

AFFECT ATTUNEMENT IN COMMUNICATIVE INTERACTIONS BETWEEN
ADULTS WITH PROFOUND INTELLECTUAL AND MULTIPLE DISABILITIES
AND SUPPORT WORKERS

Submitted by

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ERRATA

- p.xi line 9: 'cross model' should read 'crossmodal'
- p.2 line 11: remove apostrophe: 'it's' should read 'its'
- p.2 line 3: from bottom 'mortality' should read 'early mortality'
- p.4 line 9: remove semi-colon after disabilities
- p.9 line 7: insert full stop after 'affect attunement'
- p.21 line 10: remove apostrophe in 'infant's'
- p.24 line 6: from bottom bring date and page no. ('2004, p. 334') to immediately after 'Hatton'
- p.27 line 15: 'criteria' should read 'criterion'
- p.31 line 2: 'researcher' should read 'researchers'
- p.32 line 5: 'less the' should read 'less than'
- p.33 line 14: insert 'in England' after 'settings'
- p.34 line 5: insert 'in Scotland' after 'services'
- p.34 line 18: insert apostrophe: 'workers' language'
- p.35 line 5 from bottom: insert ', in Scotland,'
- p.36 line 13: insert 'the current researcher' before 'Forster'
- p.37 line 14: 'particular' should read 'particularly'
- p.37 line 17: 'caregiver's' should read 'caregivers''
- p.38 last line: 'by' should read 'but'
- p.41 line 16: 'DSW's' should read 'DSWSs''
- p.44 line 3: 'comprised of' should read 'comprised'
- p.46 line 6: 'client's' should read 'clients''
- p.47 line 2: 'potential' should read 'potentially'
- p.47 line 4: 'on' should read 'own'
- p.76 line 3: 'lead' should read 'led'
- p.76 line 12: 'Mother's' should read 'Mothers''
- p.76 line 17: 'modify' should read 'modifying'
- p.76 line 22: 'describe' should read 'described'
- p.83 line 18: 'establishement' should read 'establishment'
- p.87 line 6 from bottom: 'Consent' should read 'informed consent'
- p.120 line 18: 'of' should read 'or'
- p.120 line 19: 'uses' should read 'use'
- p.164 line 13: remove 'with people'
- p.169 line 12: remove comma before full stop
- p.173 line 10: should read 'Alternatively, or in combination, it may be due'
- p.173 line 14: 'study by Forster (2006)' should read 'the current authors earlier study, Forster (2006),'
- p.176 line 5 from bottom: remove duplicate full stop
- p.188 line 3 from bottom: 'parents their children' should read 'parents and their children'

ADDENDUM

p.6 end para 2: insert ‘To date, intersubjectivity has been examined in mother-infant dyads; father-infant dyads and other close dyads have not been examined. Given the largely nonverbal nature of these interactions and the early developmental age of the infants, these studies may have relevance to the interactions of adults with PIMD.’

p.8 line 1: insert ‘**Why this research is important**

Understanding the nature of interactions between adults with PIMD and their DSWs is pivotal for improving the life quality of adults with PIMD. Affect attunement has been proposed by Stern (1985) to be an aspect of good quality interaction; it may serve similarly in the dyads being studied, should it be found to be a feature of these interactions.’

p.103 line 1: Insert the following after ‘Percentage agreement was used for the preliminary study as an initial measure of the extent to which two raters agreed when coding a data sample.’

‘Percentage agreement, as opposed to Kappa, was selected to provide a meaningful and initial indicator of reliability, considered appropriate for the pilot phase of the study.’

p.129 line 3 from the bottom: after ‘20 min’, insert ‘Twenty minutes was comparable to the 15 min plus 5 min warm up used by Stern et al. (1985). It allowed for 10 min of continuous video to be selected for analysis.’

p.130 line 2: after ‘camera was still running’, insert ‘Intermittent non-presence of the camera operator was felt to reduce potential effects of the presence of the researcher while still ensuring continued operation of the camera’.

p.130 end line 7, insert: ‘In line with Jonsson et al. (2001; 2006) and Stern et al. (1985), the DSWs were instructed to interact “as usual”, in the context of their choice that would involve exclusively the DSW and target adult with PIMD. They were asked to select a context that did not involve intimate care.’

p.165 line 17: prior to ‘Reasons for the lower occurrence’, insert ‘The frequency of incidents may be viewed as either positive, given that affect attunement is naturally present and hence may be able to be increased with instruction, or conversely, be viewed as concerning, given that the incidents are rare and fleeting. The implications of frequency require future investigation.’

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DEFINITIONS AND ACRONYMS

Disability Support Worker

Disability support workers (DSWs) are paid to support people with disabilities. In the current study, DSWs provide support in the residential context, unless otherwise specified. DSWs provide daily care in the areas of personal care, activities of daily living, and leisure. They may be employed by government or non-government organisations.

Intellectual Disability

People with intellectual disabilities have cognitive developmental impairment that affects areas of cognition, such as attention, problem solving, and memory. Levels of intellectual disability are categorised by IQ levels: mild (50-69), moderate (35-49), severe (20-34), profound (<20) (World Health Organisation, 1996). People with intellectual disabilities will also have difficulties with adaptive behaviours, such as activities of daily care (e.g., cooking and cleaning), communication (e.g., describing past events and using text), and community engagement (e.g., engaging accurately with money or navigating communities).

Profound Intellectual Disability

People with profound intellectual disability (PID) have been described as having an IQ score of less than 20; in practice, they are often unable to score on any existing formal measure of assessment. They are severely limited in their ability to understand or comply with requests or instructions, may have little or no ability to care for their own basic needs, and require constant help and supervision (World Health Organisation, 1996). There are currently no standardized tests that are applicable for a valid estimation of intellectual capacity for people with PID.

Profound Intellectual and Multiple Disabilities

People with profound intellectual and multiple disabilities (PIMD) have core features of profound intellectual disability and physical disability. In addition, they may have sensory impairment and medical complications (Nakken & Vlaskamp, 2007).

ABSTRACT

The quality of life of people with profound intellectual and multiple disabilities (PIMD) is affected by many factors, including health status, involvement in activities, and social networks; but most critical is the quality of interaction experienced by the person on a daily basis. For many people with PIMD, most of whom reside in residential services where they receive 24-hour support, the primary people for interaction are paid disability support workers (DSWs).

Quality interaction is difficult to define and such definition is made more complicated when one of the communication partners does not use or seem to understand speech. Research on communication and people with intellectual disability has focused largely on people with existing symbolic communication skills (i.e., people who use words, pictures, or signs to communicate) or developing the skills of pre-symbolic communication so they can become symbolic (e.g., developing the use of objects as symbols or other consistent ways for expressing wants and needs). In interventions that aim to move a person to use symbolic communication, the focus has been on human agency. Agency refers to the quality of an individual expressing what s/he wants and a communication partner recognising that expression. Agency has been the underlying construct of interventions focused on enhancing choice and preference expression, and in research in which the estimated comprehension of the person with a disability is measured against the complexity of communication used by interaction partners. The findings of such research have indicated a tendency for DSWs' communication to be at a higher level than the assessed comprehension level of their clients.

Far less attention has been given by communication specialists in the intellectual disability field to concepts related to social closeness or interactive relationships, in

which the goal is not the transfer of information, but just being together with another person. Some theorists have labelled such feelings of togetherness as intersubjectivity. Although there have been differences in definitions across theorists, intersubjectivity broadly refers to the sharing of minds of two people. It has been used largely in infant development to describe the nature of interaction between parents and infants, and the way that expressions of emotion are shared through subtle intimate interactions. Stern (1985) described three particular types of intersubjectivity: interattentionality, interintentionality, and interaffectivity or affect attunement. Affect attunement refers to the use of cross model means to recast affect expressions to share feelings. The use of affect attunement by a mother with her infant has been suggested to be a key feature of the quality of an interactive relationship.

The examination of affect attunement in interactions between DSWs and adults with PIMD offers the potential to open new avenues for describing quality of interactions. The aim of the present study was to see if affect attunement is used and, if so, describe the nature of affect attunement used by DSWs in their interactions with adults with PIMD in natural interactions in residential settings. In particular, the focus was on describing the frequency, modal and amodal qualities of the behaviours of both participants, and examining relationships between DSWs' gender, parenting experience, and length of time working with the person and their affect attunement.

Interactions from 21 pairs of DSWs and adults with PIMD were video-recorded and 10 minutes of each dyad was analysed using the Affect Attunement and Behavioural Coding manual. Sixty-four incidents of affect attunement were found across 16 dyads. DSWs attuned to behaviours of the person with PIMD characterised by motor effort, attention, and some emotional expression. DSWs often used similar modes

of expression to attune to the eliciting behaviour, but also used speech to demonstrate their attunement. Five DSWs did not use affect attunement.

Exploring interaction from an intersubjective perspective has clear merit. Affect attunement is a pre-existing strength used by DSWs that may be enhanced. It may act as a much better indicator of quality of interactions than indicators focusing on the agency expressions of the person with a disability. Further research is needed to establish the relationship between the use of affect attunement and the quality of interactions. Being aware of the presence of affect attunement may have implications for therapists, both for their own engagement with people with PIMD and implications for how to encourage existing skills and support DSWs to further enhance interaction.

DECLARATION OF AUTHORSHIP

I declare that the information in this thesis is the result of work carried out by myself under the supervision of Professor Teresa Iacono of Monash University. The thesis has not been submitted to any other tertiary institution for the award of any other degree. To the best of my knowledge and belief, the thesis contains no material previously published by another person, except where due reference is made.

Sheridan Forster

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communication), and Christopher and his father Clive Tongon. They have all taught me that we can do better for people with profound intellectual and multiple disabilities.

CHAPTER ONE

INTRODUCTION

Context of the Problem

People with Profound Intellectual and Multiple Disabilities

The International Association for the Scientific Study of Intellectual Disability (IASSID) have formed the Profound Intellectual and Multiple Disability Special Interest Research Group (PIMD-SIRG) (Nakken & Vlaskamp, 2002; Nakken & Vlaskamp, 2007). The group, through discussions between prominent researchers in the area, have provided the following definition of PIMD, which is adopted in the current study:

Individuals with profound intellectual and multiple disabilities form a heterogeneous group. The 'core group' consists of individuals with such profound cognitive disabilities that no existing standardized tests are applicable for a valid estimation of their level of intellectual capacity and who often have profound neuromotor dysfunctions for example, spastic tetraplegia. In addition to profound intellectual and physical disabilities, it has been demonstrated that they also frequently have sensory impairments. Individuals with PIMD form a physically very vulnerable group of persons with a high dependence on personal assistance for everyday tasks, 24 hours a day. (IASSID Special Interest Research Group: Profound Intellectual and Multiple Disabilities, n.d.)

Profound intellectual disability is a key defining feature of people with PIMD. People with PID have a high likelihood of experiencing multiple disabilities (Arvio & Sillanpaa, 2003), hence not all people with PID can be defined as having PIMD. People with PIMD are often non-ambulatory and might have little or no use of their hands or

arms (Vlaskamp, Hiemstra, & Wiersma, 2007). In one of the largest and most detailed studies to date on this population, Kobe, Mulick, Rash, and Martin (1994) investigated the physical, developmental, and behavioural characteristics of a group of 203 non-ambulatory people with PID who lived in an institutional setting. They found that 71.8% experienced seizures, 31.5% had scoliosis, 24.7% required gastrointestinal feeding, and almost half of the group demonstrated self-injurious behaviours.

In addition, many people with PIMD, who by definition subsume those with PID, have been found to present with visual, hearing, or dual sensory impairments (Evenhuis, Theunissen, Denkers, Verschuure, & Kemme, 2001; Fellingner, Holzinger, Dirmhirn, Dijk, & Goldberg, 2009), but frequently these impairments have gone undiagnosed (Evenhuis, et al., 2001; Fellingner, et al., 2009). High rates of mental illness have also been reported in the population, with Cooper et al. (2007) reporting its occurrence (excluding autism and problem behaviours) in 19.2% of 184 adults with PID receiving clinical assessments.

People with PIMD have little or no expressive language skills (Vlaskamp, et al., 2007). Some people with PIMD may appear to be unaware of the presence of people around them (Lacey, 1995); children with PIMD are often regarded as passive and non-attentive (Brodin, 2005). People with PIMD have difficulties with information processing and short-term memory (Siegel & Cress, 2002; Ware, 2005) and may spend a large amount of time in states not conducive to learning, such as in drowsy or daze states (Arthur, 2003; Munde, Vlaskamp, Ruijsenaars, & Nakken, 2009). Many people also have been found to experience significant sleep problems (Espie, et al., 1998; Lancioni, O'Reilly, & Basili, 1999). Additionally, rates of mortality are known to be higher than that of people with other levels of ID; such rates indicate the need for more effective health care (Hogg, Juhlberg, & Lambe, 2007).

The combination of multiple impairments, physical health conditions, and severely delayed and arrested development have the potential to contribute to a very different interactional experience for this population and their interaction partners in comparison with other groups. Perception, processing, and output of information are severely compromised for a person with PIMD. People with PIMD may develop some skills as they age, however Vlaskamp (2005b) argued that their skills may not be those typically seen as important by society, such as grasping objects or making new sounds.

People with PIMD comprise a small group within the population of people with intellectual disability. In a comprehensive epidemiological study, Wellesley, Hockey, Montgomery, and Stanley (1992) reported a prevalence of 0.06% of people with PID in the population of Western Australian. However, the numbers of people in the subgroup with PIMD were not stated. More recently, Emerson (2009a; 2009b) reported that the number of people with PIMD in England, currently estimated to be 16,442 (0.03% of the population), would accelerate further in years to come, with a greater number of people reaching adulthood, a pattern that could also be true in Australia. To date, there are no data indicating prevalence of adults with PIMD in Australia.

Despite the relatively small numbers of people with PIMD, this group with significant support and health needs requires specific attention from the research and practice communities. Their needs differentiate them from groups of people with mild to severe levels of ID, and consequently the nature of the support that they receive may also need to be substantially different (Dawkins, 2009).

People with PIMD Living in Group Homes

The target group for of this study is adults with PIMD living in group homes in two Australian states: Victoria and Tasmania. To date, there have been no reports on the number of adults with PIMD living in group homes run by either government or non-

government organisations in Australia. In neither Victoria nor Tasmania is the level of intellectual disability systematically recorded, and the term PIMD is not regularly used. Subsequently, in these states, it is not possible to know how many adults with PIMD live in their family home, how many live in small group homes, or reside in large residential settings, such as institutions, congregate care homes, or nursing homes. The lack of reporting of residential contexts might have an impact on both targeting unique supports to this group, and to the capacity for engaging them in research.

Adults with PIMD living in group homes receive 24-hour care and need assistance with all aspects of daily living. Group homes usually consist of 4-6 people with disabilities; comprising those with either varying or similar levels of disability. During the day, many of these people attend adult day services.

Some people may have contact with next-of-kin, however this is not always so. Those without next-of-kin actively involved in their lives will have financial administrators (Disability Act, 2006; Victorian Department of Human Services, 2006), but few have any form of guardianship or ongoing advocacy, as both of these are usually granted in relation to a specific issue (Dearn, 2010; Department of Health and Human Services, Disability Services, & Tasmania's Disability Advocacy Services, 2007; Guardianship and Administration Act, 1986). Hence, for people without active next-of-kin, many decisions about a person's life are made by the organisations providing support, in line with a duty of care and attempts to involve the person in the decision.

Disability Support Workers

Disability Support Workers (DSWs) are paid to provide support to people with disabilities, and they hold a central place in the lives of people with intellectual disabilities (Hatton, Rose, & Rose, 2004). It is estimated that over 8,000 people work as

DSWs in the non-government sector in Victoria (VICRAID, ACROD, & CIDA, 2003). In Australia, the disability workforce comprises a large proportion of non-permanent staff, females, and part-time workers (ACT Health & Disability ACT, 2004). Features of the industry include difficulties attracting people to the work and a high staff turnover, compounded by a low level of remuneration given the nature of the work (ACT Health & Disability ACT, 2004; VICRAID, et al., 2003). One-third of non-government DSWs in Victoria work for at least two different employers (VICRAID, et al., 2003).

There are movements in the disability industry to ensure mandatory base grade qualifications, such as Certificate III or IV in disability studies (e.g., Disability ACT, 2007), however a large proportion of people working in the sector continue to have no post-school education (VICRAID, et al., 2003). DSWs have rarely received specific training or information on the particular needs of people with PIMD (PMLD Network, 2001; Vlaskamp, et al., 2007) and have often been required to provide independent support to these people with limited induction (VICRAID, et al., 2003). Despite recognition that DSW behaviour, through interactions, has a direct causal influence on the lives of people with intellectual disabilities (Hatton, et al., 2004), only some DSWs receive training in communication with people with intellectual disabilities, and often this training focuses primarily on people who have symbolic communication skills (e.g., words, signs or graphic symbols, such as pictures), with very little focus given to non-symbolic communication needs (Johnson, Douglas, Bigby, & Iacono, 2009; Workforce Development and Learning, 2008). Furthermore, it has been argued that the specialist knowledge needed to support development and social participation is often expected to be implicit and intuitive, rather than resulting from direct teaching (Maes, Lambrechts, Hostyn, & Petry, 2007).

Statement of the Problem

There have been advances in understanding of and interventions to support the communication of people with intellectual disabilities. These have been based on an understanding of interaction between people with intellectual disabilities and primary carers (families and DSWs). In contrast, the nature of interaction between people with the most severe disabilities, in particular between people with PIMD and their primary caregivers, usually DSWs, has received little attention in research. These interactions, because of the myriad of impairments and differences experienced by a person with PIMD, can be expected to be markedly different from interactions that occur between two speaking interaction partners.

The aim of this study was to describe the nature of interactions that occur between people with PIMD and their DSW. In order to address this aim, ways of describing interactions as presented in the literature were examined. The majority of existing descriptions of interaction and interventions focused on developing the agency of the person with PIMD: that is, developing the person's ability to express what he/she wants. In contrast, the interactive nature, and in particular the intersubjectivity that occurs between the person with PIMD and his/her DSW, has received little attention.

