Intensive Interaction facilitates enhanced wellbeing, may reduce distress and could help the person develop a stronger sense of self.

### **3. Impact on Practitioner**

While the earlier literature mainly focuses on how the intervention impacts on the person with ID themselves, recent research has widened the focus to how it affects both people using the approach. Eight of the studies explored this aspect in some way (Berry *et al.* 2014; Bodicoat 2013; Culham 2004; Firth *et al.* 2008; Rayner & Bradley *et al.* 2016; Samuel *et al.* 2008; Zeedyk *et al.* 2009b). Zeedyk *et al.* (2009b) highlights that interactive approaches are by their very nature dyadic, involving mutually communicative relationships, subsequently affecting both the practitioner and the person with intellectual disability.

The practitioners across the studies who have been asked about their experiences of using the approach include care staff, clinical psychologists, educators, hospital staff, speech and language therapists, social services day centre staff, support workers, volunteers and team leaders.

#### **3.1 Benefits to the Practitioner**

Rayner and Bradley *et al.* (2016) interviewed three practitioners who utilised intensive interaction. The participants discussed the effects the intervention had on their own personal development and struggled to articulate just how effective the intervention was. The authors noted that staff experienced increased job satisfaction when using the intervention. The enhanced connection they felt with the person they were supporting significantly influenced their care practices and they felt more empowered as a result. Staff also articulated that they felt a greater sense of team cohesion and unity among their fellow work colleagues who were using the intervention.

Benefits to the practitioner of using the intervention were echoed in other research studies too. Zeedyk *et al.* (2009b) suggests that the personal impact of using Intensive Interaction reported by participants is crucial for sustaining the

capacity to work with those who may have severe behavioural difficulties. Firth *et al.* (2008) highlighted that practitioners felt rewarded by a successful Intensive Interaction session. The study by Bodicoat (2013) revealed that Intensive Interaction led to staff feeling more capable of demonstrating that they cared by granting them permission to use touch or to spend more time with their patients. Practitioners in the study by Samuel *et al.* (2008) reported that the process of engaging in Intensive Interaction had supported them to become more reflective practitioners. Firth (2006) reported that in one study staff utilising Intensive Interaction felt more relaxed, tolerant and more patient when waiting for responses from the child participants.

### **3.2 Relationship Development**

Berry *et al.* (2014) reported that participants felt that Intensive Interaction helped people to feel more connected to each other. Likewise, Bodicoat (2013) reported that the attention to individual needs fostered by Intensive Interaction facilitated a greater sense of connection between the staff and the patient with ID in the hospital setting, quoting one participant saying “I thought we was friends, we’d become friends, you know and I’d like to think that he felt he could trust me” (Bodicoat 2013, p. 61).

The study by Culham (2004) was the only study to explore the male perspective exclusively. The majority of participants cited instances of success in the use of the intervention and 32.5% found relationship development to be a significant benefit. Similarly, Firth *et al.* (2008) presents evidence of Intensive Interaction enabling the development of more reciprocal interactions with service users as it improved the observational practices of staff when it came to clients’ social or potentially social behaviours. Zeedyk *et al.* (2009b) presents an account of how 11 of the 12 volunteers trained in Intensive Interaction felt that the use of the intervention had intensified their relationships with the children they were working with. The authors propounded that the development of these relationships in turn facilitated greater motivation and commitment among the volunteers. Firth (2006) in his research review reported that in one study on child participants, staff highlighted that Intensive Interaction facilitated the development of good pupil-staff relationships.

### **3.3 Concerns about Use of the Intervention**

Although much of the literature reported positive accounts of the impact of the intervention, some people utilising the intervention also raised concerns about its use. Culham (2004) found that men were concerned about issues of touch, particularly when using the intervention with female service users, with 50% reporting concerns about fear of sexual assault allegations. Attitudes of others in their work environment was cited as the most difficult aspect of using the approach. One participant in the study by Berry *et al.* (2014) questioned whether it is appropriate to compare the typical infant-caregiver relationship that the intervention is based on with the relationship between a person with an ID and a paid carer. Firth *et al.* (2008) found that some staff were unwilling to work physically close to clients when using Intensive Interaction as the proximity made them feel uncomfortable. Thus, for some participants, using Intensive Interaction evoked feelings of fear, concern and discomfort.