One form of intersubjectivity described in mother-infant literature is the use of affect attunement: that is, the immediate recasting of the emotional-behavioural state of one person by another person, using emphasized behaviours. Affect attunement is a naturally occurring interactive behaviour that occurs particularly between mothers and infants. In using affect attunement, mothers perceive an affective behaviour of their infant and recast the feeling back to the infant using different modalities or emphasis. Affect attunement involves both modal (e.g., facial expression, sounds) and amodal qualities (e.g., intensity, duration). Additionally, affect attunement has been reported to

be an indicator of the quality of interactions between mothers and their infants, and hence, has the potential, similarly, to provide some indication of the quality of interactions between adults with PIMD and their DSWs. There have been no studies to date examining discrete incidents of affect attunement in interactions between DSWs and people with PIMD.

The use of affect attunement in interactions between dyads of DSWs and adults with PIMD was selected as the system to describe interaction in this study. The nature of interactions was hence described through coding of qualities of affect attunement, including frequency, duration, intensity, shape, modalities, and nature of the behaviour of a person with PIMD that elicited an affect attunement response from a DSW.

Research Aims and Questions

The aim of the current research was to describe the nature of affect attunement used by DSWs in their interactions with adults with PIMD in natural interactions in residential settings.

The following research questions were addressed:

1. Do DSWs use affect attunement in interactions with adults with PIMD?
2. How frequently is affect attunement used by DSWs in their interactions with adults with PIMD?
3. What are the amodal and modal qualities of affect attunement used in the dyad?
4. What are the behaviours of the person with PIMD to which the DSW attunes?
5. What is the relationship between DSWs' gender, parenting experience, and length of time working with the person and their affect attunement?

Thesis Outline

This research is presented in six chapters. Literature relating to interactions between adults with PIMD and DSWs is presented, followed by a proposal for examining interaction from an intersubjective perspective with a particular focus on affect attunement. A preliminary study outlining the validity and reliability of a tool for measuring affect attunement follows the literature review. The main study is presented with a chapter addressing the method and measures of reliability, followed by the study results. The research concludes with a discussion focusing on the implications of the study for both DSWs and professional staff supporting DSWs (e.g., speech pathologists) and addressing needs for further research.

CHAPTER TWO

LITERATURE REVIEW

Introduction

This chapter provides a review of the literature pertaining to interactions between adults with PIMD and DSWs. The importance of this dyad is positioned within the context of quality of life. An overview of literature regarding the individual communication skills of people with PIMD is provided, followed by research focusing on dyadic communication. Dyadic interaction is described in the contexts of descriptive and intervention studies. A contrasting perspective for examining the dyad will then be presented: intersubjectivity, and in particular, affect attunement

Profound Intellectual and Multiple Disabilities

Since 1999, with the establishment of a Special Interest Research Group on PIMD within the International Association for the Scientific Study of Intellectual Disabilities (IASSID) (Nakken & Vlaskamp, 2002), research focusing on this group of people has grown, but has been beset by several challenges. Nakken and Vlaskamp (2002) identified 35 articles on people with PIMD published from 1996 to 1999. In conducting this review, they also noted 13 different descriptors for identification of people with PIMD (e.g., multiple disabilities, severe and profound multiple learning disabilities, pre-symbolic communicators). Difficulty with population definition continues to be a problem in both research and in practice, contributing to reduced visibility of the specific needs of people with PIMD (Carnaby & Pawlyn, 2009; Granlund & Olsson, 1999; Hogg, et al., 2007; Nakken & Vlaskamp, 2007). More recently, there has been evidence of an increase in the use of the term PIMD in research in international forums (e.g., Fornefeld, 2008; Hogg, 2007). Additionally, in some countries, such as Finland (Arvio & Sillanpaa, 2003; Patja, Iivanainen, Vesala, &

Oksanen, 2000) and some counties in the UK (Carnaby & Pawlyn, 2009; Emerson, 2009b; Gittins & Rose, 2008; Samuel & Pritchard, 2001), registers and labelling of people with PIMD has enabled greater access to people with PIMD for research participation and more effective lobbying for their specific needs.

Also impacting on the body of research on people with PIMD, in addition to issues of identification, small population numbers, and problems with definition of PIMD, has been the increased regulation of ethical review processes (Boxall & Ralph, 2009). People with PIMD are not able to provide informed consent for participating in research because of their cognitive impairment. In acknowledgement of the inability to gain fully informed consent, some researchers have incorporated forms of assent in research methods, indicated through lack of signs of distress that might be associated with their involvement in the research process (Kellett & Nind, 2001). For most people with PIMD, consent must be provided by another person. Regulations about who can provide consent vary both across and within countries, and the types of research being conducted. In some places (e.g., Austin, TX, as cited by Advocacy Incorporated, 1997), next-of-kin can provide consent for adults without capacity to provide their own consent only if they have been appointed as legal guardians. However, a problem may arise if the person does not have active next-of-kin or formal guardian. For these individuals, DSWs may seem an obvious alternative given they often know the person with a disability well. However, these individuals have been frequently excluded from this role: for example, Iacono (2009) noted that legislation within Victoria, Australia, precluded paid carers from being able to provide proxy consent. Similarly, Boxall and Ralph (2009) noted concerns expressed by some ethics committees that staff loyalties to organisations would preclude them from being appropriate for providing proxy consent

(Boxall & Ralph, 2009) . Issues arising regarding who can provide consent may severely constrain the participation of people with PIMD in research (Iacono, 2006).

Nevertheless, research focusing on people with PIMD has grown in the past two decades, with over 100 peer reviewed articles published between 2006-2009, as indicated by a systematic search (search terms used were profound intellectual and multiple disabilit*, profound and multiple learning disabilit*, PIMD, PMLD, or multiple disabilit*) compared to the 35 identified by Nakken and Vlaskamp 10 years earlier. Carnaby (2004), in a report commissioned by MENCAP, reviewed research focusing on people with PIMD. He focused on journals published in the UK (e.g., *Journal of Intellectual Disability Research* and *Tizard Learning Disability Review*) from the late 1980s, alongside practitioner focused and academic texts. He identified seven topic themes, which are outlined in Table 2.1. The majority of articles included in this review, and in more recent peer-reviewed journals, were descriptive studies either using quantitative observation tools (e.g., Samuel, Nind, Volans, & Scriven, 2008; Vlaskamp, de Geeter, Huijsmans, & Smit, 2003) or survey and file review methods (e.g., Neilson, Hogg, Malek, & Rowley, 2000; van der Heide, van der Putten, van den Berg, Taxis, & Vlaskamp, 2009). The number of participants with PIMD in studies was mostly less than 15 (e.g., Elgie & Maguire, 2001; Jones, Pring, & Grove, 2002; Zeedyk, Caldwell, & Davies, 2009), with the exception of several studies from the Netherlands, in which sample sizes ranged from 100-260 (e.g., van der Heide, et al., 2009; van der Putten, Vlaskamp, & Poppes, 2009; Vlaskamp & Zijlstra, 2004). Several systematic reviews (e.g., Hogg, Cavet, Lambe, & Smeddle, 2001; Hostyn & Maes, 2009) and non-systematic reviews (e.g., Dobson, Upadhyaya, Conyers, & Raghavan, 2002) have also been published. In addition, numerous opinion papers exploring issues relating to people with PIMD have been published, in areas such as communication (e.g.,

Thurman, Jones, & Tarleton, 2005; Ware, 2004) and policy development (e.g., Dawkins, 2009). A review of this research base indicates that a focus has been on describing people with PIMD and their families from various perspectives, with there being a few intervention studies and no randomized control studies or meta-analytic reviews.

Table 2.1

Carnaby's (2004) Review of Research on People with PIMD: Themes

Theme	Number of journal articles cited	Summary findings
Service design and quality of life	14	Lower levels of engagement in activities and poorer quality of life for people with PIMD compared to people with mild-severe ID
Choice and decision making	4	People with PIMD can indicate preference and methods of assessing preferences have been developed
Communication	10	Pre-intentional communication has been described and there has been some research on communication between people with PIMD and DSWs
Meeting personal needs (therapeutic interventions, promoting independence, and skill teaching)	18	Clinical interventions, such as multisensory environments and Intensive Interaction, have shown some evidence of effectiveness in small studies
Sensory needs	2	Frequent sensory impairments experienced by people with PIMD have been described and recommendations for intervention have been made in practitioner texts
Staff training and staffing issues	5	Limited focus on staff training in research with evidence of the gaps in training in intimate and personal care
Parent and carer issues	9	Significant pressure on families of children and adults with PIMD, particularly with basic care tasks and stress on family relationships
Mental health and well-being	8	Small body of research looking at mood and depression in adults with PIMD
Challenging behaviour	5	High prevalence of challenging behaviour in people with PIMD has been reported
Physical health	6	Many people with PIMD have ongoing health care needs, including epilepsy and being severely underweight, which are complicated by inability to verbally report pain and distress
Personal relationships	3	Limited research exploring the nature of friendship and the complexities of relationships with people with PIMD

Quality of Life

The conceptualization of quality of life for people with PIMD has changed over the years. In the 1970s, quality of life was described mainly in terms of skill description and development (Meyers, 1978). Later, Whitaker (1989) stated that improvements in skills and choice making opportunities were key dimensions of quality of life of people with PIMD. At this time, the importance of the relationship with DSWs and human contact in which carers value the person with a disability and spend time building a relationship was also beginning to be discussed (Whitaker, 1989). More recently, there is evidence that relationships based on a safe attachment between people PIMD and their DSWs has been considered as essential to the person with PIMD's well-being (Petry & Maes, 2007). Hence, communication in the form of skills, choice making, and relationships, has, for many years, been considered to be an important part of the quality of life for people with PIMD.

Broadly, quality of life for people with intellectual disabilities has been conceptualised according to domains of physical wellbeing, material wellbeing, social wellbeing, emotional wellbeing, and development and activity (Felce & Perry, 1995b). Petry, Maes, and Vlaskamp (2005), interested in whether the same domains held true for people with PIMD, spoke to 40 parents and 36 DSWs about their perspective on quality of life for a person with PIMD for whom they cared. They found that while the domains described were the same as those described by Felce and Perry (1995b), the subdomains and operationalisation of the domains were quite different for people with PIMD. These subdomains are summarised in Table 2.2. A large number of the subdomains are related to communication (e.g., positive affect, choice, and social participation) and, in particular, the interactive relationship between the person with PIMD and those providing care. Basic security was mentioned by 80.3% of caregivers who referred

specifically to “a secure attachment with a sensitive responsive parent and/or direct support staff” (Petry, et al., 2005, p.41). Positive affect was mentioned by 82.1% of respondents, referring to the need for a warm, sensitive approach in which “direct support staff felt committed and could express attention, warmth and affection” (Petry, et al., 2005, p. 43).

Table 2.2

Domains of Quality of Life for People with PIMD Identified by Participants in Petry et al. (2005)

Percentage of participants	Domains				
	Physical well-being	Material well-being	Social well-being	Development and activities	Emotional well-being
80-100	Mobility Health Hygiene Nourishment	Living environment Technical environment	Communication Basic security	Involvement in activities Influence and choices	Positive affect
60-79			Family bonds Social relationships Individual attention		Individuality
40-59	Rest	Transportation		Development	Respect, status, and self-esteem Atmosphere
20-39			Social participation		

Note. Adaptation of findings of Petry, et al.(2005). Subdomains are listed in order of most frequently mentioned by parents and DSWs to least frequently mentioned.

In a further study by Petry, Maes, and Vlaskamp (2007), the subdomains of quality of life were operationalised through the assignment of a number of indicators, which were then validated by 45 experts who participated in a Delphi group. The experts were classified as theory-experts (i.e., researchers), practice-experts (e.g., DSWs and allied health professionals), and experience-experts (i.e., non-paid interaction partners such as families), and were from Belgium, Germany, the Netherlands, and UK/Ireland. The final list of indicators consisted of 176 items in which 68 items featured communication/relationship indicators, highlighting the importance of these things to the quality of life of people with PIMD. Examples of such items included: (a) the person gets the opportunity to make clear his/her feelings, needs, and wishes; (b) the person experiences affection; (c) the person gets the opportunity to express affection; (d) the individual has a personal bond with the people around him/her; and (e) new DSWs, as well as the person, get the chance to gradually build relationships with each other.

Other researchers have also highlighted the importance of relationships between DSWs and people with intellectual disabilities (Campo, Sharpton, Thompson, & Sexton, 1997; Marquis & Jackson, 2000; Reinders, 2002). Marquis and Jackson (2000) explored the perceptions 26 people with various levels of disabilities (but restricted to people who could describe their experience) using repeated in-depth interviews and observations conducted over two years. The researchers found that the quality of life of the people supported was strongly influenced by the nature of the interactions with their DSWs. They argued that the interpersonal relationships between people with disabilities and those who supported them had the potential to support the development of a sense of identity and connection with others or suppress the development of positive social relationships (Marquis & Jackson, 2000). Reinders (2002; 2008), a professor of ethics

and a theologian, in his book exploring the nature of humanity and relationships of people with PIMD, stated that an essential quality of a good life for people with PIMD is friendship, and that this friendship may occur with paid staff. The nature of interaction in the relationship between people with PIMD and DSWs is a central theme of this thesis.

Communication of People with Mild to Profound ID

People across all levels of intellectual disabilities experience communication impairment (Bedrosian & Calculator, 1988). In general, people with mild intellectual disability tend to have problems with pragmatic skills (e.g., turn-taking, topic maintenance, narrative) and in understanding abstract concepts (Haney, Wilson, & Halle, 1988). Social communication problems may be a key marker for identifying children with mild intellectual disability in schools (Simonoff, et al., 2006). These impairments can affect interpersonal relationships, which require comprehension and use of subtle rules in interactions (Tracy, et al., 2008).

People with moderate intellectual disabilities have the most heterogeneous communication skills, perhaps as a result of the wide range of associated aetiologies. For example, people with moderate intellectual disability caused by Williams syndrome often have delayed language development and in adulthood show stronger comprehension skills than their expressive skills, except in language comprehension of spatial concepts (e.g., behind, in front) (Brock, 2007). In contrast, the communication skills of people with Down syndrome, many of whom also have moderate intellectual disabilities, is often characterised by reduced speech intelligibility, problems with sentence construction, and comprehension difficulties (Abbeduto, Warren, & Connors, 2007). Most people with moderate intellectual disabilities use speech, with others using

augmentative and alternative communication systems (e.g., signs or communication boards), arguably because of inadequate motor speech skills (Ronski & Sevcik, 1997).

People with severe intellectual disabilities may express themselves using single or combined words, other symbolic forms of communication (e.g., pictures or sign language), or conventional gestures, such as pointing or giving objects (McLean, Brady, McLean, & Behrens, 1999). They are often able to understand single or two step directions in familiar contexts, but may experience difficulties understanding abstract concepts outside of everyday routines (Casella, 2004).

People with PIMD experience the greatest difficulties with communication, usually using non-symbolic or unintentional communication. As a result of their significant communication impairments, they rely on familiar communication partners who interpret the possible meaning of the person's facial expression, eye gaze, and vocalisations (Vlaskamp, 2005a). Unintentional communication acts can be much more difficult to read and interpret than intentional and conventional acts (Dunst & Lowe, 1988), making it more difficult to ascertain the needs, wants, or preferences of people with PIMD than those of people with less severe levels of intellectual disability (Ware, 2004).

Frameworks to Explain Communication of People with PIMD

In order to understand how the communication of people with PIMD is conceptualised, it is useful to review theories influencing communication, in particular, theories of infant cognition and communication development.

Cognitive and Social Theories

Particularly influential to how communication is viewed has been Piaget's theory of cognitive development (Adamson, 1996; Piaget, 1950/2003). Piaget's theory focused on infant organized engagement with objects. He argued that the hallmark of

intelligence was intentionality: that is, the ability to establish goals for actions before actually acting (Adamson, 1996). Piaget's sensorimotor stage of development has been particularly influential in the intellectual disability context since an examination by Woodward of the applicability of Piagetian stage concepts to people with intellectual disabilities in the 1950s (Woodward, 1959, as cited in Vlaskamp, 2005b) and development of Uzgiris and Hunt's *Ordinal Scales of Psychological Development* (Uzgiris & Hunt, 1975, as cited in Hogg & Sebba, 1986). Uzgiris and Hunt's scale, based on Piaget's theory of cognitive development, has been used to measure cognitive functions in people with PIMD. A problem, however, has been that the physical and sensory impairments of people with PIMD can severely affect engagement in the assessment (Vlaskamp, 2005a).

During the 1970s, the study of the development of communication expanded to encompass more social perspectives. Bruner, with interest in the social environment of infants, described prelinguistic communication, giving a rich description of the communication of young infants with mothers prior to the development of language (Bruner, 1978). At the same time, Dunst proposed a new definition of communication to encompass "any overt *conventional* or *nonconventional behavior*, whether used intentionally or not, that has the effect of arousing in an onlooker a belief that the signal producing organism is attempting to convey a message, make a demand, request etc. to an onlooker" (Dunst, 1978, p. 111). In addition to the recognition of prelinguistic communication in the 1970s, was a focus on the bidirectional nature of the mother-infant communication. Lewis and Rosenblum (1974) explored the impact of the mother on the communication of her infant and, conversely, the impact of the infant on his/her mother.

With influence from the mother-infant literature, people with PIMD moved from being viewed as people who did not communicate to being viewed as people who could communicate, albeit through pre-intentional means (Calculator, 1988; Mirenda, Iacono, & Williams, 1990). Subsequently, since the 1990s, recognition of the existing communication skills and options for interventions suitable for people with PIMD and their support networks have received more attention from researchers and practitioners (Mirenda, et al., 1990).

Behaviour State

Behaviour state research originated in infant studies in the late 1950s when Wolff began investigating the attention state of infant's (e.g. alert-inactive, alert-active, and drowsy states) and their relationship to infant ability to respond adaptively to different situations (Wolff, 1965). In the late 1980s, behaviour states begun to be examined in people with PIMD (Guess, et al., 1988; Guess, et al., 1993; Guy, Guess, & Mulligan, 1993; Richards & Richards, 1997). In a recent review of studies relating to alertness of people with PIMD, Munde et al. (2009) found 34 empirical studies that had been completed from January 1993 to December 2007, with 21 of these focusing on the particular construct of behaviour state. An understanding of behaviour state and ability to modify it to optimal states has been proposed as a means to enhancing quality of life (Richards & Richards, 1997).