Given the dyadic nature of communication it is not surprising that a common theme to emerge in the use of this communication technique is its impact on the practitioner. Research findings reveal that although using Intensive Interaction can be a rewarding experience, it can also perpetuate feelings of discomfort for some individuals.

#### **4. Barriers to Implementing Intensive Interaction**

Some elements of the literature featured reference to barriers to implementing the intervention. The most commonly cited barriers comprised of environmental constraints and resistance from practitioners and other staff members.

##### **4.1 Environmental Constraints**

The environment where the research into Intensive Interaction took place varied between the studies. Some studies reported elements of the environment having a significant impact on the participants' ability to utilise the intervention effectively. Staff interviewed by Bodicoat *et al.* (2015) spoke of the restrictions of utilising the intervention in a hospital environment. These included time constraints, staffing shortages, the pressurised environment and how hospital procedures could cause their patients distress and affect their ability to build a relationship with them. Similarly, Firth *et al.* (2008) presented finding that limited time, as a result of staff shortages, was the greatest barrier to successful



implementation of Intensive Interaction. Staff felt that Intensive Interaction was competing with more urgent care tasks for finite staff time and domestic and care issues needed to be prioritised in many instances.

## **4.2 Resistance and Uncertainty**

Despite the evidence of the positive effects of Intensive Interaction, some of the research is punctuated by reports of uncertainty about the effectiveness of the interaction. Zeedyk *et al.* (2009b) reported that many of the volunteers had initial doubts about using Intensive Interaction and did not anticipate the positive outcomes. This initial resistance was also seen among participants in the study by Rayner *et al.* (2016) who were unsure of what to expect. Although in both studies this initial resistance was overcome after participants witnessed the positive effects of the intervention, the original uncertainty still presented as a notable challenge. A small number of participants in the study by Firth *et al.* (2008, p. 63) referred to the approach as “just another thing”, “treating clients like children” and “too idealistic”. This uncertainty about the effectiveness of Intensive Interaction is mirrored in the study by Culham (2004). He found that 33% of respondents to the questionnaire expressed concerns about negative attitudes held by ‘mainstream’ staff about the use of Intensive Interaction. One respondent stated “There are those who can’t see the point, or who would wish to see more in the way of prescribed outcomes...” (Culham 2004, p. 85). Zeedyk *et al.* (2009b) propound that these moments of uncertainty may be an integral part of learning to use Intensive Interaction.

Although it was not the most dominant theme in the literature, there were a number of studies which identified some barriers to the implementation of Intensive Interaction.

## **Summary**

The studies on Intensive Interaction vary in how robust their design methodology is, where they are set, who their participants are, how long their baseline and intervention periods last and in the level of previous experience their participants have, which makes comparison between studies quite challenging. There appears to be no standardisation of training in Intensive Interaction. Perhaps standardisation of training could increase its uptake in various professions by allowing for accreditation and ensuring a minimum standard of

basic principles and practical skills are taught in every training session. However, this could also potentially 'professionalise' the intervention which may discourage those without the official training from utilising it.

Empirical research into the effectiveness of Intensive Interaction is difficult to conduct (Hutchinson & Bodicoat 2015). Samuel *et al.* (2008) highlights that the studies are context bound and the heterogeneity of people with profound ID lessens any claims of generalizability. The studies in this review have utilised a variety of methodologies to appraise their data including (in order of popularity) video observations of objective outcome measures, thematic analysis, interpretative phenomenological analysis and grounded theory methodology. Some studies make reference to the inability to articulate some of the effects of the intervention. Rayner *et al.* (2016, p.66) states that "Words are clearly insufficient when staff described their experiences". Watson and Fisher (1997) observe that assessment scales like the PVCS failed to capture some of the observed behaviour during Intensive Interaction. Hutchinson and Bodicoat (2015) felt that the positive effects reflected in anecdotal evidence were often disregarded as 'insufficient evidence'. These reports seem to suggest that the full effects of Intensive Interaction may not be encapsulated in their entirety within the strict parameters of current empirical research methodology.