Coding systems have been used predominantly in educational settings of children with PIMD (Arthur, 2003, 2004; Green, Gardner, Canipe, & Reid, 1994; Guess, et al., 1988; Guess & Siegel-Causey, 1995; Richards & Richards, 1997; Richards & Sternberg, 1992). Behaviour state coding, however, has been subject to criticism, with some researchers questioning the reliability of coding systems for describing states of people with PIMD (Mudford, Hogg, & Roberts, 1997; Mudford, Hogg, & Roberts,

1999). Nevertheless, the construct of behaviour state continues to be used as an important indicator of educational opportunities, and a basis for provision of intervention in classrooms; in particular, there has been a focus on training teachers to recognise behaviour states and implement interventions that improve the states of children in the classroom (Arthur-Kelly, Bochner, Center, & Mok, 2007; Arthur-Kelly, Foreman, Bennett, & Pascoe, 2008; Foreman, Arthur-Kelly, & Pascoe, 2007).

Arthur (2004) examined the behaviour states of 10 children with PIMD over a complete school day within the context of their classrooms. He also coded environmental factors, such as the broad nature of activities, the presence or absence of communication partners, and the nature of communicative interactions. Arthur coded four mutually exclusive communication indicators: (a) communication interaction, student communicative cue; (b) no partner response, partner communicative cue; (b) no student response; and (d) no communication behaviour. According to Arthur's system, communication interactions are coded when a student and partner are engaged in an interaction that involves an exchange of meaning, and turn-taking processes that demonstrate cueing and responding. On the student's part, the cue could be any behaviour that was a potential cue for the partner and could include pre-intentional acts interpreted to be meaningful by the partner (Arthur, 2003). The coded data were analysed for transitional properties (i.e., the likelihood of particular behaviour states to be sequential) and the relationship of states with environmental characteristics. Arthur (2004) found a great degree of state stability: that is, a state of drowsy was likely to be followed by further drowsiness; a state of alert inactivity was, similarly, most likely to be followed by the same state. Communicative interactions were found to occur on only few occasions. When they did occur, however, they were accompanied by positive states of alertness that continued beyond the interaction.

Although behaviour state coding has contributed to understanding of people with PIMD, a limitation of has been the narrow focus in terms of the nature of the behaviour used by the communication partner (i.e., the presence or absence of a partner). The exact nature of the behaviour of the partner, beyond simple presence, needs further examination to determine which specific interaction behaviours contribute to optimal levels of arousal.

Affect Expressions

People with PIMD are usually able to communicate through expressions of affect. Coupe O'Kane and Goldbart (1998) have stated that affective communication involves the external and internal emotional response of a person to changes in the environment and the people around him/her. People with PIMD primarily use sounds and facial expressions to express their pleasure and displeasure, and positive or negative moods (Petry & Maes, 2006). In addition to the skills required by the person with PIMD, affective expression involves the sensitive interpretation of the behaviour by a communication partner (Coupe O'Kane & Goldbart, 1998), however such interpretation can be difficult. Hogg, Reeves, Roberts, and Mudford (2001), for example, found that DSWs were able to distinguish between different affective communication expressions of people with PIMD who they were familiar with, however they differed in their relative judgements (e.g., *some* versus a *great deal* of positive affect). The complexity of determining affect was emphasized by Hogg et al. (2001) because of the interpretative nature of the task, which could be affected by a context bias (i.e., the DSW presumes the affect based on knowledge of the activity rather than observation of the current behaviour), an individual bias, and the possibility that the expression by the person with PIMD might have varying functions and aetiology (e.g., smiles caused by reflexes rather than a true affective expression of pleasure).

The importance of positive affect expression has been highlighted by researchers who believe that expressions of happiness can be used as an indicator of subjective quality of life in people with PIMD (Cummins, 2005; Lyons, 2003, 2005; Petry & Maes, 2006). Several interventions have been designed with an explicit goal to increase signals of happiness in people with PIMD (Davis, Young, Cherry, Dahman, & Rehfeldt, 2004; Favell, Realon, & Sutton, 1996; Ivancic, Barrett, Simonow, & Kimberly, 1997; Lancioni, O'Reilly, Singh, Oliva, & Groeneweg, 2002; Lancioni, et al., 2006; Lancioni, Singh, O'Reilly, Sigafoos, Didden, et al., 2007; Singh, et al., 2004).

In such interventions and observation studies, pleasure has been treated as a desirable outcome, with negative expressions, such as anger or frustration, and neutral expressions, treated as undesirable (Dillon & Carr, 2007). However, these negative expressions may also have much communicative and socio-emotional value. Coupe O'Kane and Goldbart (1998), for example, examined the value of negative expression in the intervention implications of the Affective Communication Assessment (ACA). The ACA is an observation tool used to describe the behaviours that an individual may use to indicate want, rejection, like, and dislike. In intervention planning, Coupe O'Kane and Goldbart (1998) emphasized the need for opportunities to develop not only pleasure expressions, but also the simple negation expressions of dislike and rejection.

Choice-Making

As stated by Hatton, "The exercise of choice by people with intellectual disabilities is becoming increasingly central to legislation and policy. For example, in the UK, the policy statement *Valuing People* (Department of Health, 2001) put choice as one of its four key principles alongside legal and civil rights, independence, and inclusion" (Hatton, 2004, p. 334). Choice and preference continues to be a strong theme in the literature on communication and people with PIMD (Cannella, O'Reilly, &

Lancioni, 2005; Petry & Maes, 2007). Numerous case-studies have been published demonstrating that individualised microswitch programs can be used by people with multiple disabilities to indicate choice (Lancioni, et al., 2009; Lancioni, et al., 2008; Lancioni, Singh, O'Reilly, Sigafoos, Oliva, et al., 2007; Lancioni, Tota, et al., 2007; Singh, et al., 2003). Cannella et al. (2005) reviewed 30 studies published from 1996 to 2002 relating to the assessment and intervention of choice and preferences of people with severe to profound ID. The majority of the studies focused on formats for assessing preferences and using those preferences as reinforcers of target behaviours. Canella et al. (2005) found that the choice interventions frequently led to decreases in inappropriate behaviour and increases in appropriate behaviour, and allowed for identification of potentially reinforcing stimuli. Most of the researchers cited in Canella et al.'s (2005) review reported overall positive results demonstrating improvements in choice or preference indicating skills within the controlled intervention environments. However, many of these studies also included participants who did not present with positive results, leading to the conclusion that "there are not enough data at this point to suggest that choice intervention and preference assessment strategies will be effective at all times or for all individuals" (Cannella, et al., 2005, p. 10)

Other researchers have focused on choice from a sociocultural perspective as it occurs in the daily lives of people with PIMD, as opposed to isolated controlled choice opportunities (Grove, Bunning, Porter, & Olsson, 1999; Porter, Ouvry, Morgan, & Downs, 2001; Ware, 2004). This perspective is based on a key feature of the communication of people with PIMD relying on interpretation by communication partners. The need for interpreting the behaviour of people with PIMD has been particularly important in the policy context that requires that people with disabilities make choices about their own lives (Grove, et al., 1999; Porter, et al., 2001). The

meaning of the behaviours, at times expressed idiosyncratically and often in reaction to the current context (rather than a choice of an abstract concept), can be ambiguous, as the choice is expressed through behaviours, not words. Choice, therefore, becomes a construct of interpretation or negotiation by communication partners (Grove, et al., 1999).

Grove et al. (1999) described the process of choice from a social constructivist perspective, in which information from subjective, intuitive insights of communication partners are combined with information obtained through observation and testing. They stated that this process of ascription is a necessary part of interaction with people with PIMD, as “to depend only on the interpretation of unequivocal signals would involve a breakdown of communication, and indeed any attempt to engage in a communicative relationship” (Grove, et al., 1999, p. 192). They developed systematic ways to interpret the communication of people with PIMD, most notably through *See What I Mean* (SWIM) (Grove, Bunning, Porter, & Morgan, 2000), a tool used to prompt family members and significant others to share information in order to build a profile of the person’s expressions and examine how their own biases may be influencing the interpretation (Grove, et al., 2000; Grove, et al., 1999; Porter, et al., 2001). Underlying this process was the recognition that ascription of a meaning and intent to the behaviour of the person with PIMD was inherently problematic, a premise that is often overlooked in policy and descriptions/assessments of communication (Grove, et al., 1999).

Intentionality

The construct of communicative intentionality has played an important role in conceptualizing the communication of people with intellectual disabilities (Dollaghan & Miller, 1986; Green & Cobb, 1991; Ogletree, Fischer, & Turowski, 1996). Criteria for intentional communication require establishing whether the person is deliberately trying

to send a message to his/her communication partner. According to Wetherby and Prizant (1989), these criteria include demonstration of the following behaviours by the person: (a) alternating eye gaze between a goal and a listener, (b) persistence in signalling until the goal is reached, (c) changing quality of the signal until the goal is reached, (d) using a conventional or ritualised signal within a specific context, (e) waiting for a response from the receiver, (f) terminating the signal when the goal is reached, and (g) indicating satisfaction if the goal is reached or dissatisfaction if it is not reached. People who do not meet these criteria are said to be communicatively pre-intentional: that is, they rely on a partner to interpret behaviours as being meaningful and serving a function, hence the behaviours may have a communicative effect on the partner, without being intentionally produced to serve a communicative function or goal (Wetherby & Prizant, 1989).

Determining whether people are using pre-intentional and intentional acts has, however, proven to be problematic. Iacono, Carter, and Hook (1998) argued for a modified criteria for children with severe and multiple disabilities that would take into consideration the sensory and physical impairments that may preclude people from demonstrating the full criteria. Carter and Iacono (2002) examined judgements made by teachers and speech pathologists of the intentionality of communication acts of a typically developing child, children with Down syndrome, and children with severe and multiple disabilities. They found that the judgements made by these professionals were largely inconsistent with the researcher judgements (made according to published criteria), with the professionals judging acts as intentional more frequently than the researchers. Agreements between teachers and speech pathologists with the researchers on acts considered to be intentional (81.3% and 77.6% respectively) were greater than the agreement on acts judged as non-intentional (30.8% and 51.3%), highlighting the

particular difficulties with reliably judging pre-intentional acts. Agreements on acts of the children with Down syndrome were statistically higher than the agreements for the children with multiple disabilities. This finding complements an earlier finding by Yoder (1987) who examined trained coder identification of communication cues in infants with various levels of disability. He found that cue recognition was most variable in the samples of children with the most severe cognitive and physical disabilities (i.e., multiple disabilities).

Many people with PIMD have been judged to not have intentional communication skills, and goals for intervention have often focused on developing this skill (Carter & Iacono, 2002; Green & Cobb, 1991; Iacono, et al., 1998). Intentional communication acts have been argued to be important because they are more easily read than are pre-intentional communicative acts (Carter & Iacono, 2002). In the previous mentioned study by Iacono et al. (1998), the complexity of making judgements about the function of pre-intentional communication acts contributed to the researchers' decision to use consensus coding to identify and then determine the function of acts considered to be pre-intentional. A further rationale for interventions focusing on developing intentional communication skills is that they have the potential to result in greater communicative independence (Kangas & Lloyd, 1988). Use of intentional communication will enable the person to be less reliant on familiar people reading potential meanings of unconventional or idiosyncratic behaviour, and more able to communicate a range of clear messages to familiar and unfamiliar communication partners.

Conceptualisation of intentionality has changed over the years. In early studies, infants were thought to show their first intentional acts at about 9 months of age (Bates, 1979; Bates, Camaioni, & Volterra, 1975). However, some researchers have argued that

infants are born with communicative intentionality (Zeedyk, 1996). In infant literature, addressing the centrality of intentionality no longer appears to dominate, however it has maintained strongly in the developmental disability context (e.g., Bloomberg, West, & Johnson, 2004; Bloomberg, West, Johnson, & Iacono, 2009; Cannella, et al., 2005). However, this is not the only perspective of intentionality held by researchers of people with PIMD. Several researchers have highlighted the difficulty with the dominant definition in that there is no clear distinction between the internal intent and the external behaviours that are interpreted for determining intent, contributing to difficulty in really knowing whether someone is intentional or not (Granlund & Olsson, 1999; Grove, et al., 1999). Grove et al. (1999), citing the work of Dennett (1987), presented a different theory of intentionality whereby any individual will be at one of four levels of intentionality. These four levels are listed below with examples from Granlund and Olsson (1999):

- level 1 unawareness of any intent (e.g., automatic reaction to thirst);
- level 2 goal-intentional, which may be social or object directed (e.g., that of getting something to drink);
- level 3 means-intentional (e.g., making someone get the drink); and
- level 4 partner-intentional (e.g., making someone understand the thirst).

For Grove et al. (1999) and Granlund and Olsson (1999), this model accommodates the social construction of intention and acknowledges the inherent lack of certainty about whether intent is present or not. This model has greater consistency with a strategy frequently advocated in interventions of ascribing intentionality to the act of the person with a disability, regardless of whether the person is judged to be an intentional or pre-intentional communicator (e.g., Nind & Hewett, 1994, 2001).

Integrating Affect, Choice, and Intentionality

Much of the description of the communication of people with PIMD has selectively focused on only one of behaviour state, affect, choice, or intentionality. In contrast, Mar and Sall (1999), in one of the largest studies of the communication of people with PIMD, described a multidimensional profile of skills of 38 children and adolescents with PIMD, recruited from a school setting (alongside 65 students with severe ID). No exclusion criteria were presented, and impairments of the students included sensory, motor, and medical disorders. The lack of exclusion criteria differs from many previous studies of non-symbolic communication in people with severe and profound ID, in which people with multiple disabilities were excluded, as were people who failed to demonstrate intentional communication behaviours (e.g., Cirrin & Rowland, 1985; McLean & Snyder-McLean, 1987; Ogletree, Wetherby, & Westling, 1992). Mar and Sall's (1999) data were from classroom observation (30-60 mins per student) and structured interactions with the researchers, ensuring opportunities for both naturalistic and probed communication.

The form of each potentially communicative act was described by Mar and Sall (1999) as being a reactive behaviour, direct behaviour, gesture, vocalisation, sign, speech, or augmented communication acts. Each student's communication skills was then categorized according to four attributes rated on a 5-point scale, from lowest level of complexity to highest level of complexity. The attributes and their levels of complexity were: (a) use of symbols rated as non-symbolic, pre-symbolic, and basic, extended, or elaborated use of symbols; (b) intentionality rated as reactive behaviours, pre-intentional communication, basic intent, awareness of social context, or deliberate communication; (c) social reciprocity rated as nonspecific behavioural reactions, simple specific response, emerging reciprocity, brief social exchanges, or reciprocal

interaction; and (d) complexity rated as simple reactive behaviours, single behaviours, simple combinations, short combinations, and formal language. The researcher found that 37% of the people with PID had the lowest rated scores in each area (i.e., were rated 1 on the scale), and 56% received ratings in the second levels for some attributes. Hence, a large number of the student's communication were described as non-symbolic, reactive, non-intentional, and nonspecific, which required extensive interpretation by the communication partner to ascertain internal states or needs. Some of the students with PID demonstrated some pre-symbolic skills, such as gestures that were pre-intentional and linked closely to the immediate activity or needs. Some of these individuals could initiate a simple interaction, however could not continue them in a truly reciprocal nature.

Dyadic Communication with DSWs

In addition to understanding the communication of people with PIMD according to developmental phases and skill levels, communication also has been described according to dyadic interaction. Dyadic communication has focused on parent, teacher, and DSW as communication partners. In this section, dyadic interaction between adults with PIMD and DSWs is examined firstly through descriptive studies and then intervention studies.

Descriptive Observation Studies

Early descriptive studies of interactions between DSWs and people with PIMD were conducted in institutional settings. Acknowledging hitherto the lack of simultaneous focus on both the adult with a disability and nursing staff in prior research, Moores and Grant (1976) sought to describe staff-patient interactions in two hospitals for adults with unspecified levels of ID. In their study, both partners were observed and coded according to a coding schedule that included verbal and nonverbal categories.

Social activities, such as casual conversation, singing, reading stories, and joking with patients, were found to occur for a quarter of the interactions (24.9% in hospital A and 26.8% in hospital B), and an average of 30.2% of the interactions in both settings were described as supervisory in nature (e.g., restraining people, waiting with patients, and giving simple commands). Between 42.8-63.0% of interactions lasted less than 10 s.

Similarly, Duker et al. (1989), in the Netherlands, examined interactions between people with intellectual disabilities and DSWs in an institution, with a focus on the characteristics of the residents. They found that, in comparison with other residents in the institution, fewer interactions were directed towards people who were not ambulant, who did not appear to be looking at any person or object, or were asleep. Furthermore, the percentage of initiatives by ward staff correlated negatively with the frequency of resident stereotype behaviours. Duker et al. (1989), in examining the implications of the findings, argued for the need to modify not only DSWs' behaviours, as suggested in previous studies (e.g., offering scheduled activities and supervision as recommended by Seys & Duker, 1986), but also resident behaviours. In particular, they argued for the need to modify ambulation, looking, positioning, and stereotyping, as these would act to encourage staff interaction.

Over 10 years later, still in a Dutch institutional setting, Duker et al.'s (1989) study was expanded to examine further resident characteristics across 452 people with severe and profound intellectual disability (Seys, Duker, Salemink, & Franken-Wijnhoven, 1998). Each unit of living, containing a mean of 10 residents, was observed for 36 hours. The following behaviours were recorded: (a) staff-resident initiatives coded as routine custodial care, stimulative custodial care, training, or recreation; (b) staff affection coded as positive, negative, or neutral; and (c) staff communicative behaviour coded as verbal, physical-verbal, or physical. They found that those people

who were not ambulant received less stimulative care and less verbal communication from DSWs. Recreational care was most frequently offered to people who were ambulant, showed attentive behaviour, and used few vocalisations. Positive affect from DSWs was mostly directed to residents who used little stereotypic behaviours, had attending behaviours, and verbalized. Physical only interactions (in absence of speech) were directed mostly to the residents who were positioned in a lying position throughout the day and used the least verbal skills. Similar to Duker et al. (1989), this study demonstrated that those people with PIMD (i.e., people who were less ambulant, less attentive, and had less communicative behaviour) received lesser quality and quantity of care from DSWs compared to their ambulant, verbal peers.