## **Conclusion**

The purpose of this literature review was to explore the literature on the use of Intensive Interaction with people with severe-profound intellectual disability. Research findings reveal that Intensive Interaction can increase social engagement for the person with severe-profound ID, have a positive impact on their overall wellbeing, and can affect the practitioner using the intervention. Although its use can be beneficial to the practitioner and strengthen their relationship with the people they support, it can also be uncomfortable for them, raising certain concerns about touch and proximity. Despite evidence of significant improvements among people with severe-profound ID attributed to Intensive Interaction, its implementation faces certain barriers in practice, particularly the initial resistance from practitioners due to uncertainty about its effectiveness and the constraints of busy work environments where staffing levels may be low.

The research base on Intensive Interaction has expanded in recent years but a dearth still remains. The move to exploring both the perceptions of those

implementing the intervention as well as its effects on the person with ID has provided a new layer of understanding of other benefits and limitations. Given the importance of community inclusion in our current climate of transitioning from institutional care, exploring the use of Intensive Interaction by members in the individual's local community may provide valuable insights into its utilisation in increasing community inclusion. Intensive Interaction could also potentially be utilised as a tool for strengthening or developing family contact and a study exploring its use by family members of people with severe-profound ID could deepen our understanding of its role in relationship development. A study on the experiences of the Registered Nurse in Intellectual Disability using Intensive Interaction would provide insight into its contextualisation within this profession. An Irish based study would assess its relevance in the Irish context and could highlight any culturally specific barriers to its implementation in Ireland. Finally, a large scale quasi-experimental design carried out over a longer period of time would serve to strengthen the existing research base. This type of study could further explore the effects of the intervention on incidence of self-injurious behaviour given that previous studies have been too short in duration to see any substantial change in these often long established behaviours.

Overall, there is evidence to suggest that Intensive Interaction does in fact enhance social engagement and communication for people with severe-profound intellectual disability, warranting its use in clinical practice. However, it is possible that the existing research methodologies utilised are not capturing the full effects of Intensive Interaction. Furthermore, its implementation in practice is not without limitations and barriers and being aware of these will allow the Registered Nurse in Intellectual Disability to be sensitive to these issues and maximise the likelihood of successful implementation in practice.

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### Appendix 1. Summary Table for Research Studies included in Review

Author(s) and Title	Study Aims & Objectives	Research Design	Sample	Data collection methods	Data Analysis Method	Findings relevant to the review
Barber M. (2008) Using Intensive Interaction to add to the palette of interactive possibilities in teacher-pupil communication.	To examine the effects of intensive interaction on the communicative behaviours of students and staff	Quantitative AB design. A: 12 week baseline B: 30 week intervention	N= 3	Video	Second-by-second analysis of video data for 'Indicators of Involvement'. These included no interactive behaviours, look at face, smile, socially directed physical contact and engagement.	All participants displayed a decrease in 'No interactive behaviours' 2 participants showed an increase in 'Look at face' 2 participants increased under 'Smile' All participants showed increased physical contact and engagement
Berry R., Firth G., Leeming C. & Sharma V. (2014) Clinical psychologists' views	To explore how clinical psychologists conceptualise intensive	Clinical psychologists interviewed about their views on	N=8	Interview	Qualitative description/thematic analysis	Intensive interaction (II) thought to be difficult to define. II found to be useful for those difficult to reach