In the early stages of deinstitutionalisation, observation of interactions appeared to focus on the comparison of interactions in institutional settings to those occurring in group homes. Thomas, Felce, de Kock, Saxby, and Repp (1986), for example, compared activity of staff and residents in small and large group home settings with institutional settings. They examined interactions between 50 people with severe and profound intellectual disability and staff in the three settings. The staff verbal and physical behaviours were judged as positive (i.e., approval), neutral, or negative (i.e., disapproval). Reciprocal interaction with staff and other people was examined; reciprocity in this context was not defined. Observations were conducted throughout the day, with the exception of mealtimes. Thomas et al. (1986) found that the highest rates of staff contact (10.5% of the time) occurred in the small homes, however most of the interactions were rated as neutral in character. Several years later, Felce and Repp (1992) again compared institutional and large and small group homes, finding positive outcomes for client functioning and higher levels of staff/client interaction in the group homes. Later, Felce and Perry (1995a) in a study focusing only on group homes, found

that the amount of interaction initiated by each DSW was related to resident characteristics. In particular, they found that more able residents received much higher rates of interaction.

McConkey, Morris, and Purcell (1999), in addition to institutions and group homes, also examined interactions within day services. They analysed 15 min video-recordings of 43 DSW-client dyads. Levels of intellectual disability were not reported, but 24% of the people with disabilities were reported not to use speech, communicating using non-verbal signals, suggesting severe or profound levels of intellectual disability. Speech pathologists rated the appropriateness of the interactions given the context and known communicative competencies of each client, using the following definition of appropriateness: “communication acts were judged appropriate if these served to continue an interaction or activity, or the effect was neutral. Inappropriate acts were those which interfered with or stopped an interaction or activity, or which failed to be used when the context demanded it” (p 197). The researchers reported that DSWs overly relied on verbal acts and tended to favour directives and questions. The majority of the DSWs were rated as failing to adjust their language to the client’s level of understanding.

Healy and Walsh (2007) also highlighted problems with care workers language. They examined the communication of staff nurses in residential centres for adults with severe and profound intellectual disabilities in Ireland. It is not possible from the article to know whether these staff were equivalent to DSWs or if they were staff with graduate training. Healy and Walsh (2007) video-recorded interactions in order to analyse frequencies of verbal acts (i.e., questions, reinforcements, comments, instructions, talk, suggestions, corrections, and opinions) and non-verbal communication acts (i.e., looking, touching, pointing, facial expressions, gesture, head nods, and posture). In

addition, they interviewed and conducted focus groups with 10 nurses to investigate the strategies that they reported to use. The researchers found a mismatch between the nurses' reported and observed strategies. The researchers made a point of nurses failing to adjust their language according to the recommended strategies of speaking slower, repeating and rephrasing sentences, and using fewer complex and long sentences. However, there was an indication in the report that the researchers themselves may have used language likely to be beyond their participants with PID's comprehension. The researchers reported that they invited these participants using a written letter, which they claimed "was simplified and explained to the service user participants before each videoing recording session" (Healy & Walsh, 2007, p. 131). Given that adults with severe and profound intellectual disabilities are known to have significant limitations in language understanding, it is unlikely that the researchers were able to modify their language adequately. This inconsistency, alongside the researchers' comment that nurses reported that they would interact with verbal and non-verbal service users in the same way, highlights that judging the perceived match between the comprehension of people with PIMD and the language use of DSW/nurses may be an overly simplistic way of viewing a much more complex phenomenon.

A contrasting observation study to those involving assessment or rating of partner interaction was reported by Burford (1988). Influenced by the work of Stern (1977), Trevarthen (1979), and theories of a biological programming towards interaction, Burford (1988) examined the coordinated timing of interactions between children and adults with PID who were ambulant, and their caregivers. Interactions of 12 children and 6 adults were filmed for 10 mins across 12 sessions in familiar surroundings with staff or parents and with non-familiar interaction partners who were either experienced or inexperienced in interacting with people with PID. Frame-by-

frame analyses of the movement patterns of interaction partners were evaluated (e.g., use of tapping, patting, stroking, or manipulating the person with a disabilities body). Rhythmic groups of cyclical movements were found to occur across the interaction partners and the person with PID. The rate of the action appeared to be related to the mood of the person with a disability. Burford (1988) reported that caregivers usually appeared to match their rate to their child's needs and moods, however the matching was somewhat less for the inexperienced strangers. In considering the implications of the findings, Burford (1988) reported the tendency for researchers and practitioners to overlook frequently observed behaviours. She advocated for the need to become more aware of the daily used subtle strategies of caregivers, and to understand why these behaviours contribute to successful communication.

A similar focus on subtle daily interactive behaviours was expressed by DSWs interviewed by Forster and Iacono (2008) about their interactions with adults with PIMD. These workers, reflecting on their interactions with one woman with PIMD, described how they chose to use touch and close contact in their interactions with the woman because she responded to them, despite their perceptions that such contact ran contrary to their organisational policy. One of the DSWs, in considering the best way to interact with the woman with PIMD, stated that "Getting a smile from Nen makes all the other crap [*laughs*] worthwhile, because you know you did it right" (Forster & Iacono, 2008, p. 143).

Several other studies have been based on interviews with DSWs about what they believe makes good interaction between DSWs and adults with PIMD (Bogdan & Taylor, 1989, 1998; Dennis, 2002). Dennis (2002) interviewed DSWs and allied health professionals, asking their perceptions on qualities of people who were good listeners for people who did not use speech to communicate. Respondents talked about the

importance of practitioner values and experience. Values included the belief in various factors, such as: (a) the person having something to say (albeit nonverbally); (b) the mutual nature of the relationship; (c) commitment to being present and listening; (d) respect for self and other; and (e) valuing difference, relationship, privacy, boundaries, and experiences. Personal attributes seen as important to the interaction included: (a) confidence to make assumptions and make mistakes; (b) desire to connect and get to know the person; (c) capacity to be patient, sensitive, flexible and persevere; (d) experience with the person and other people who do not use speech; (e) comfort with self as learner, and (f) self-awareness. Dennis (2002) also discussed the need for authentic listening and the need for liking each other.

Bogdan and Taylor (1989, 1998) also interviewed interaction partners (including foster carers and DSWs) of more than 100 people with severe and profound levels of intellectual disabilities to explore how these carers conceptualised interaction. The researchers were particularly interested in the qualitative process of the way the interaction partners created the humanness of the person with a disability through the language used about the person. From these interviews, the researchers categorised the caregiver's perspectives according to four dimensions: (a) attributing thinking to the other, (b) seeing individuality in the other, (c) viewing the person as reciprocating, and (d) defining a social place for the other.

Recently Hostyn and Maes (2009) synthesized several of the observation studies and interview studies into an explanatory model of interaction between persons with PIMD and their partners. Their review focused on both children and adults with PIMD. Through their review of 15 papers, an explanatory model of interaction between people with PIMD and partners was developed to include central dyadic factors important for interaction, individual factors related to the person with PIMD and, separately, to the

partner, and contextual factors. Dyadic factors included the need for sensitive responding, joint attention, an emotional component, and co-regulation, which encompassed mutuality, reciprocity, and turn-taking. Factors in the person with PIMD focused on the person's abilities and disabilities, communicative and interactive behaviour, and the perceived personality and role of the person with PIMD. Factors related to partners included the communicative and interactive strategies used, their knowledge, and their perception and role. Finally, also recognised in the model was the role of contextual influencing factors of setting and circumstances, which shaped the interaction.

Intervention Studies

Some of the research into interactions between DSWs and adults with PIMD has been evaluations of interventions. In one of the earliest intervention studies examining communication dyads, Clegg, Standen, and Cromby (1991b) examined 10 min video-recorded interactions of eight DSWs with people with PIMD. The researchers initially focused on describing the behaviour of the person with PIMD. The interactions were analysed using a narrative description, from which a list of five categories of the person with PIMD's behaviour were developed: positive, negative, stereotyped, neutral, and uncodable. Positive interactions included looking and smiling at, reaching towards or touching the person, and behaviours indicating contentment without an obvious social component (e.g., humming or rocking). Negative interactions were those in which the person with PIMD seemed to be rejecting social contact or demonstrating a negative affective state: for example placing hands over ears, screaming, or engaging in self-injury. Similarly, stereotyped behaviours had a repetitive component, but were not accompanied with a perceived negative state, and neutral behaviours were those in which the person with PIMD was alert but not active. Following establishing qualities of

interaction, the researchers listed five strategies for DSW interaction that they had selected from existing literature: (a) talking to the person with a disability; (b) presenting choice; (c) instructing the person; (d) contingently responding to the person; and (e) engaging in social routines, such as tickling games.

In the second part of their study, Clegg et al. (1991b) recruited nine dyads from residential and day service settings and the DSWs were asked to interact with their dyad participant for 3 min using, firstly, no specific strategies, followed by use of each of the five specified strategies: talking to the person in a natural manner (no specific topic or content), presenting choice, instructing the person in an area relevant to the person's needs, using contingent responding to something that the person with a disability did, and engaging in social routines, such as tickling games or other exchange routines. Following the video-recorded interactions, a rater measured the amount of time spent in each of the quality categories for behavioural responses of the person with PIMD. The duration of positive behaviour from the person with PIMD was statistically higher in the conditions of staff talking and use of social routines than in baseline, choice, instruction, and contingent responding situations. Stereotyped behaviours were most frequently observed during the contingent responding strategy.

Clegg et al. (1991b) then examined the relationship between contingent responding when the developmental age of the person with PIMD was considered. Two situations were recorded: baseline interaction and a contingent responding session. No significant difference in the amount of positive or neutral behaviour was found between the two sessions. Furthermore, there was no significant correlation between developmental age and change in client behaviour. The researchers concluded that contingent responding was not generally successful in facilitating positive behaviour from the groups of people with PIMD in the study.

In a further study, Clegg, Standen, and Cromby (1991a) examined the staff talking strategy further, through sequential description of the interaction. Twenty adults with PIMD and 16 DSWs (four being a dyad partner for two people with PIMD) were recorded in five 3-min dyadic talk interactions and baseline interactions. The DSW and researcher selected the two best sessions for analysis. The variable of DSW talking was analysed sequentially (simultaneous, 1, 2, and 3-s lags) according to the behavioural response of the person with PIMD. Despite the researchers reporting that the strategy and environmental conditions represented ideal conditions, the people with PIMD responded positively only for approximately a third of the session time. The researchers reported that this result demonstrated that, despite best efforts by the DSWs, it was difficult to generate positive responding from the person with PIMD. Levels of turn-taking, as indicated through responsiveness of the people with PIMD to the DSWs, were also found to be low despite considerable responsiveness of the DSW to the person.

Given that the immediate environment and people in the environment have been argued to provide the best context for intervention to improve communication skills of people with disabilities (McLean & Snyder-McLean, 1987), several researchers have focused on training DSWs. In Sweden, Granlund, Terneby and Olsson (1992a) used a pyramidal method of training occupational therapists and psychologists, who then trained 100 DSWs in a communication intervention and collaborative problem solving for enhancing the communicative behaviours among adults with PIMD. The majority of the DSWs worked in an institution, with others working in group homes and day services. One hundred and two people with PID were included in the study: for 64, their DSW had received the training (forming the intervention group); for the remaining 38, their DSWs were not trained (forming a control group). The training focused on “the practical implications of profound cognitive disability and to provide guidelines for

interacting with profoundly disabled persons” (p. 233), and was followed by monthly supervision meetings. DSWs had assignments to complete between meetings. Changes in the person with PID were measured through the Early Social Communication Scales (Karlán, Ward, Pennington, & Granlund, 1985) (measuring complexity of social interaction, joint attention, and behaviour regulation) and Goal Attainment Scaling (Simeonsson, Bailey, Huntington, & Brandon, 1991) (measuring outcomes from individual intervention objectives). DSW changes were measured using a researcher developed survey aimed at gathering information on the social and physical environment, which indicated how DSWs perceived their own and their client’s behaviours. Significant improvements in DSW ability to create opportunities and set goals for intervention were reported, alongside improvements in clients reaching goals (i.e., scores on Goal Attainment Scaling). Changes, however, on the Early Social Communication Scale were not found, indicating increases in complexity of communication functions did not occur for the people with PIMD.

Dobson, Upadhyaya, and Stanley (2002) reported on an interdisciplinary therapeutic training programme aimed at improving day service DSW’s knowledge about disability, altering their communicative practice and providing them with practical solutions to the communication difficulties of service users. Within a series of site-based weekly workshops, they used video-recordings of nine people with PID, with a focus on DSW nonverbal skills, obtaining joint focus of attention, acknowledging service user’s behaviour, and active interpretation of the service user’s communication. The DSWs selected a client to work with, with five of the selected people rated as pre-intentional communicators. The DSWs described the person’s communication and chose a goal to work on within an activity. The activity was video-recorded several times throughout the intervention and these videos were used in the training and for the

analysis. First and third recordings were analysed according to the number of utterances, types of utterances (attention, request open, request closed, request action, give information, acknowledge), nonverbal interaction (positioning, eye level, monitoring of service user's gaze), number of repetitions and topic changes. Significant increases in the total number of utterances, and number of acknowledgments and praise were reported. Interaction style was reported to have improved in terms of eye level and eye gaze monitoring, and fewer topic changes. The researchers noted that "most of the observed successes related to an increased expectancy that the service users could and would respond and do so as equal partners in the interactions rather than as passive or compliant responders to requests" (p 53).

Such enhanced sensitivity was also a goal of Bloomberg and colleagues in both intervention (Iacono, Bloomberg, & West, 2005) and in the development of an assessment tool (Bloomberg, West, & Iacono, 2003; Iacono, West, Bloomberg, & Johnson, 2009) for DSWs to use to describe the communication skills of adults with severe and profound ID. Bloomberg et al. (2003), influenced by Granlund and colleagues (Granlund, 1993; Granlund, Björck-Åkesson, Brodin, & Olsson, 1995), conducted an intervention with 16 pairs of DSWs working with adults with profound and severe levels of ID. In this study, an intervention was conducted with one person in each pair, and focused on (a) improving DSW ability to interact with the person they supported, and (b) increased participation of the person. Intervention focused on improved knowledge of communication, enhanced problem solving, and improving the environment for communication, and involved six training sessions, work assignments, and individual supervision. Following the intervention, the researchers reported increases in DSW knowledge of communication and improvement in their recognition of potentially communicative acts. Video analysis showed improved responses by both

DSWs and the people with a disability in interactions, but no significant change in the number of initiations used by the people with a disability.

Singh et al. (2004) also used DSW training, however, their training was not focused on specific communication skills. Using the premise that changed behaviour of DSWs could result in changed levels of happiness in people with PIMD, they trained DSWs in mindfulness techniques. They examined pre- and post-indices of happiness in people with PID who interacted either with DSWs receiving the mindfulness intervention or DSWs who had been given general disability readings (as a form of control group). They found that when the person with PIMD interacted with the mindfulness trained DSW, increased indices of happiness were observed. Examples of individual behavioural indices of positive affect included grinning; eyes open wide in excitement, open mouth together with furrows high on forehead, eyes close together, drooling, and happy vocalisations; high-pitched shrieks; clapping or arm waving; humming or singing; body contortions together with loud, happy vocalizations; and happy growling sounds. The researchers suggested improvements in interactions could be attributable to the fact that DSWs “were more responsive than reactive and they appeared to be non-judgementally accepting of the behaviors that the individuals displayed” (Singh, et al., 2004, p. 216).

Roemer and van Dam (2004, 2006), who also focused on the need for developing sensitivity in caregivers, began their intervention according to the starting knowledge base of DSWs, rather than targeting pre-identified intervention goals. Roemer and van Dam (2004, 2006) argued that DSWs who had worked with people with PIMD held a wealth of practical knowledge. This knowledge included understanding the subtle signals used by people with PIMD and how to structure their own interactions so they could make themselves understood by the person with PIMD.

Roemer and van Dam noted that there were, however, problems with transferring this largely invisible knowledge to new and less familiar DSWs. Their intervention comprised of (a) recording in detail the practical knowledge of experienced DSWs, (b) a Delphi study to clarify the practical knowledge that needed to be conveyed to less experienced DSWs, (c) a three-day course for less experienced DSWs, and (d) evaluation of changes. In Table 2.3, some of the practical knowledge reported by the DSWs is presented as an illustration of the types of behaviours and interpretations involved in the interactions between DSWs and people with PIMD, as identified in Roemer and van Dam's study. Roemer and van Dam stressed that the DSWs were often uncertain about the interpretation, as no one-to-one correspondence between a behaviour and interpretation could be reported. The DSWs recognised that the reactions of people supported provided them with feedback on their own behaviour toward the person. The researchers noted that talking to clients was mentioned frequently by the DSWs, with recognition that it was not so much the content of the speech that mattered, but the intonation, which provided a way of making and keeping contact with the person with PIMD.

Table 2.3

Practical Knowledge of Experienced DSWs Reported by Roemer & van Dam (2004)

Interaction partner	Report by DSW	
	Reported behaviours	Interpretations and intentions
Person with PIMD	Posture, physical reactions, breathing, muscular tension, facial expression, smiling, crying, self-directed behaviour, auto-mutilation (self injurious behaviour), movement, sounds, position and changes in position, moving, physical contact, and dealing with people and objects instrumentally.	Physical condition (ill, pain, physical discomfort and fatigue); mood (good mood, bad mood, scared); the level of peace and relaxation; the level of the person's awareness of his/her surroundings; interpretations related to wanting or not wanting.
DSW	Posture, position and changes in position, facial expressions, smiling, moving, physical contact, changing the person's position, caring for the person and taking him/her along, showing and using objects, and doing household chores.	To change the person's mood and behaviour, to make clear that they give personal attention to the person and use forms of behaviour to introduce activities, invite people, motivate and stimulate them to enter into certain activities, to comfort them, to have them make choices.

The focus of the course then was on improving the sensitive responsiveness of DSWs, with sensitive responsiveness defined as observing and interpreting signals correctly and making sure that one's own actions were in line with the signals and the possibilities of the person with PIMD. In addition to an understanding of communication levels, forms, and development, the course focused on observing and interpreting behaviour, tuning into behaviour, and interpreting reactive behaviour of the person with PIMD as feedback on the DSW's own actions. Evaluation of the course consisted of a video-test and a questionnaire as measures of sensitive responsiveness.

The video-test involved watching three video fragments and answering questions about the behaviours observed and generating interpretations. Significant positive changes were reported on the test scores of course participants. However, no significant change was found on the questionnaire. Participants, nevertheless, reported benefits in knowledge of communication and responded positively to the use of video for recognising client's signals and viewing their own actions.

Most prominent in the intervention literature of relevance to people with PIMD has been an approach and intervention called Intensive Interaction (Elgie & Maguire, 2001; Hewett & Nind, 1998; Leaning & Watson; Nind, 1996; Watson & Fisher, 1997). Intensive Interaction was modelled on mother-infant interactions and, hence, involves aspects of motherese, such as physical proximity, tone of voice, and simplified speech (Nind, Kellett, & Hopkins, 2001). Intensive Interaction was initially developed as a teaching approach in which practitioners recognised the pre-verbal nature of the communication of people with PIMD and addressed a need to develop the very beginnings of sociability and communication in people who are severely socially withdrawn (Nind, 1996). Interactive games were used as the core in the curriculum. According to Nind and Hewett (1994, 2005), a key feature of the intervention was to impute intentionality to the behaviours of the person with a disability, thereby responding as if the behaviours were initiations with communicative significance. Practitioners were taught to tune into the non-verbal behaviour on a moment-by-moment basis and adapt their behaviour in response to these. A key feature of Intensive Interaction has been the use of imitation of the sounds or movements of the person with PIMD (Caldwell, 2006). Caldwell (2006), however, emphasized the need for careful introduction of surprise material to balance the use of imitation, as she believed that

imitation could be habituated quickly by the person with a disability. She also highlighted that imitation could potential become a withdrawn focus of the person with a disability rather than being the source of genuine interest in a communication partner (i.e., imitation of a partner could act like an extensions of the person's on self-stimulatory behaviour).

Since the first published study on Intensive Interaction by Watson and Knight (1991) following its development in the late 1980s, there has been accumulating evidence for its effectiveness, ranging from perspectives on outcomes for people with PIMD to measures of social validity for DSWs. The studies have varied in rigour and size, with most studies being single case descriptive studies (e.g., Elgie & Maguire, 2001; Forster & Taylor, 2006; Irvine, 2002; Kellett, 2005; Lovell, Jones, & Ephraim, 1998). Studies have included children (Barber, 2008; Kellett, 2005; Watson & Fisher, 1997) and adults (Elgie & Maguire, 2001; Forster & Taylor, 2006), and on people with PIMD (Elgie & Maguire, 2001; Watson & Fisher, 1997) and autism (Caldwell, 2006; Nind, 1999). Interaction partners have included teachers (Barber, 2008; Kellett & Nind, 2003; Watson & Knight, 1991), DSWs (Firth, Elford, Leeming, & Crabbe, 2008; Lavers-Preston, 2004; Samuel, et al., 2008), and expert practitioners (Zeedyk, et al., 2009). Outcomes have been measured in regards to problematic behaviours (e.g., reduction in self-injurious and self-stimulatory behaviours) (Elgie & Maguire, 2001), communicative behaviours (e.g., eye contact) (Kellett, 2005; Leaning & Watson, 2006), and affective behaviours (e.g., smiling) (Lovell, et al., 1998; Nind, 1996).

Specifically, a number of descriptive studies have focused on adults with PIMD. Several small case studies written by practitioners have been published reporting positive outcomes for adults with PIMD in day services with clinical psychologists (Elgie & Maguire, 2001), music therapists (Leaning & Watson, 2006), and DSWs

implementing Intensive Interaction (Forster & Taylor, 2006). One of the first detailed empirical studies on Intensive Interaction was by Nind (1996). The participants in this study were described as having severe and complex disabilities; examination of participant descriptions suggests that several would have met criteria for PIMD. These adults lived in a long-stay hospital where Intensive Interaction was being developed and implemented by teachers. A multiple baseline across subjects interrupted time-series design was used by Nind (1996) to investigate the effectiveness of Intensive Interaction for improving social and communication skills. Improvements were reported on various measures of change, including real-time observation, video analysis, and a published early communication skills scale (Kiernan & Reid, 1987). All participants developed some new interactive behaviours that were not evident in baseline, such as looking at their teacher's face and exhibiting happy vocalisations and facial expressions, and showed some evidence of increased initiating of social contact.

A partial replication of this study was conducted by Samuel et al. (2008) with four women with PIMD living in group homes. In this study, DSWs who were new to Intensive Interaction implemented the intervention. In addition to skills changes in the women with PIMD, use of Intensive Interaction techniques by the DSWs was evaluated. The coding focused on five participant with PIMD behaviours of visual scanning, looking at face, engagement, joint focus, and initiating social/physical contact, and three DSW behaviours of mirroring vocalisations, contingent responding, and forcing/overriding. Samuel et al. (2008) reported increased frequency in DSW use of mirroring of movements and vocalisations, and contingent responding following intervention. The researchers, however, also reported a decreasing frequency of completion of interaction reflection records by DSWs over time, raising some concerns about the sustainability of the intervention under the existing conditions. Nind (1996)

and Samuel et al.'s (2008) studies, although informative, provide only preliminary evidence of the benefits of Intensive Interaction, given their small participant numbers.

Recently and using inferential statistics, Zeedyk et al. (2009) examined the rapidity of behavioural change when Intensive Interaction was used by an expert practitioner with 10 adults with PIMD with long histories of social avoidance. The researchers decided on four behavioural indicators of engagement, derived from existing infant research. These indicators were eye gaze, body orientation to partner, proximity to partner, and emotional valence (neutral/negative, positive, very positive). Coding of these indicators was completed by the researchers watching video-recordings of intervention sessions and then recording the time in which a change of code occurred. Increases were noticed on at least two of the four indicators within the first few minutes of the interaction session (3-14 mins), suggesting that behaviour change could be observed rapidly in Intensive Interaction sessions. In particular, increases in positive emotion were commented on as being very notable by raters, as their observations suggested a sense of joy in the expressions of some participants. The researchers suggested that although four indicators of engagement had been selected as criteria for improvement in the study, in clinical contexts, all four may not be necessary for signifying engagement in the context of individuals who may have a long history of minimal responsiveness; in practice changes in one or two may be sufficient indicators of improvement.

According to Firth et al. (2008), Intensive Interaction has been used increasingly in recent years, but inconsistently in adult services in the UK. Firth et al.(2008), wanting to know more about what DSWs thought about the approach, interviewed 29 DSWs about issues relating to the use of the intervention and analysed these through a grounded theory approach. All of the DSWs had been trained and supported in the use

of Intensive Interaction over a 6-month period. The DSWs reported positive increased and novel client responses, but also mentioned practical (such as comfort with proximity and feelings of self-consciousness) and philosophical (such as comfort in using an approach that may be perceived to be age-inappropriate) issues in using the approach. The researchers reported that DSWs described feeling rewarded by an interactive episode that went well and felt that interactions with more responsive clients were superior experiences. Furthermore, some DSWs reported that they were now persevering more with people who gave limited feedback, rather than discontinuing interactions.

Recently, Firth (2009) suggested that throughout the last two decades of development of Intensive Interaction, two different general process models have been used to describe and conceptualise it. The first, which he referred to as a social inclusion process model, has focused on responding to the communication of the person with a disability and establishing communication. The second, referred to as a developmental process model, has focused on Intensive Interaction as a tool for developing the communication skills of the person with a disability. The goals of using Intensive Interaction may, hence, vary across disciplines and contexts, from teaching to just being with a person.

Methodological Issues in PIMD Communication Research

Warren, Brady, and Fey (2004) suggested four inherent challenges in research addressing communication in people with ID: (a) the large amount of developmental variability in the population; (b) the difficulty and expense of recruiting sufficient numbers of participants; (c) difficulties in establishing and demonstrating experimental control over measures that are undergoing development at the time of intervention; and (d) the complex nature of communication and language development, which makes both

the conceptualisation and measurement of dependent and independent variables challenging. Although the issue of development is of less relevance to adults than to children, the other three challenges have relevance to the current literature addressing interaction between DSWs and adults with PIMD.

Definition of the population of people with PIMD, as addressed previously, in particular, creates difficulties in identifying research that has included people with PIMD as participants. In addition, studies of adults with PIMD continue to have small participant numbers.

Warren et al.'s (2004) fourth point regarding the complex nature of communication is the most pertinent to existing research. The implication of the complex and multidimensional nature of communication is that it can be described according to varied theoretical and descriptive frameworks, as evidenced by the previously reviewed literature. A related issue and challenge is the coding system or means of measuring communicative behaviours, and potential problems in obtaining acceptable levels of inter-rater reliability.

In Table 2.4, the variables selected by researchers examining videos of interactions between DSW and adults with PIMD, alongside reliability measures, are reported. In these studies, interaction variables have been measured largely using duration and frequency. Researchers have examined inter-rater reliability by having a second rater independently coding between 10-50% of the sample. Various metrics of agreement have been used, including percentage agreement, Spearman's rank order coefficient, and Cohen's kappa. A number of the researchers reported mean scores across categories only, limiting the degree to which reliability of scores for individual variables and participants can be examined. Bloomberg et al. (2003), Healy and Walsh (2007), and McConkey et al. (1999) all reported high ($\geq 90\%$) mean overall agreements.

Despite the high mean, Healy and Walsh (2007) and McConkey et al. (1999) also reported lower percentage agreements on some of their variables, in particular, both reported 60% agreement on coding of gestures.

Table 2.4

Reports of Reliability in Studies of Video Coding of Dyadic Interactions with People with PIMD

Study	Participants	Rating design	Measure of reliability	Number of sample for reliability	DSW		Person with PIMD	
					variable	Finding	Variable	Finding
Bloomberg et al., 2003	16 DSWs ^{d,r} 8 adults with severe and multiple disabilities	Frequency of behaviours in 5 min segment	Point-to-point agreement	20 samples	Getting attention, needs satisfaction, simple negation, shared attention, initiation, responding, other.	90% agreement across categories.	Getting attention, needs satisfaction, simple negation, shared attention, initiation, responding, other.	90% agreement across categories.
Clegg et al., 1999b, study 1	9 DSWs ^{d,r} 9 adults with PID	Total time (s) spent in variable state	Percentage agreement and kappa scores	All sessions for 3 dyads			Positive, negative, stereotyped, neutral, uncodable.	62-86% agreement Kappa range from 0.38-0.73.

Study	Participants	Rating design	Measure of reliability	Number of sample for reliability	DSW		Person with PIMD	
					variable	Finding	Variable	Finding
Clegg et al., 1999b, study 2	13 DSWs ^{d,r} 16 adults with PID	Time (s) spent in variable state	Second-by-second percentage agreement and kappa scores	Two sessions (each of the 2 conditions) for 3 dyads			As above.	Range 74-99% Kappa for each session was reported as 0.66, 0.53, 0.9, 0.97, 0.53, and 0.43.
Clegg et al., 1991a	16 DSWs ^{d,r} 20 adults with PID	Time (s) spent in variable state	Second-by-second percentage agreement and kappa scores	Two sessions (each of the 2 conditions) for 3 dyads			Positive, negative, stereotyped, neutral or uncodable.	Dyad 1, video 1 - 93%, $k = .89$ Dyad 1, video 2 - 57%, $k = .40$ Dyad 2, video 1 - 87%, $k = .64$ Dyad 2, video 2 - 54%, $k = .31$ Dyad 3, video 1 - 31%, $k = .16$ Dyad 3, video 2 56%, $k = .45$.

Study	Participants	Rating design	Measure of reliability	Number of sample for reliability	DSW		Person with PIMD	
					variable	Finding	Variable	Finding
Dobson. Upadhyaya & Stanley., 2002	9 DSWs ^d 9 adults who were labelled pre-intentional communicators	Rating, however scale is not reported	Spearman's rank order coefficient	Not reported	Positioning	0.79		
					Eye level Monitoring service user gaze	0.96 0.96		
Healy & Walsh, 2007	10 nurses ^r 10 adults with SID/PID	Frequency of acts in 10 min	Percentage agreement ^a	50%	Verbal acts – Non-verbal acts-	90% overall agreement (range 60% on gestures – 100% for questions, instructions, looking and touch).		

Study	Participants	Rating design	Measure of reliability	Number of sample for reliability	DSW		Person with PIMD	
					variable	Finding	Variable	Finding
McConkey et al 1999	43 DSWs ^{d,r} 43 adults with ID, 10 who used non-verbal signals for communication	Frequency of DSW communication acts	Percentage agreement	23%	Nonverbal – gestures, posture shifts, facial expressions, head movements, touch. Verbal acts – comments, closed & open questions, instructions, reinforcement, request repetition, negative, & unclassifiable.	Overall 93.6% (range 70% for comments – 100% reinforcement).	Nonverbal – gestures, posture shifts, facial expressions, head movements, touch. Verbal acts – comments, closed & open questions, instructions, reinforcement, request repetition, negative, & unclassifiable.	Overall 93% (range 60% for gestures – 100% questions, instructions, clarifications, reinforcements).
		Appropriateness of DSW communication acts (yes/no)			As above, but rated for appropriateness.	Overall 92.5% (range 70% for head nods and questions, 80% for commenting, - 90% for all other acts).		

Study	Participants	Rating design	Measure of reliability	Number of sample for reliability	DSW		Person with PIMD	
					variable	Finding	Variable	Finding
Samuel et al., 2008	24 DSWs ^r 4 adults with PIMD	Frequency of behaviours in five min sample	Mean kappa scores	12%	Visual scanning	$k = 0.73$ (range 0.54–1.00)	Looking at face	$k = 0.70$ (range 0.62–0.84)
					Contingent responding	$k = 0.69$ (range 0.54–0.93)	Initiating social/physical contact	$k = 0.84$ (range 0.66–1.00)
					Forcing/overriding	$k = 0.83$ (range 0.61–1.00)	Joint focus	$k = 0.76$ (range 0.59–1.00)
							Engagement	$k = 0.73$ (range 0.62–0.86)

Note. Includes only studies that refer directly to adults with PIMD or probable equivalents and DSW or probable equivalents (e.g., nursing staff in residential services for adults with disabilities), in which reliability measures are reported for coding of video-recorded interactions.

^a not stated whether this is total or point-by-point agreement, ^d = day service context, ^r = residential service context, k = kappa coefficient

The studies in Table 2.4 in which the most detailed examination of inter-rater reliability was described were by Samuel et al. (2008) and Clegg et al. (1991a; 1991b). Both groups of researchers used Cohen's kappa as a measurement of agreement, hence factoring in chance agreement. Samuel et al. (2008), in their study of DSW use of Intensive Interaction, examined three DSW variables and four variables of behaviours of people with PIMD. Mean kappa scores for each variable were between 0.69-0.84, which would be considered to move from substantial to almost perfect (Landis & Koch, 1977). However, the range for individual variables was as low as 0.54 (moderate agreement) for the variables of DSW visual scanning and contingent responding.

Clegg et al. (1991a; 1991b) also reported considerable variation in kappa scores. In both of their studies, the affect of the person with PIMD was rated each second as positive, negative, neutral, or uncodable. Inter-rater reliability was examined for two videos each for three dyads. In examining the percentage agreement and kappa coefficients for each of the dyads, it is apparent that agreement was higher for some dyads than others, across the two video-recorded sessions. For example, in Clegg et al. (1991a), Dyad 1 had a kappa score of 0.89 and 0.40 for each video-recording, whereas Dyad 3 had lower kappa scores of 0.16 and 0.45 for the two video-recordings. In completing these studies, Clegg et al. (1991b) highlighted difficulties inherent in gaining acceptable reliability in coding of interactions of people with PIMD. They noted that the reasonable, yet at times poor levels of reliability underlined the problems of obtaining reliable interpretations of the behaviour of some people with PIMD. In particular, they reported poorest levels of reliability for ratings on people with extremely limited movement or blindness (Clegg, et al., 1991a).

Obtaining high levels of inter-rater reliability, though possible, may be a challenge in research on interactions between DSWs and adults with PIMD. The

variables selected for describing the interactions will impact the levels of reliability obtainable. Hatton et al. (2004) noted that an issue in research focusing on observing DSWs was the use of fairly generic categories of staff behaviour. For example, in some studies, DSW behaviour descriptors have been limited to staff presence/absence (Arthur, 2004) and the use of particular speech acts (e.g., Healy & Walsh, 2007). The use of clearly observable behaviours may enhance the reliability of analysis, but conversely may reduce the usefulness of findings, particularly in light of the potential subtlety of communicative behaviour of people with PIMD, and possibly the subtle behaviours of DSWs.

Conceptual Issues in PIMD Research

In addition to the methodological issues in existing PIMD research, there are numerous conceptual issues. In particular, there is a lack of social validity in both the observation and intervention research (Schlosser, 1999). DSWs are often direct stakeholders of interventions but rarely have they been included in decisions about the type of communicative behaviours that should be seen as important in interaction and the levels of behaviours that should be aspired towards.

Much of the social validation issues stem from a lack of best practice definitions for interaction between adults with PIMD and their DSWs. Hatton et al. (2004), in a review of DSW research, commented on the lack of consensus of core competencies that are required of staff in services for adults with ID. They highlighted that without clear definitions and operationalisations of staff skills, assessment and training programs cannot be developed. Granlund and Olsson (1999) also argued that rather than assessment and intervention being based on careful analyses of communicative assets and difficulties, there has been a tendency to base these on individual researcher/practitioner values and beliefs. This practice can be exemplified in existing

research in which judgements are made of the adequacy of DSW interaction performance and interventions are implemented to change performance, in the absence of best practice goals.

One example of the problem of lack of clearly defined best practice is the variable way in which DSWs use of talk has been viewed by researchers. Some researchers have been critical of the complexity of DSW talk directed at people with intellectual disabilities (e.g., Dobson, Upadhyaya, & Stanley, 2002; Healy & Walsh, 2007; McConkey, et al., 1999). Such criticism appears to be based on the premise that using speech that is not commensurate with the person's understanding is inherently problematic. However, if this premise is taken to its extreme logic, then speech may not be recommended at all in interactions with people who lack linguistic comprehension skills. However, this absence of speech being used with people who did not vocalise was clearly characterised as negative when observed by Seys et al. (1998) in their study of interactions within institutional settings. In practice-based research, the perceived inappropriate use of complex speech has been seen as a rationale for DSW training (Healy & Walsh, 2007).

Some researchers appear to consider some forms of spoken communication to be inherently better than others. For example, while Dobson et al. (2002), in their intervention with DSWs, viewed the increased use of utterances as a positive outcome, they considered some forms as more favourable than others (e.g., acknowledgements were preferable to requests for action). This level of complexity discrimination was made despite the fact that approximately half of their participants with PIMD were unintentional; hence, their ability to comprehend any speech, regardless of its discourse function, is questionable. Clegg, et al. (1991b), however, viewed the use of talk very differently. They found that DSW use of talk, irrespective of the complexity, led to

greater positive responses for people with PIMD, compared to baseline performance and other interaction strategies (e.g., contingent responding, offering choice), hence seeing all talk as positive.