of Intensive Interaction as an intervention in learning disability services.	interaction with regard to the currently accepted psychological theories, and to look at other factors that influence their adoption and advocacy	intensive interaction. Qualitative data.				through conventional means of communication. Perceived benefits of the approach incorporated comments on increased social connectedness, increased awareness of impact on environment and intentionality, and greater self-awareness and engagement.
Bodicoat A. (2013) <i>The Effectiveness of Intensive Interaction and its Use in Hospital Settings. Part Two: Using Intensive Interaction in Hospital Settings.</i>	To explore how hospital staff, who attended a training course on Intensive Interaction, experienced using the	Semi-structured interviews to produce qualitative data.	N=7	Interview	Interpretative Phenomenological Analysis	3 main emergent themes were 'Using Intensive Interaction', 'Attempting to Improve the Patient's Experience in Hospital', and 'Involving Others'. The overarching



Unpublished PhD Thesis, University of Hull, Hull.	approach with people with intellectual disabilities					concepts of 'The Ideal' and 'Struggles Identified', highlighted the difficulties encountered in using the intervention.
Culham A. (2004) Getting in touch with our feminine sides? Men's difficulties and concerns with doing Intensive Interaction.	To explore male practitioner's experiences of using Intensive Interaction	Quantitative and qualitative	N=36 for questionnaire N=4 for interview (Randomly selected from the 36)	Questionnaire and interviews	Thematic analysis	Men using Intensive Interaction are concerned about issues of touch and the potential for their interactions with learners to be misinterpreted and misrepresented.
Elgie S. & Maguire N. (2001) Intensive Interaction with a woman with multiple and profound disabilities: a case	Evaluating the use of Intensive Interaction with a woman with a profound intellectual	Quantitative  AB design used for hand contact and self-injurious	N=1	Direct observational measures and video analysis	Data analysed by two therapists and compared for inter-rater reliability.  Outcome measures utilised were 'Hand	Obvious increase in amount of hand contact initiated, no appreciable change in self-injurious behaviour and notable increase in vocalisations

study.	disability	<p>behaviour measures</p> <p>A: Baseline (6 months)</p> <p>B: Intervention (Three 25 minute sessions a week for 16 weeks)</p> <p>BA intervention utilised for vocalisation measures.</p> <p>B: 20 minute session</p> <p>A: Therapist removed themselves</p>			<p>Contact per Session', number of incidents of self-injurious behaviour and 'Incidence of Vocal Behaviours in Five Minute Time Periods'.</p>	<p>during intervention and decrease after session</p>
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		from the room for 10 minutes				
Firth G., Elford H., Leeming C. & Crabbe M. (2008) Intensive interaction as a novel approach in social care: care staff's views on the practice change process.	To report on the significant and influential issues for care staff when adopting Intensive Interaction as a novel approach in the social care setting for clients with profound and multiple learning disabilities	Qualitative	N=29	Semi structured interviews	Grounded theory methodology	Emergent themes: 'The level of client responses attributed to Intensive Interaction', 'Staff's conceptualisation of Intensive Interaction and its potential outcomes', 'Staff's views of client's communicative means, personal attributes and level of understanding', 'Issues related to staff – client relationships', 'Philosophical issues influencing the care environment', 'Practical, personal and temporal issues affecting the use of Intensive Interaction'

						and 'Issues related to the momentum of approach adoption'
Kellett M. (2000) Sam's story: evaluating Intensive Interaction in terms of its effect on the social and communicative ability of a young child with severe learning difficulties.	To evaluate the efficacy of the Intensive Interaction approach	AB design  Quantitative and qualitative  Longitudinal quasi-experimental	N=1	Systematic video-recorded observation and historical log	Videos coded for 8 indicators of social behaviour: no interactive behaviour, looking at face, happy/smiling face, reciprocal social physical contact, eye contact, joint focus/activity, contingent vocalisation, engaged. Pre-Verbal Communication Schedule (PVCS) and Physical	'No interactive behaviours': decrease  'Looking at face': 0% baseline to highest point 52%  'Happy/smiling face', 'social physical contact', 'eye contact' and 'contingent vocalisation': modest increase  'Joint focus/activity': increase from 19.8% to 52% peak  PVCS score increased