Furthermore, several qualitative researchers, rather than viewing talk as a linguistic tool for information sharing, have viewed DSW talk as a way of DSWs validating the humanness of the relationship between the person with PIMD and DSW (Bogdan & Taylor, 1989, 1998; Forster, 2006; Forster & Iacono, 2008). That is, DSWs talked to the person because that was viewed as a natural way to relate to a person, irrespective of whether the person with a PIMD was able to understand or not. The lack of consensus across researchers about the value of talk in interactions with adults with PIMD highlights the problem of social validation within the existing research.

A further conceptual issue may be the dominant focus of interventions and observation on notions of human agency. In the next section the concept of agency will be described in order to explore the argument that agency has been a dominant focus.

Agency

Bandura (2001) stated that “To be an agent is to intentionally make things happen by one’s action” (2001, p. 2). According to Bandura, people use their sensory, motor, and cognitive skills to accomplish tasks and goals of exploration, manipulation, and influence. He argued that this agency gives life meaning, direction, and satisfaction. The core features of human agency, according to Bandura, included intentionality, forethought, self-reactiveness, and self-reflectiveness. He further argued that metacognition plays a central role for agents in examining their own functions, planning, and believing in ability to bring about outcomes.

Rustin (1997), in an examination of infancy and agency, made a distinction between agency and a sense of agency. She stated that while agency may be inherent to

infants, a sense of agency is interactively determined: that is, infants gain a sense of themselves as an agent only when people around them acknowledge their agency alongside successful experiences of agent action. Within the mother-infant dyad, the infant gains awareness that the other person is aware of them, and within these “moments of meeting” (Rustin, 1997, p. 46) the sense of agency is enhanced.

Intentionality is a central feature of agency. Intention, according to Bandura (2001), is a representation of a future course of action to be performed that is followed by an action to bring about the representation. The intention may be partial to start off with and is then filled in, adjusted, revised, refined, or reconsidered given the information received during execution of the intention (Bandura, 2001). Actions need motivation, self-regulation, and belief in capacity to bring about the desired outcome.

Bandura’s goal-directed interpretation of intentionality and agency, however, has not been accepted universally. Zeedyk (1996) categorised several of the varying perspectives of intentionality, including goal-directedness, *as-if*, and innate capacity. The most common perspective of goal-directedness, as described by Zeedyk, is consistent with Bandura’s theory. In this perspective of intentionality, a person must hold a mental representation of a goal and be able to separate the ends and means of an action. Piaget, also exemplifying goal-directed intentionality, believed that infants could not be regarded as acting intentionally until they were able to clearly demonstrate, through behaviour or speech, that their actions were guided by mental states. Zeedyk (1996) differentiated Piaget’s goal-directed theory of intention from that of theorists, such as Vygotsky, who she described as having an *as-if* perspective. *As-if* theorists, according to Zeedyk (1996), subscribe to a theory of intentionality arising from parental scaffolding, in which the parent treats the child as if s/he were intentional even if not at

the stage at which intentionality is thought to emerge. It is through these early scaffolded interactions with parents that infants develop intentionality.

A third perspective of intentionality offered by Zeedyk (1996) is that of innate capacity. Classifying Trevarthen, Brazelton, and Tronick in this group, she described their perspective of seeing intentionality as “fundamentally an emotional interpersonal phenomenon and that infants are born with an innate capacity for it, which evidences itself within their early social interactions” (Zeedyk, 1996, p. 429). As with the as-if theories, intentionality occurs in interpersonal relations, but in contrast to other theories, the intentionality is present at birth in the infant who has a biological motive to communicate. These moments of sharing intention occur within the context of sharing minds, a state referred to as *intersubjectivity* (Zeedyk, 1996). The intersubjective conceptualisation of interaction is a departure from Bandura’s goal-directed agency view of interaction and will be explored in the next section.

Reconceptualising Interactions

Intersubjectivity

Intersubjectivity broadly refers to how two people are able to share their minds, which occurs both in linguistic and pre-linguistic stages of communication (Beebe, Knoblauch, Rustin, & Sorter, 2005b; Trevarthen, 1979; Zeedyk, 2006). It refers to how people influence each other’s arousal and inner state moment-by-moment (Beebe, Knoblauch, Rustin, & Sorter, 2005a). In contrast, subjective motives refer to those experiences directed to one’s own body, and these differ from motives that are intersubjective and interpersonal (Trevarthen & Aitken, 2001). As with differing definitions of intentionality, intersubjectivity has been conceptualised differently across theorists (Beebe, Knoblauch, et al., 2005a). Beebe, Sorter, Rustin, and Knoblauch (2005) compared three theorists of intersubjectivity in infant research: Andrew

Meltzoff, Colwyn Trevarthen, and Daniel Stern, and in recognising the varying definition of intersubjectivity, they choose to use the term *forms of intersubjectivity*. Two commonalities across the three theorists were that they all addressed how an infant could sense the state of another person, and all saw crossmodal correspondences as a central aspect.

Meltzoff's intersubjectivity focused on imitation (Beebe, Sorter, et al., 2005). Meltzoff argued that infants have the capacity to detect correspondences between their own and others' action, and through this the infant gains a sense that *you are like me* (Meltzoff, 2007). Through a series of studies, he provided support for hypotheses that imitation is not reflexive, but intentional, goal-corrected, and mediated by memory (Meltzoff & Moore, 1989). The imitative interactions between the mother and newborn are, to Meltzoff, the first origin of intersubjectivity (Beebe, Sorter, et al., 2005). Nagy (2006) also focused on the importance of imitation, in particular in neonates, stating that "the earliest communication originates from imitation and this communicative ability presumably later evolves to language" (p. 223). Imitation serves multiple functions including copying, learning, reproducing a movement, achieving a potential goal, and being connected to another person through intimate preverbal interactions (Nagy, 2006).

Trevarthen and Aitken (2001), and Trevarthen (2008), as with Meltzoff, believed in innate intersubjectivity and that the infant entered the world already able to communicate, share experiences, and be receptive to the subjective states of others. Trevarthen's theory was more dyadic in form than Meltzoff's, with intersubjectivity being felt by both mother and infant (Beebe, Sorter, et al., 2005). Emotions formed the basis of the communication and thoughts of infants (Trevarthen, 2008). Trevarthen expanded the concept of intersubjectivity to account for primary and secondary forms. *Primary intersubjectivity* referred to the sharing between the infant and caregiver

through correspondences of form, timing, and intensity. In using primary intersubjectivity, the infant “possess[es] an active and immediately responsive conscious appreciation of the adult’s communicate intentions” (Trevarthen & Aitken, 2001, p. 5). *Secondary intersubjectivity* involved reference to a third element, such as object or referred concept, and was thought to develop at 9-12 months of age when symbolic functioning emerged (Trevarthen & Aitken, 2001).

Initially contrasting with Meltzoff and Trevarthen’s theories of innate intersubjectivity, Stern (1985) considered intersubjectivity as innate but only truly developing between 9 and 12 months of age, when the infant has discovered his/her own mind (Beebe, Sorter, et al., 2005). Hence, Stern’s conceptualization was initially more akin to Trevarthen’s secondary intersubjectivity (Stern, 1985). However, later, particularly with mounting evidence from the discovery of the action of mirror neurons, which may provide a neurobiological mechanism for intersubjectivity (Stern, 2005), Stern has argued that intersubjectivity is evident at birth in a primitive form (Stern, 2004; Stern, 2005).

Stern’s particular contribution to intersubjectivity was to initiate a shift in attention away from overt behaviours to inner states, with his belief in the infant’s capacity to feel what has been perceived in the other (Beebe, Rustin, Sorter, & Knoblauch, 2005). According to Stern (2004, 2005), intersubjectivity can either be one-way in that a person has a sense that they know what the other is feeling or it can be two-way in which the sense is more like “I know that you know that I know” (Stern, 2005, p. 79). According to Beebe, Rustin, et al. (2005), Stern focused on “*changing with the other, through micro-momentary shifts in intensity over time that allow us to feel what has been perceived in the other*” (p. 59). Another feature of Stern’s theory is a focus on the presence of an innate amodal perception, in which infants can receive

information from one sensory modality and translate it into other modalities leading to experiences of perceptual unity (Stern, 1985).

In contrast to Trevarthen and Aitken (2001) who categorised intersubjectivity into primary and secondary types, Stern (1985) conceptualised the concept according to three categories: interattentionality, interintentionality, and interaffectivity. Of the three categories, interaffectivity, otherwise known as affect attunement (Stern, 1985), was seen to be the first and most important mode of sharing subjective experiences (Beebe, Sorter, et al., 2005; Stern, 1985). Interaffectivity referred to the infant's ability to make a match between the feeling state as experienced within themselves with the feeling state of another (Stern, 1985).

Stern described intersubjectivity as an innate motivation system essential for species survival (Stern, 2004), because it contributes to promoting group formation, enhancing group functioning, and ensuring group cohesion (Stern, 2005). Stern (2004) further argued that intersubjectivity is necessary for language and identity development. He argued that intersubjectivity requires psychological intimacy, in a way that differs from the need for physical contact and psychological security, two conditions necessary for attachment (Stern, 2005).

In 2005, Stern summarised intersubjectivity:

Intersubjectivity is the capacity to share, know, understand, empathize with, feel, participate in, resonate with, and enter into the lived subjective experience of another. It is a form of nonmagical mindreading via interpreting overt behaviors such as posture, tone of voice, speech rhythm, and facial expression, as well as verbal content (p. 78).

Intersubjectivity and agency, as referred to previously, do not appear to be mutually exclusive concepts, in that many theorists have referred to how elements of one become apparent through the other. For example, Zeedyk (2006) suggested that it is

through intersubjectivity that mothers engage in the agency of their infants, and social theorists also have acknowledged the importance of social interaction to the development of intentionality. Nevertheless, agency and intersubjectivity represent two contrasting ways of viewing communication: (a) agency focuses on the skill of the individual to bring about outcomes, and (b) intersubjectivity focuses on how two people in a dyad experience a sense of togetherness. These two constructs have relevance to literature on the communication of people with PIMD.

Implications for PIMD/DSW dyad

It is evident from the literature on communication and people with PIMD that there has been greater focus on agency, and, in particular, more focus on enhancing agency rather than on intersubjectivity. The focus on choice-making (e.g., Cannella, et al., 2005), intentionality (e.g., Carter & Iacono, 2002), and even affect (e.g., Hogg, Reeves, et al., 2001), within the context of affect being used as an indicator of likes and dislikes, all point to a focus on agency. However, this focus creates particular difficulties in relation to examining and understanding communication and relationships of people with PIMD.

Concern regarding a dominant agency perspective has been expressed by Reinders (2008), who recently explored how friendship with people with PIMD can be conceptualised. His theory addressed both how humanity is conceptualised and how the disability rights movement has developed. According to Reinders (2008), for many people, humanity is defined by agency or the ability to act for a purpose. Similarly, the disability rights movement has been dominated by perspectives centred on empowerment: for example, a focus on a person with disability having more control over where, how and with whom s/he lives. People with PIMD, with severe limitations in use of agency, present an enormous challenge to both the conceptualisation of

humanity and the foundation of the disability rights movement (Reinders, 2008).

Reinders (2008) argued that the disability rights movement has little to say about people with PIMD, because they do not comply with the vision of liberation through reclamation of the authority of their own story, given that they cannot know what it is to have a story. Perspectives in which agency are placed in the forefront of both humanity and living with a disability are rendered incomprehensible when the focus is turned to people with PIMD. Reinders argued for a focus that sees humanity as an endowment, not an achievement exercised through agency. His perspective, which includes a theological perspective, focuses on the importance of friendship, relationships, and the simple importance of participating in the lives of another person (Reinders, 2002; 2008): that is, intersubjectivity.

Of the current interventions focusing on adults with PIMD, Intensive Interaction has made some movement towards a greater focus on intersubjectivity. Zeedyk et al. (2009) related Intensive Interaction to Stern's work on *communion*, in which the feeling of connection, rather than a transfer of information has been the dominant theme. Caldwell (2006) also related Intensive Interaction to intersubjectivity, stating that Intensive Interactions are those "where the emotions, the topic, and the content of the exchange all emerge from the interaction of the two partners" (p. 279), rather than creating a third object for joint attention. However, in the absence of tools to describe intersubjectivity, outcomes of Intensive Interaction have been described largely using terms more aligned with agency than intersubjectivity. In particular, outcomes usually have been described in terms of individual skills (e.g., smiles, looking at faces) rather than descriptions that encompass the dyadic nature of the interaction.

In research incorporating observations of people with PIMD in interactions, Burford (1988) focused on intersubjectivity. She believed that the style of

communication used by adults with infants could be a useful guide to interaction with people with PIMD. Burford (1988) largely drew on the work of Stern and Trevarthen, and their experiments of the co-ordinated timing that occurs in interactions between infants and their caregiver. She suggested that, given the limited behavioural and vocal repertoire of the person with PID, there seemed to be good reason to believe that the style of communication observed in primary intersubjectivity would be suited to interactions with people with PID (Burford, 1988). This work, however, does not appear to have been developed further in the literature.

Nevertheless, Stern's type of intersubjectivity, referred to as affect attunement (Beebe, Sorter, et al., 2005), may have particular relevance to interactions between adults with PIMD and DSWs. Stern (2002) stated in his influential book *The first relationship: Infant and mother* that "for the baby, the music comes before the lyrics" (p. 4), meaning that the feeling or the affect in interactions was more important than the word meanings and that affect attunement has an important role in interaction between mothers and infants. Perhaps this may also be true for adults with PIMD and their DSW, as will be explored in the next section.

Affect Attunement

Stern (1985) stated that the use of affect attunement in interactions contributes to the quality of the relationship between mothers and their infants. He asserted that affect attunement plays an important function in developing an infant's knowledge of his/her own affectivity and sense of self (Stern, 1985). In using affect attunement, Stern (2002) believed an infant was able to learn that experiences were not restricted to him/herself, but could be shared experiences with another person.

Stern (1985) also noted that although affect attunement could be considered to be a commonly occurring phenomenon, it had also been very difficult to study. This

complexity, argued Stern (1985), was because affect attunement occurs rapidly and largely out of awareness. He believed that the phenomenon of affect attunement was often first sensed as an intuition by an observing clinician, rather than an easily articulated event.

Stern (1985) sought to clarify the phenomenon of affect attunement by specifying its constituents, which are summarised in Figure 2.1. For mother-infant affect attunement to occur, three processes were said by Stern (1985) to be necessary: (a) the parent read the feeling state of the infant from their overt behaviour, (b) the parent performed a behaviour that corresponded with the infant's overt behaviour, and (c) the infant was able to read the corresponding parental response as having something to do with his/her own original feeling experience.

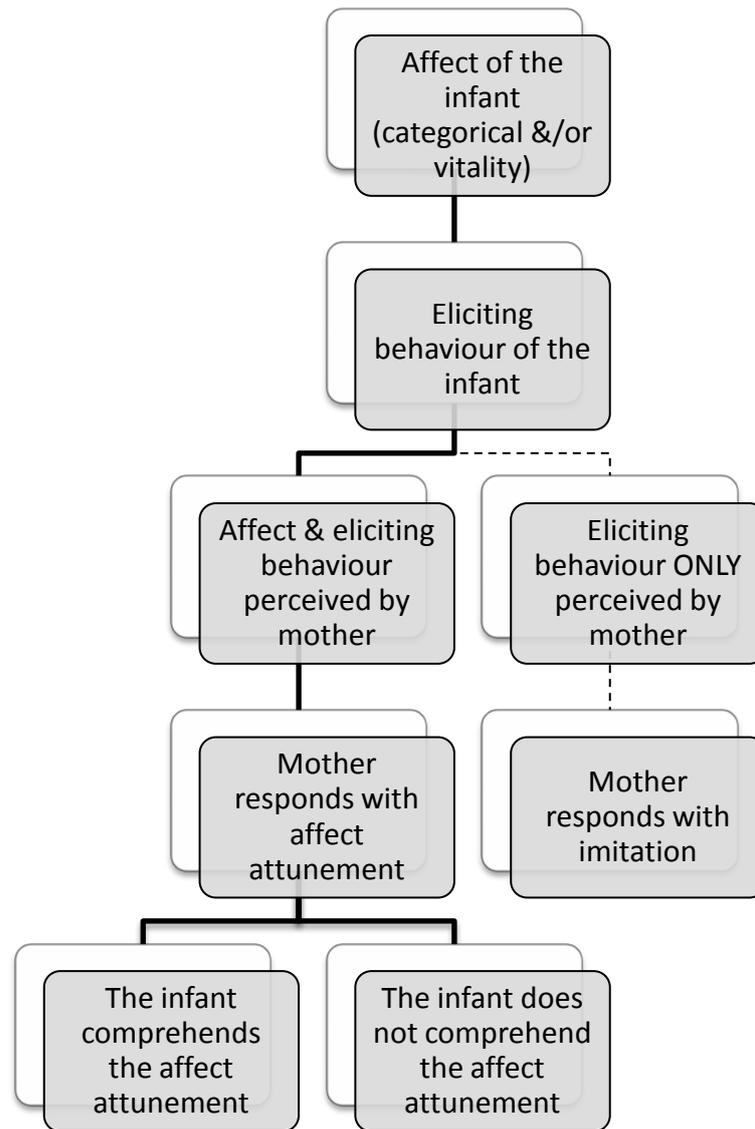


Figure 2.1. Affect attunement process between mothers and infants.

Stern (1985) used examples liberally to illustrate the components of affect attunement, including the following:

A ten-month-old girl finally gets a piece in a jig saw [sic] puzzle. She looks toward her mother, throws her head up in the air, and with a forceful arm flap raises herself partly off the ground in a flurry of exuberance. The mother says ‘YES, thatta girl.’ The ‘YES’ is intoned with much stress. It has an explosive rise that echoes the girl’s fling of gesture and posture.

One could easily argue that the ‘YES, thatta girl’ functions as a routine response in the form of a positive reinforce, and it certainly does do so. But, why does the mother not just say ‘Yes, thatta girl’? Why does she need to add the intense intonation to ‘YES’ that vocally matches the child’s gestures? The ‘YES’, I suggest, is an attunement embedded within a routine response. (Stern, 1985, p. 141)

In this example, the role of cross-modal correspondence is emphasised. The explosive rise of the infant’s arm movements are met with the explosiveness of the mother’s vocalisation. The example also introduces another key component of Stern’s affect attunement – *vitality affect*.