					Sociability Assessment Scale (adaptation of Cuddliness Scale)	from 0 to nearly 90.  Physical Sociability Assessment Scale increased from 1 up 4 (8 is the highest point of the scale)
Kellett M. (2003) Jacob's journey: developing sociability and communication in a young boy with severe and complex learning difficulties using the Intensive Interaction teaching approach.	To evaluate the efficacy of Intensive Interaction in developing the social and communication ability of a young boy with severe learning difficulties	AB design Quantitative (coded video data) and qualitative (historical log) A: 5 week baseline B: 42 week intervention (disruption from week 13 to week 24)	N=1	Video observation	Video data coded using social behaviours including eye contact, looking at face, smiling, social physical contact, vocalisation and stereotypical activity. Pre-Verbal Communication Schedule (PVCS) and Physical	Average Percentages for Coded Behaviours:  <u>No interaction</u> Baseline (B): 82.9% Intervention (I): 11.6%  <u>Looking at face</u> B: 8.4% I: 48%  <u>Joint focus</u> B: 3.7% I: 65.5%

		Longitudinal quasi- experimental			Sociability Assessment Scale (adaptation of Cuddliness Scale)	<u>Eye contact</u> B: 0.6% I: 18.6%  <u>Physical contact</u> B: 0% I: 23.9%  <u>Engagement</u> B: 2.6% I: 46.4%  <u>Stereotypy</u> B: 66.7% I: 3.8%  <u>PVCS</u> B: 14.3 I: 56.6
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						<u>Physical Sociability</u> <u>Assessment Scale</u> B: 1 I: 4 (out of 8)
Kellett M. (2004) Intensive Interaction in the inclusive classroom: using interactive pedagogy to connect with students who are hardest to reach.	To examine the role of Intensive Interaction in interactive pedagogy for students with severe and complex learning difficulties.	AB design Quantitative A: 6 week baseline B: 1 year weekly intervals (reducing to fortnightly later in the study)  Longitudinal quasi- experimental	N= 1	Systematic 5 minute videotaped observations	Video data coded using social behaviours; eye contact, looking at or towards the face of the interactive partner, smiling, vocalization and engagement.	Average Percentages for Coded Behaviours: <u>Looking at face</u> B: 5% I: 31%  <u>Social physical contact</u> B: 2.5% I: 28.2%  <u>Eye contact</u> B: 0% I: 42% (peak)  <u>Joint focus</u> B: 14% I: 67% (highest peak)

						93%)  <u>Engagement</u> B: 2% I: 82% (peak)
Kellett M. (2005) Catherine's legacy: social communication development for individuals with profound learning difficulties and fragile life expectancies.	To evaluate case study evidence to illustrate how an 11 year old girl's quality of life was transformed by Intensive Interaction.	Quantitative Longitudinal quasi-experimental	N= 1	Video observations	Video data coded using social behaviours; eye contact, looking at face, smiling, contingent vocalisation, joint focus and engaged social interaction.  Not all social behaviours were relevant to Catherine due to certain mobility restrictions.	Average Percentages for Coded Behaviours:  <u>No interaction</u> Baseline (B): 82% Intervention (I): 56%  <u>Eye contact</u> B: 14% I: 37%  <u>Joint Focus</u> B: 0.4% I: 28% (peak of 40%)



<p>Leaning B. &amp; Watson T. (2006)</p> <p>From the inside looking out - an Intensive Interaction group for people with profound and multiple learning disabilities.</p>	<p>To describe the use of a new project, 'from the inside looking out' (FILO), to develop communication, interaction and emotional literacy skills with people with profound and multiple learning disabilities.</p>	<p>Quantitative (video data) and qualitative (discussion among facilitators)</p> <p>Baseline: 50 minute video observation prior to session</p> <p>Intervention: 8 weekly 50 minute sessions.</p> <p>Follow up: 4 weeks after intervention</p>	<p>N= 5</p>	<p>Video observations</p> <p>Notes recorded of discussions</p>	<p>Momentary time sampling to code video data based on 5 behaviours; eye contact with others, object orientated eye contact, self-stimulation, smiling and active avoidant behaviour.</p>	<p>3 of 5 clients' results presented in paper.</p> <p><u>Mark</u></p> <p>Previously very avoidant. Began to present with more positive behaviours and reduced the amount of avoidant behaviours. Active avoidant behaviours had increased again at follow up and smiling and eye contact had decreased again.</p> <p><u>Nina</u></p> <p>Difficult to engage initially. Increase in smiling, eye contact with</p>
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						<p>others and eye contact orientated to objects. Active avoidant behaviours reduced from 83% to below 20%. Scores reverted to baseline at follow up.</p> <p><u>Sheila</u></p> <p>Low frequency of eye contact to either self or other at baseline and follow up but significantly higher levels during intervention.</p>
Rayner K. & Bradley S., Johnson G., Mrozik J. H., Appiah A. & Nagra M. K. (2016) Teaching intensive interaction to paid carers: using	To ask three paid carers that trained in Intensive Interaction	Qualitative	N= 3	Semi-structured interviews	Interpretative Phenomenological Analysis (IPA)	<p>Emergent themes:</p> <p><u>Investment</u></p> <ul style="list-style-type: none"> <li>Feelings of personal development</li> </ul>

<p>the 'communities of practice' model to inform training.</p> <hr/>	<p>about their experience and how training had changed their work with people with learning disabilities.</p>					<ul style="list-style-type: none"> <li>• Connection to client</li> <li>• Experiential nature of the training</li> <li>• Joy and amazement at progress and effectiveness of programme</li> </ul> <p><u>Transformation</u></p> <ul style="list-style-type: none"> <li>• Change in clients</li> <li>• Shift in staff attitudes</li> <li>• More choice and autonomy among clients</li> <li>• Empowerment of staff and clients</li> <li>• Unity within the</li> </ul>
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						<div>team</div> <div><ul style="list-style-type: none"><li>• Need for entire workforce training</li></ul></div> <div><u>Challenges</u></div> <div><ul style="list-style-type: none"><li>• Initial resistance due to fear of unknown</li><li>• Change in attitude from resistance to inclusion</li><li>• Staff and clients profoundly affected</li><li>• Need for Intensive Interaction to be a 'way of life', not just an intervention</li></ul></div>
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Samuel J., Nind M., Volans A. & Scriven I. (2008) An evaluation of Intensive Interaction in community living settings for adults with profound intellectual disabilities.	To evaluate the use of Intensive Interaction in community living settings for adults with profound intellectual disabilities	<p>Quantitative and qualitative</p> <p>Quasi-experimental interrupted time-series multiple-baseline design</p> <p>Staff training: half day workshop</p> <p>Staggered baseline phase of six weeks commencing a week apart for each</p>	N= 28 4 participants 3 practitioners and 3 observers per participant	<p>Video observation</p> <p>Staff questionnaires</p> <p>Session reflection records</p> <p>Historical logs</p>	<p>Video data coded using behaviours;</p> <p>Practitioner behaviour codes; mirroring vocalization and movement, contingent responding and forcing/overriding.</p> <p>Participant behaviour codes; visual scanning, looking at face, engagement, joint focus and initiating social/physical contact.</p>	<p>Increase in practitioner's use of mirroring of movements and vocalization and contingent responding.</p> <p>Indications that the process caused practitioners to become more reflective practitioners.</p> <p>Participants showed increased ability to engage in social interaction and do joint focus. Development of initiation of social/physical contact was difficult to reliably capture.</p>
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		participant. Intervention: 5 sessions per week over 20 weeks			Assessment schedules	<p>PVCS score showed improvements compared to baseline.</p> <p>Improvements noted for all four participants in the Interactive Sequence measure.</p> <p>Physical Sociability Scale improvements evident for all.</p> <p>Staff questionnaire data indicated a belief that Intensive Interaction would enhance the skills of the participants and lead to progress.</p>
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						<p>Reflection records reported eye contact throughout for all participants.</p> <p>Staff questionnaire analysis revealed 'team cohesion' as the most dominant theme.</p> <p>Observer data revealed 'benefits for staff' as most common theme. Reflection record data generally rated experience as 'positive' for participants and practitioners.</p>
Watson J. & Fisher A. (1997) Evaluating the effectiveness of	To evaluate the effectiveness of Intensive	Quantitative Sessions	Research study 1: N= 6	Research study 1: Observations	Research study 1: Video tape analysis Observation note	<p><u>Research study 1:</u></p> <p>Discrepancies between PVCS description and</p>