Conventionally, affect has been conceptualised using Darwinian affect categories, such as joy, sadness, and anger (Stern, 1985). Stern (1985), however, recognised that there were many other qualities of feelings that did not fit into existing taxonomies of affect and he wanted to examine more broadly the feeling qualities experienced while doing all of life’s activities. He chose the term vitality affects to describe the dynamic, kinetic qualities of feelings (Stern, 1985). Specifically, vitality affects referred to the “subjectively experienced shifts in internal feeling states that accompany the temporal contour of the stimulus” (Stern, 2004, p. 64). In describing vitality affects, he included terms such as fleeting, bursting, and hesitating (Stern, 2004). Vitality affects could exist separately or simultaneously to the Darwinian categorical affects, for example, a rush of movement or a rush of anger (Stern, 1985).

Stern’s (1985) description of affect attunement also attended to modal and amodal qualities. Modal qualities referred to the specific form of the behaviour, such as vocal, gestural, postural, or facial. Amodal qualities referred to how the behaviour occurred and included the intensity, timing and shape, and patterns of their change.

Affect attunement involves cross modal matching of the amodal qualities, such as matching a facial expression with a vocalisation delivered with the same intensity and timing quality (Beebe, Sorter, et al., 2005). According to Beebe, Sorter et al. (2005), infants perceive the amodal qualities, recognise correspondence, and from this, capture the quality of another's feeling state.

Stern was careful to explain the differences across affect attunement and imitation. Unlike imitation in which the focus is on the external behavioural act, the affect attunement focus is on the internal state of the infant (Stern, 1985; Stern, 2004). In imitation, there may be an absence of similar inner feelings despite shared behavioural expressions (Stern, 1985). Stern highlighted the problem of imitation alone, stating that "If we could demonstrate subjective affect sharing only by true imitation, we would be enormously limited, maybe even robot-like" (Stern, 1985, p. 252). He also, however, acknowledged that affect attunement and imitation act more as two ends of a spectrum than a true dichotomy (Stern, 1985).

Affect Attunement Empirical Studies

A small number of empirical studies have been conducted using Stern's concept of affect attunement in mother-infant dyads. These are summarised in Table 2.5 and described further below.

Table 2.5

Empirical Studies of Affect Attunement in Mother-Infant Dyads

Study	Aim	Dyad numbers	Measure of affect attunement	Finding
Stern, Hofer, Haft, and Dore (also reported in Stern), 1985	Describe the nature of affect attunement.	10	Single incident measures of modality, dimensions (intensity, timing and shape), and matching, and type. Maternal attributed function.	Broad description of affect attunement frequency, nature, and mothers' perceived function for using affect attunement.
Haft (also reported in Haft and Slade), 1989	Examine relationship between maternal attachment and use of affect attunement.	15	Single incident measures on a scale of <i>sharedness</i> : -2 or -1 for negative attunement, 0 for comments, +1 or +2 for positive attunement. Maternal attribution of function.	Securely attached mothers were more attuned than insecurely attached mothers. Secure mothers attuned to a broader range of infant behaviours (e.g., dismissing mothers did not attune to infant negative affect).
Siegel, 1996	Examine relationship between infant attachment and use of affect attunement.	53	Single incident measure of modality, maternal response, and perceived sharedness of maternal response (affectively dominant, affective blends, affectively neutral, and affectively negative).	No significant difference in affect attunement use across secure and insecurely attached infants.
Jonsson et al., 2001	Examine proportion of affect attunement to imitation across time from 2-12mths of age.	39	Single incident measure of modality and dimensions (intensity, rhythm, shape and duration). Imitation and affect attunement discriminated from each other.	Imitation used more frequently in early months, with affect attunement used more after 6 mths of age.
Jonsson and Clinton, 2006	Examine the types of infant behaviours to which mothers' respond with affect attunement.	27	As above with description of infant eliciting behaviours on 10 dimension scales (0,1,2,3) (loss, sudden, fall, risk, attention, affect, negative, striving, effective action).	20% of incidents involved infant categorical affects alone. Clusters of infant's behaviours included: pleasurable motoric behaviour, effect initiation, focusing, loss of balance, uncontrolled behaviour, and displeasure.

In the first of these studies, Stern (1985) extended his theory by developing objective criteria for describing incidents of affect attunement and studying the phenomenon. He described three requirements for rating a brief interaction as affect attunement: (a) the infant displayed any affect that represented a marked change over an immediately preceding behaviour; (b) the mother then displayed a behaviour that gave the impression of imitating, mirroring, matching or attuning to the infant's behaviour, as opposed to a behaviour solely commenting on the infant's behaviour; and (c) the infant could see or hear the behaviour (Stern, 1985). The behaviour was further analysed in regards to modal and amodal qualities.

In his first study addressing affect attunement in the mother-infant dyad (Stern, 1985; Stern, Hofer, Haft, & Dore, 1985), Stern observed 10 mother-infant dyads through 77.5 mins of video-recording and noted 151 affect displays. Thirty-three percent of these displays were rated as comments, 19% as imitations, and the remaining 48% as affect attunement. The mothers were then shown the videos of incidents and were asked to describe why they did what they did. Their responses indicated that they appeared to be largely unaware of why they responded in the way that they did, frequently stating it was “‘to be with’ the infant, ‘to share,’ ‘to participate in,’ ‘to join in’” (Stern, 1985, p. 148). Stern described the mothers' descriptions as being most aligned with the concept of *communing*, which he distinguished from communication. He described communication as involving the transmission of information, with the frequent intention of altering another's belief or action (Stern, 1985). In contrast, he described *communing* as two people participating together or sharing one another's experience without an intention to alter the other person's behaviour. Beebe, et al. (2005) extended this definition of communion to include maintaining a thread of feeling-connectedness, which contributes to a sense of security and intimacy.

In his observations of the mother-infant dyads, Stern (1985) also noted that the infants frequently showed no discernable response to their mothers' attunement responses. This finding led to perturbation studies (Stern, 1985; Stern, et al., 1985) in which the mother was asked to deliberately misattune her response to her infant's affect display. Trials of misattunement were conducted, in which the mother responded with far greater vigour to the infant than would have matched the infant's behaviour, followed by trials of under-responding in intensity. In both situations, unlike in the regular attunement incidents, infants turned and paused, apparently recognising the discrepancy. In conclusion, Stern believed that infants often responded as if nothing special had happened when mother's correctly attuned to their infant (Stern, 1985).

Later, Haft and Slade (Haft, 1989; Haft & Slade, 1989) extended Stern's studies to examine the relationship between affect attunement and maternal attachment in dyads of mothers with older infants aged from 10 to 13 months of age. Mother's maternal attachment style was assessed and categorised according to a scale—the Adult Attachment Interview (George, Kaplan, & Main, 1985). Affect attunement incidents were assessed on a subjectively derived dimensional scale of sharedness, in which the degree of attunement was rated. High order attunement was rated when the mother appeared simply to be trying to share the infant's experience, as opposed to modify the infant's behaviour.

In Haft and Slade's study (Haft, 1989; Haft & Slade, 1989), the concept of misattunement was expanded to include three different types. The first type involved using a bit of attunement, but adding to it a cognitive or teaching element. The second type was described by Haft and Slade (1989) as a benign misattunement, referring to times when it made sense for the mother to modify the intensity of attunement: for example, attuning to anger or distress in a way that validates an infant expression, but

also attempted to calm it. Thirdly, was a misattunement when the mother attempted to alter the baby's experience or downplay his/her distress by reducing the intensity of the behaviour. Haft (1989), and Haft and Slade (1989) found that the securely attached mothers (determined by scores on the Adult Attachment Interview) were more attuned to their infants than the insecurely attached mothers. The securely attached mothers attuned consistently to a broad range of infant behaviours, in contrast to dismissing mothers who did not attune to negative infant affect, and preoccupied mothers who randomly attuned to both positive and negative states. Patterns of misattunement and selective attunement, Haft and Slade (1989) believed, gave messages to infants about the kinds of affective experiences that could be shared and those that could not. They suggested that when a mother selectively attuned to a particular kind of emotion in the baby, the baby learnt not only that this state held special status for the mother, but also that recreating it served an important function for achieving intersubjectivity.

Research by Siegel (1996) expanded the work of Haft (1989), and Haft and Slade (Haft, 1989; Haft & Slade, 1989) by focusing on the role of affect attunement in the infant's quality of attachment as opposed to the mother's attachment. Siegel used Ainsworth's Strange Situation (Ainsworth, Bell, & Stayton, 1978) to assess infant attachment style. Siegel (1996) developed a Affect Attunement Coding System to measure affect attunement. This system involved rating sharedness as affectively dominant, affective blends, affectively neutral, and affectively negative. She found no difference between infant attachment groups for rates of maternal affect attunement, suggesting that "though moments of affect attunement are touching and compelling to observe in and of themselves, these interactions may not be sufficient to provide infants with pronounced feelings of security or insecurity" (Siegel, 1996, p. 91). Siegel,

however, also questioned whether the attunement instrument was sufficient for measuring the constructs of interest.

More recently, Jonsson and colleagues examined affect attunement with younger infants (Jonsson & Clinton, 2006; Jonsson, et al., 2001). Their research focused on discriminating imitation and affect attunement in light of Stern's earlier delineation of the two constructs. They examined whether proportions of occurrence of imitation and affect attunement were related to age of infants. In their first study on the topic, Jonsson et al. (2001) observed interactions of mothers and their infants aged 2-12 months. They modified Haft's Affect Attunement Coding System to create the Affect Attunement Protocol to rate the intensity, rhythm, shape, and duration of the mothers' and infants' behaviours. Criteria for rating as affect attunement was that (a) one or more of the dimensions matched, and (b) clear affective emphasis was present. Imitation was rated when exactly the same modality was used by both people and no emphasis was present. The researchers found a negative association between imitation and age, with greater proportions of imitation used with the younger infants and greater affect attunement used with the older infants.

In contrast to Stern (1985) and Stern et al.'s (1985) reports of affect attunement occurring from 9 months of age, Jonsson and Clinton (2001) recorded incidents of affect attunement being used with the younger infants. They argued that their differing finding may be because Stern did not systematically investigate affect attunement in infants younger than 8 months (Jonsson, et al., 2001). However, an alternative explanation may be that in Stern's original conceptualisation, he required the infant to have a concept of self to enable the infant to sense the difference and correspondence of behaviours, but Jonsson et al (2001) did not examine this proposition.

The exact nature of the eliciting behaviour of the infants was then examined by Jonsson and Clinton (2006) in a follow up study. Complementing the Affect Attunement Protocol, they developed a rating scale called the Behavioural Themes in Affect Attunement (BeTA) that allowed them to identify themes that categorised the infant's eliciting behaviour for each observed incident. Ten behavioural themes, which were developed by the first author, and then discussed with other researchers, were rated on a four-point scale. Cluster reduction was then used to create the following six clusters of infant behaviours that elicited attunement responses from mothers: pleasurable motoric behaviours, displeasure, focusing, loss of balance, effect initiation, and uncontrolled behaviours. The researchers commented on the rarity of incidents that were distinct categorical affects, supporting Stern's contention of vitality affects being responded to more frequently than were categorical affects.

While the term affect attunement has been used by other researchers of mother-infant interaction, the definition has not always been synonymous with Stern's construct. For example, Legerstee, Markova, and Fisher (2007) were interested in the role of affect attunement in dyadic and triadic communication. However, they used the term maternal attunement, defined as maintaining attention and warm sensitivity. Similarly, Feldman and Greenbaum (1997) also referred to maternal affect attunement, but their definition focused on maternal positive affect and the degree to which the mother followed the child's affective signals.

Affect Attunement in Adult Contexts

Stern's construct of affect attunement has received attention from practitioners and researchers in the area of adult psychoanalysis (Beebe, Rustin, et al., 2005). McCluskey (2005) has been particularly instrumental in examining the relationship of affect attunement to adult interactions between adult careseekers and adult caregivers.

She suggested that when careseeking is aroused in adults, like infants, these adults require attunement to affect and affect regulation (McCluskey, 2005). According to McCluskey, affect attunement plays an important role in the adult context because “if the caregiver does not attune to the affect of the careseeker, careseeking will not be assuaged, but even more importantly the careseeker will have no evidence on which to base their confidence that the caregiver would be able to support them in their exploration, discovery and potential action” (McCluskey, 2005, p. 76). The attunement to the careseeker’s vitality affects communicates that the caregiver is aware of the subjective states of the careseeker (McCluskey, Hooper, & Miller, 1999). The caregiver may also be involved in tuning down the affects to bring the careseeker’s level of arousal to a level that allows clear thinking (McCluskey, et al., 1999). McCluskey extended this concept further, suggesting that the caregiver also needs empathy, a construct that in development succeeds attunement. According to McCluskey (2005) empathy is a metacognitive capacity that requires the ability to see things from another’s point of view, understand and resonate with the emotions, and convey in words the appreciation in a way that can be understood by the person. This empathy is also used as a way to help the careseeker move toward a goal. McCluskey’s (2005) formulation, hence, was referred to as *goal-corrected empathic attunement*. In this formulation, emphasis was given to how words are used to express the empathic attunement.

McCluskey (2005), McCluskey et al. (1999), and McCluskey, Roger and Nash (1997) completed a series of experiments to examine affect attunement in interactions. In the first study, McCluskey et al. (1997) video-recorded interactions during adult psychotherapy sessions. The recordings were shown to nine experts in adult psychotherapy and 31 postgraduate social work students, who were asked to rate

whether the interactions were attuned or not attuned. The following definition, which McCluskey (2005) acknowledged blurs the distinctions between empathy and attunement, was provided to participants: “Attunement is a way of communicating to the other that one has recognised the affect they are experiencing. Attunement conveys to the other that one has a feeling sense inside of what it feels like to be them right now” (McCluskey, 2005, p. 92). The experts demonstrated a high degree of agreement on their ratings of attunement in interactions, however the students had poor agreement. No statistical difference was found between accurate and inaccurate respondents according to personality types, age, gender, and previous experience in social work or counselling. In the second experiment, the students were taught more explicitly what to observe and then asked to describe why they rated the videos as attuned or not attuned. With clearer definition and direction, the students improved in their rating of affect attunement.

In a third study, McCluskey (2005) sought to develop a tool for measuring goal-corrected empathic attunement. She summarised that “After almost a year’s work and two failed attempts we eventually achieved a correlation of 0.8 between two independent raters based on the average score of seven 1.5 min segments of interaction from each of 12 videotaped interviews” (McCluskey, 2005, p. 137), highlighting the complexity of reliability for this construct over longer periods of time. In their final descriptions, they moved away from single incidents to measuring blocks of time and process, in contrast to Stern’s (1985) focus on single incidents of affect attunement.

Affect Attunement in Disability

Affect attunement has received only limited attention in populations with disabilities. Furthermore, variation from Stern’s definitions of affect attunement is evident.

Damen (2007) and Damen, Kef, Worm, Schuengel, and Janssen (2008) sought to examine the relationship between affect attunement and meaning negotiation in the context of adults with congenital deafblindness. These researchers drew strongly on the work of Janssen, Riksen-Walraven, and Van Dijk (2003a) who used affect attunement as one of the core principles for developing an intervention model referred to as CONTACT. Specifically, Damen (2007) was interested in how, using the CONTACT framework, interaction partners could be sensitive and communicative about each other's sensations, needs, and feelings. In this observational study of one man with congenital deafblindness across three interaction samples with different partners, Damen (2007) reported that higher levels of affect attunement were associated with higher levels of shared meaning within the dyad. Affect attunement, in this context, referred to "the way infants and their mothers adjust timing, form and energy of expressions to obtain harmonious transitions and complementarity in interaction" (Damen, 2007, p. 5). Damen proposed that affect attunement was equivalent to *affective mutuality* as described by Pianta (1995) and hence used Pianta's Dyadic-Level Rating Scales for Parent-Child Interaction Tasks (Pianta, 1995) to rate the construct. The scale, which allowed for a judgement across a whole interaction (as opposed to single incidents), focused on aspects such as a child's feeling of security, reciprocity, and freedom to express him/herself. Such a focus contrasts to Stern's single incident construct that requires much less inference about internal states.

Pavlicevic (1997, 2002) examined a very similar construct to affect attunement in music therapy intervention that she referred to as *dynamic forms*. She equated such forms to Stern's vitality affects, arguing that music provides a medium for reproducing properties that belong to feelings, movement, shape, contour, and intensity (Pavlicevic, 1997). Pavlicevic described how music therapists developed intersubjective musical and

emotional relationships through clinical improvisations. In these improvisations, the therapist needed to read the dynamic forms of his/her client and then respond using similar forms, albeit using music as the modality. According to Pavlicevic (2002), a therapist could then offer variations on themes, testing the interactive potential of the improvisation. Within this context, attunement of the therapist was necessary for the development of a mutual relationship.

In a very different context, Häggström, Jansson, and Norberg (1998) interviewed and observed five carers in a group home for people with dementia. Stern's affect attunement was used to frame an understanding of the interactions. Affect attunement was seen as a way of achieving understanding between the carers and people with dementia. As an example, the researchers suggested that the carers' way of performing in slow motion could be understood as affect attunement: that is, their reading of the residents' feeling state took a period of time before becoming well attuned (Häggström, et al., 1998). They also felt that the carers' personal ways of achieving an understanding of the residents through affect attunement could be seen as a communion between the carer and the resident. Häggström et al. (1998) concluded that the priority means for developing personal communication strategies should be the development of carers' affect attunement and establishment of mutual and reciprocal relationships.

In further examination of interactions in people with acquired disabilities, Jansson and Sundin (2003) explored nursing carers of patients with stroke and aphasia. They again referred to the intersubjective relationship between the care provider and the patient, and the way in which patient feelings were shared using affect attunement and communion. Qualities of communion included a sense of the patient and carer understanding and being understood, and the carer making him/herself available to the patient on an emotional level.

In summary, an interest in affect attunement in the impairment/disability context is evident in the literature. However it has been limited in populations studied (e.g., deafblindness and dementia) and varied in conceptualisation. The construct usually has been presented descriptively, rather than tested empirically.

Summary

Much of the existing conceptualisation of communication in people with PIMD has focused on agency: that is, enhancing the ability of people with PIMD to express what they want and have these expressions heard by communication partners. Much less focus has been on intersubjectivity, or the way in which a dyad of a person with PIMD and a DSW can share mind and feelings.