Intensive Interaction teaching with pupils with profound and complex learning difficulties.	Interaction teaching pupils with profound and complex learning difficulties	videoed at six weekly intervals on up to six separate occasions for each staff/pupil pair over the course of one school year	Research study 2: N= 5	Videotaped records  Research study 2: Observations Videotaped records	analysis PVCS  Research study 2: Video tape analysis and independent analysis of sample video extracts Observation note analysis	observed behaviour during Intensive Interaction  Behaviours observed during intervention;  Ben: Giving ball to his teacher on request. Cueing the end of the session by looking at door and moving towards it while holding teacher's hand.  Chris: Initiated games.  Anna: Shows/gives object in response to nursery rhyme. Indicates when she
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						<p>wants to be helped up or down by arm gesture.</p> <p>Pointing to picture accompanied by vocalisation.</p> <p>Using some basic vocabulary appropriately.</p> <p>Sean: Swaying in time to music.</p> <p>Indicating through arm movement when he wishes to leave the room/stop activity</p> <p>Theresa: Displayed expressive, contented sounds and laughter.</p> <p>Joseph: Vocalising</p>
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						<p>during session.</p> <p>Overall conclusion: Intensive Interaction provided context which facilitates communication</p> <p><u>Research Study 2:</u></p> <p>All pupils demonstrated higher levels of active participation and enjoyment during Intensive Interaction sessions.</p> <p>Martin: Showed signs of initiating games through arm and leg movements.</p>
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						<p>Showed increased eye contact, smiles and physical contact.</p> <p>Increased tolerance of handling</p> <p>Increased control over his movements</p> <p>Developed an understanding of cause and effect relationships</p>
<p>Zeedyk M. S., Caldwell P. &amp; Davies C. E. (2009a) How rapidly does Intensive Interaction promote social engagement for adults with profound learning disabilities?</p>	<p>To extend the evidence base for Intensive Interaction by investigating the rapidity with which an increase in engagement becomes apparent.</p>	Quantitative	N= 10	Videotapes	<p>Videos microanalytically coded for four measures of engagement; eye gaze, bodily orientation to partner, proximity to partner and emotional valence.</p>	<p>Increase for all participants on at least two measures of engagement.</p> <p>70% of sample showed increases in all four measures.</p> <p>Shifts occurred within a few minutes of the onset</p>

					Non-parametric analyses.	of the session (ranging from three to fourteen minutes).
Zeedyk S., Davies C., Parry S. & Caldwell P. (2009b) Fostering social engagement in Romanian children with communicative impairments: the experiences of newly trained practitioners of Intensive Interaction.	To foster social engagement in Romanian children with communicative impairments by training volunteers in the use of Intensive Interaction.	Quantitative (video data) and qualitative (volunteers' written accounts)  Training of volunteers: two 30min sessions	N= 40 (12 volunteers and 18 children)	Videotapes  Micro analytic observational techniques  Written accounts by volunteers	Videotapes coded to assess children's level of social engagement with volunteers before introduction of Intensive Interaction and then during the interactive sessions.  Thematic analysis of volunteer accounts	<u>Quantitative data:</u>  Intensive Interaction effective in promoting social engagement- Children spent significantly longer looking at partners when Intensive Interaction was being used than when it was not.  <u>Qualitative data:</u>  All volunteers reported observing increases in the children's social engagement.

						<p>Four key behaviours identified by volunteers included attention to partner, positive affect, proximity to others, and flexibility of interaction.</p> <p>Eight of the volunteers noticed a reduction in children's distress and self-harm.</p> <p>Eleven of the 12 volunteers commented on how Intensive Interaction had intensified their relationships with the children.</p>
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						<p>Four volunteers described feeling uncertain about their effectiveness in employing Intensive Interaction.</p> <p>Six volunteers commented on initial doubts and surprise at the positive outcomes observed.</p>
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## Appendix 2. Summary Table for Literature Reviews and Systematic Reviews

Author(s) & Title	Research Question/ Purpose	Search Strategy/ Inclusion/ Exclusion Criteria	Search Terms	Detail of Literature /Study Selection	Quality Assessment (where applicable)	Data Synthesis (where applicable)
Firth G. (2006) Intensive Interaction: a research review.	To explore the research papers that are clearly focused on the social responses of the learning disabled person to intensive interaction.	Papers sourced through <a href="http://www.intensiveinteraction.co.uk">www.intensiveinteraction.co.uk</a> and by following a reference trail through the appropriate papers.	Not stated	3 studies with adult participants 3 studies with child participants	Not stated	Not stated
Hutchinson N. & Bodicoat A. (2015) The effectiveness of Intensive	What are the effects of using Intensive Interaction with a person with an	Computerized search including CINAHL, PsychInfo, Medline, ERIC and Web of Science.	Synonyms for 'intellectual disabilities' or 'autism' combined with	Studies included: (i) participants of any age with an intellectual	Studies were not excluded based on quality due to small literature	Narrative synthesis, with themes of: training practitioners,

Interaction, a systematic literature review.	intellectual disability or autism on social communication, self-injurious behaviour and repetitive behaviour? Are these effects influenced by the training of practitioners or staff experience?	<p>Inclusion/Exclusion Criteria:</p> <p>Studies relating to people with intellectual disabilities and autism were included.</p> <p>No age restrictions applied.</p> <p>Studies from a social and educative background were included.</p> <p>No restrictions placed on amount or type of training received by practitioners.</p> <p>Both quantitative and qualitative studies included.</p> <p>Purely narrative descriptions of case studies excluded.</p>	<p>synonyms for 'Intensive Interaction';</p> <p>'menta*' OR 'mental*' OR 'handicap*' OR 'mental* retard*' OR 'mental* impair*' OR 'mental* disab*' OR 'mental* subnormal*' OR 'learning disab*' OR 'learning difficult*' OR 'intellectual difficult*' OR 'intellectual* disab*' OR</p>	<p>disability or autism, (ii) using intensive interaction as an intervention, (iii) examining the effect (s) or outcome (s) of using Intensive Interaction and (iv) in a peer-reviewed journal, or be in the process of submitting to a peer-reviewed journal, or be</p>	<p>base.</p> <p>The single case experimental design (SCED) checklist (Tate <i>et al.</i> 2008) was used to assess the quality of any single case or small sample experimental designs.</p> <p>Qualitative studies were assessed using a quality framework</p>	<p>effectiveness of intensive interaction, staff experience, anecdotal evidence and sustainability of interventions.</p>
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			<p>‘intellectual impairm*’ OR  ‘developmental disabilit’ OR  ‘autis*’ OR  ‘ASD’ OR  ‘Preverbal’ OR  ‘Prelingual’ OR  ‘develop* dela*’  AND ‘intensive interaction’ OR  ‘augmented mothering’ OR  ‘Hanging out program’ OR  ‘From Inside Looking Out’  OR ‘FILO’ OR  ‘imitative interaction’.</p>	<p>in the process of submitting to a peer-review journal for publication.</p>	<p>from the (National Institute for Health and Care Excellence (National Institute for Health &amp; Care Excellence 2012)).</p>	
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### Appendix 3- Overview of Search Strategy