Stern's (1985) construct of affect attunement, which is a form of intersubjectivity, may be a way of beginning to address this gap. To date, there has been few researchers who have considered affect attunement, however this focus has not always been consistent with Stern's (1985) concept. For example, some researchers have considered attunement as a global rating/description, rather than an objective single incident that can be described. Stern's work, and the work of other researchers examining affect attunement (largely in the mother/infant context), may provide a new and useful way of examining the interactions of people with PIMD and their DSWs.

CHAPTER THREE

PRELIMINARY STUDIES: CODING AFFECT ATTUNEMENT

In the literature review, it was argued that affect attunement, as described by Stern (1985), has potential as a construct to facilitate understanding of the nature of interactions between adults with PIMD and their DSWs. In the current chapter, the applicability of two coding systems developed by Jonsson and colleagues (Jonsson, 2001; Jonsson & Clinton, 2006; Jonsson, et al., 2001) to dyads of a person with PIMD and DSWs were examined. The development of a manual to guide the coding of affect attunement in PIMD/DSW dyads—the Affect Attunement and Behavioural Coding (AABC)—was described according to a process. This process included application of the AABC to two further adults with PIMD and their respective DSWs, and determining reliability across two raters. Subsequently, this application was used to determine the most appropriate and feasible method of achieving reliable coding in the larger study.

Background

Research into affect attunement has involved the development of coding systems developed in an attempt to capture incidents of affect attunement and describe their nature. Jonsson and colleagues developed two tools for this purpose: the Affective Attunement Protocol (AAP; as described in Jonsson, et al., 2001) and Behavioural Themes in Affect Attunement (BeTA; as described in Jonsson & Clinton, 2006). Both tools are consistent with Stern's conceptualisation of affect attunement.

The applicability of the tools has been demonstrated in two studies of interactions between mothers and infants. In the first study, Jonsson et al. (2001) used the AAP to examine the ratio of maternal imitation use to affect attunement use in interactions between 39 mothers (22 Swedish and 17 Yugoslavian) and their infants aged from 2 to 12 months. The AAP was used to determine if incidents were imitation

or affect attunement, and to then examine aspects of the affect attunement, such as duration and intensity. The AAP was completed by pairs of psychologists who used the following steps: (1) jointly identified possible incidents, (2) independently completed the AAP for each incident, (3) compared ratings and discussed discrepancies for each incident, and (4) engaged a third rater to resolve ratings in which consensus was not reached. Only ratings in which there was a final consensus were used in the analysis: five out of 71 incidents were removed because of lack of consensus. Spearman correlation coefficients were calculated for the each pair of ratings, yielding high levels of agreement of 0.87 and 0.86 for incidents of imitation and affect attunement, respectively.

The second tool—the Behavioural Themes in Affect Attunement (BeTA)—was developed by Jonsson and Clinton (2006) as an adjunct to the AAP to enable further description of the nature of the attunement eliciting behaviour used by the infants. Incidents of affect attunement between 27 mother-infant pairs (10 from Sweden and 17 from the former Yugoslavia) were identified using the AAP. The BeTA was then used to rate the infants' eliciting behavioural themes on a 4-point graded scale. The behavioural themes were: loss of control over actions, sudden or unexpected behaviours, falling, risk behaviour, motor effort in actions and movements, attention and curiosity, affect, negative emotion, striving, and effective action. The Swedish dyads were rated using a consensus method, which aided the development of a manual for the BeTA. The dyads from the former Yugoslavia were then rated by two independent raters and Spearman correlation coefficients were calculated for ratings on each of the behavioural themes. Coefficients ranged from 0.46 to 0.92 ($M = 0.73$), indicating that reliability was poorer on some themes, such as effective action ($r = 0.46$) and striving ($r = 0.65$), than other themes, such as sudden behaviours ($r = 0.92$) and loss

of control ($r = 0.87$). Jonsson and Clinton (2006) then examined how the behavioural themes clustered together to create distinct forms of infant behaviours to which mothers attuned. For example, 46 of the 141 incidents were described as pleasurable motoric behaviours, which were characterised by motor effort and affect, and low scores on negative affect.

Together, these two studies have contributed to the evidence on both the measurement of affect attunement and the knowledge about the nature of affect attunement in mother-infant dyads. These tools have not been used in any other contexts. The applicability of the tools to dyads of adults with PIMD and DSWs required examination according to both validity and reliability.

There were two questions addressed in these preliminary studies: (1) does the AAP and BeTA have face validity in application to adults with PIMD and DSWs, and (2) can the AAP and BeTA be used for the reliable description of affect attunement in dyads of adults with PIMD and DSWs? An additional aim of these studies was to develop a manual that combined the AAP and the BeTA, and enhanced reliability of measurement of affect attunement in these dyads.

Study 1: Face Validity

Method

Ethical considerations. Approval for this study was obtained from the Monash University Human Research Ethics Committee. Consent was given by the DSWs for their own participation, and a next-of-kin for the person with PIMD.

Participants. This phase of the study involved three participants. All participants were recruited from a government funded group home in Australia. A participant with PIMD was recruited first. Daphena (pseudonyms are used for all participants) was a woman aged in her early 40s who lived with four other adults who had disabilities. She

had lived in this house for over 20 years, before which she lived in a large institution for children with disabilities. Formal information available regarding her impairments was limited. The DSWs reported that she had cerebral palsy and epilepsy, the latter of which was partially controlled through multiple medications. Daphena was of small stature and low weight. She frequently refused to eat or drink, and required support in all tasks of daily living: for example, with dressing, hygiene, eating. Daphena was able to ambulate in a room by shuffling along seated on her bottom, or by using her feet to project herself when seated in a tiny scooter-like chair. She could grasp objects and engaged in mouthing or flapping the object in the air or onto her body. The DSWs believed that her hearing and vision were adequate. Daphena was observed to look towards DSWs, but rarely make eye contact. She used various facial expressions, frowns and occasional smiles, which appeared to be related primarily to activities in which she was engaged. Daphena used open vowel vocalisations in a repetitive fashion.

Two DSWs participated in this study. Yvonne had worked with Daphena for more than 15 years and Linda had worked with Daphena for two years, and had worked in other similar homes for 15 years. Both were fulltime DSWs and believed they knew Daphena very well.

Data collection and preparation. Video-recorded interactions between the DSWs and Daphena were recorded at Daphena's home. Each DSW was instructed to select contexts in which each could interact with Daphena as usual. Approximately 30 min of interactions were video-recorded across contexts of greeting, object play, and massage. Two separate continuous segments of recordings were selected for coding: 252 s from Linda's recordings and 300 s from Yvonne's. The segments were chosen on the basis of their being the best video for coding because of clear viewing of the faces of both participants.

As an example of the nature of the interaction, an excerpt from the transcript of the selected segment of interaction between Daphena and Linda is presented. In this excerpt, Linda and Daphena are involved in play in which both are seated on the floor (i.e., floor play). The detailed transcription was completed using Jeffersonian transcription notation (Jefferson, 1984; Sacks, Schegloff, & Jefferson, 1974) as described in the transcription software Transana 2.20-Win™ (Fassnacht & Woods, 2007). This transcription involved recording subjective ratings of speed, volume, intonation, prolongations, and overlapping of Linda's speech, alongside descriptions of Daphena's behaviour, usually in terms of her vocalisations, body movements, facial expressions, and eye gaze.

<38.0>((Linda (L) enters the lounge room. Daphena (D) is seated on the floor with a cushion playing with the clothing protector around her neck))

<38.6>L: >hey ninni< (0.8)

>whatcha doin↑< ((grabs another big cushion from behind Daphena and places it on the floor))

<43.1>D: ur:

<43.7>L: >°hey hey got your cushion°<

<43.8>D: ((grasps cushion with right hand and pulls it to right side, pats right hand down on cushion))

<46.4>D: uuh↑ ur↓

<48.4>L: >here it is:<> sniff

<49.1>L: ((places wash bucket of objects on cushion in front of D))

<49.9>D: ur↓ (places hand in the bucket to objects, looking at objects, grabs bit of red fabric and lifts to forehead level)

<51.5>L: °yeah° (flips bit of fabric out of the bucket)

<52.1>L: (grabs squeaky piranha toy)

<52.3>L: squeak: squeak-squeak-squeak squeak:::

D: (strips red fabric with left hand, right hand holding up above head level)

<54.9>L: squeak::: ↓↑↓ (moves it closer to D's left hand with contact)

squeak_squeak_squeak::: ↓↑↓↓ (drops it in D's lap)

<57.0>L: °xx°

<58.0>L: got the streamers↓ today↓

<59.6>D: ur:: ur

<61.3>L: hey (wiggles beads in front of D's eyes)

<63.0>L: >this one↑<

<63.1>D: (grasps beads between two hands at eye level, not appearing to look, L releases her hands and D bangs towards head)

<64.9>L: (grasps another fabric and drops in front of D)

<67.0>D: (drops beads and grasps fabric)

<67.2>L: >what about the ba:ll:↓<

<68.0>D: ur ur::

<68.7>L: >do you want the ba:l:↑<

<70.7>L: (throws ball small up then puts on cushion in front of D)

<71.7>L: >you want the streamers today↓<

<73.6>L: >this one Nen< (shakes different beads in front of D, then drops in front of D)

<75.6>L: hey↑

<76.1>L: (places the ball back in bucket)

<77.0>L: sniff

<80.2>L: [squeaky↑] (picks up piranha and holds D's chest height in front of left hand)

L: [squeak] squeak squeak squeak:

<80.3>D: (drops red cloth)

<81.2>D: (grasps piranha with both hands, L lets go and D bounces it towards her head)

<83.1>D: (pauses with object held eye level but not looking clearly at it)

<84.5>L: make it squeak↑

<84.9>D: (reaches towards object as D moves it down to bounce on cushion)

<85.6>L: (grasps the piranha still held by D and makes it squeak)

squeak_squeak_squeak:::

<86.5>D: (releases right hand and then drops it with left hand to left side, and instantly grasps black fabric under right hand and raises it up)

<87.6>L: n↑o: your not squeaken today::↓
 <89.8>L: [squeak::: ↑↓↓]
 L: [no squeak today↓]
 <94.1>L: hey↑
 <96.1><96947>L: this one↑. (*holding beads up*)
 <97.1>D: ur::: uh
 <97.7>L: has this cushion got strings↑ (0.4) or is this one without strings↓ (1.8) i'll swap it for ya (.) hang on (1.6) >°I knew you didn't want that cushion°< (.) want the blue cushion↑ (2.0) blue cushions got strings on it (*drops other cushion on the floor in front of D*)
 <111.7>D: ur: ur:
 <115.5>L: >put em on the better cushion< (*carries discarded cushion to the corner of the room*)
 <118.3>D: ur
 <122.2>L: >cause it's got strings< *squeak-squeak-squeak::* (*rearranges cushion while seated on the ground again*)
 <127.0>D: ur hur
 <127.5>L: hey↑
 <130.4>L: (*holds piranha towards D who is stretching a band in front of her eyes, she appears to be looking at the piranha*) *squeak-squeak-squeak-squeak-squeak-squeak::* ↓↓
 <131.4>D: (*makes a slight movement, only about an inch, out to reach for the piranha*)
 <131.6>L: (*brings the piranha back to her lap*)
 <132.1>D: (*reaches out with a flap hand swipe grab but >20cm away from it*)
 <133.2>L: you wan it↑ *sniff squeak::* ↓↓ (*continues to watch D*)
 <138.6>L: (*leans closer into D who begins chewing the band of fabric*)
 <139.8>L: you↑ gonna eat em:↓ (0.6) yu:ck:y:↓
 <143.3>L: *squeak-squeak-squeak-squeak-squeak::* ↓ (*puts down piranha on the cushion*)
 D: (*appears to have a sustained gaze at L*)
 <147.0>L: (*leans in her head to about 20cm away from D's*)
 <147.9>L: >wazat taste like↓
 <150.0>L: *cough cough:* (*sits back a little as she coughs and covers her mouth*) (1.2) oh (.) nasty flu Nin↑ *sniff* (1.0) >are your feet cold< (*reaches and touches D's feet under the cushion*) (.) they're alright↑ (0.8) *squeak-squeak-squeak-squeak::* ↓
 <159.6>D: (*rises up suddenly by straightening her back and wobbling her head a little to the side*)
 <160.7>L: what. (2.0) *squeak-squeak-[squeak::* ↓
 <164.8>D: [*looks down to piranha in L's hand*]
 <166.0>L: *squeak:* squeaks doe'n't↑ (.) *sniff* (.) *squeak::*

<169.8>D: (*very small left right movement of head while watching piranha*)
 <171.6>L: no↑: (2.0) >do'n want the squeaky toy↑< (2.6) *squeak* (1.0) o:↓*kay. sniff*
 (*shuffles the toys on the pillow, with D watching the cushion*)
 <184.7>D: (*turns her head to look up at L*)
 <185.4>L: (*turns to look at D*)
 <185.9>L: (*leans in towards D*)
 <186.5>L: what
 <187.2>D: urf
 <188.0>L: urf
 <188.3>D: (*lifts up band fabric to eye level, looking at that*)
 <194.1>D: (*turns and looks up at L*)
 <195.9>L: what
 <198.1>D: (*turns her head slightly away*)
 <198.7>L: (*reaches to D's head and ruffles her hair*)
 <198.8>L: what
 <199.3>D: (*smiles while maintaining eye contact*)
 <199.8>L: (*removes her hand from D's hair still looking at her*)
 <202.7>L: (*leans in towards D*)
 <203.0>L: what. (1.0) >what↑samatter<
 <205.9>D: ah
 <206.7>L: yep (*still watching each other intently*)
 <210.3>L: (*turns away to TV*) >what are watchin< (0.4) >big bird↓< (1.0) (*turns head back to D*) >clap-clap-clap< (1.4) >clap-clap-clap-clap-clap<
 <217.4>D: oorph (*sneeze like sound with a little upper body jump*)
 <218.9>L: you're not havin a clap today↓> (0.4) >clap-clap-clap< (1.3) nup↑ (*touches objects on cushion*)
 <227.2>D: (*makes upward torso straightening movement*) umph
 <228.8>L: ufff (*with exaggerated facial expression*)(0.2) (*leaning towards D*) uff uff
 (4.0) (*watching D*) >°come on Nin dontcha wanna play with you↑r toys↓°< (2.2) a:↑
 a↓ (.) °this one° (*lifting up bead then red scarf*) °this one°
 <245.5> *squeak squeak squeak:::*
 <246.7>D: (*turns away slightly*)
 <249.3>L: urgh!
 <250.3>L: the face::↓ *sniff* (.) >you don want the squeaky toy↓<
 <254.3> >you always like squeaky toy↓< (*picks up one toy and puts it in the basket, moves another closer to D, then watches D*)
 <260.1> nu:h: *sniff*
 <262.1>D: (*straightens up sitting suddenly*)
 <265.9>L: (*leans in towards D with face going lower than D's face level*)

<266.9>D: (*turns face up towards L*)
 <267.7>L: (*straightens upright half way*)
 <267.9>L: wha↑t
 <270.3>L: >give your feet a massage in a min↓ute<
 <273.0>L: >give you a foot massage↓<
 <274.7>D: (*gives a sudden raise of head upward*)
 <275.0>L: (*raises her head a little and accentuates a pout*)
 <275.9>D: (*brings head to look down*)
 <276.4>L: mm↑↓ (.) maybe:↓
 <278.2>D: (*looks up to L*)
 <278.2>L: >think about it<
 <281.3>L: ur:↑
 <283.3>L: alrigh. *squeak squeak* >I'll let ya play with ya toys<
 <285.8>L: (*ruffles D's hair as she goes to stand up*)
 <287.9>D: (*looks up and follows L with her gaze as L leaves the room*)
 <288.7>L: *sniff* >I'll be back in a minute Nin (0.2) o:kay::↑<
 <290.4>D: (*lifts up hair tie and begins stretching it between her hands*)
 <290.4>L: (*leaves the room and interaction ceases*).

The context of the segment of Yvonne and Daphena was an interaction during a mealtime.

Tools. As a first step, the AAP was used to code Linda and Daphena's interaction. As a second step, both the AAP and BeTA were used to code the interaction between Yvonne and Daphena.

The AAP and BeTA were obtained directly from Professor Jonsson (personal communication, Jonsson, June 3, 2007). The AAP was written in English and was accompanied by a short manual. The BeTA was written in Swedish and a variety of methods were used to translate this into English. Firstly, a translation was completed using an online translation tool (Google Translate). Secondly, this translation was refined by comparing the translation to Jonsson et al.'s (2001) English publication of the results of using the BeTA. Thirdly, further clarification was sought from Professor

Jonsson (personal communication, July 13, 2007) on the translation of the key constructs.

Procedures. Coding using the Affective Attunement Profile (AAP). The original AAP protocol (see Appendix A) was used to code potential incidents of imitation and affect attunement in the video-recording of Daphena and Linda. As a result, coding was completed in relation to the person with PIMD rather than the child/infant, and DSW rather than mother. Coding using the AAP involved the following steps:

1. An incident on the video-recording that appeared to be either an imitation or affect attunement was identified and a written description was made on the AAP coding form.
2. The incident was rated using 3-point scales (not at all, somewhat, and markedly) on 9 dimensions: catching, changing, changing with effect, comment, mimicking, presence of affects (infant's, mother's, and degree of matching), intensity (infant's, mother's, and degree of matching), matching of duration, and matching of rhythm and form.
3. The modality of the infant and mother's behaviour was rated according to presence of facial expression, vocalisation, gesture, and posture, and the degree of matching of participant's modality.
4. Finally, a judgement was made on the degree of affect attunement and imitation (each rated as not at all, uncertain, or clear).

Coding using the Behavioural Themes in Affect Attunement (BeTA). Coding using the BeTA built upon each incident identified using the AAP. Following step 4 of the AAP, the eliciting behaviour of the person with PIMD was watched on video again in order to rate the presence of each of the 10 behavioural themes using a 4-point graded

scale (anchored by 0 = no presence, to 4 = strongly present). The incident was watched as many times as were needed to make a judgement on the scale.

Analyses. Descriptive measures of frequency of affect attunement and frequency of modal and amodal qualities were used. Mean scores were produced for scale measures such as time duration.

Results

Ten incidents of affect attunement were identified in the 252 s sample of interaction between Linda and Daphena. The mean duration of these incidents was 1.6 s (range 0.9 - 3.5 s). An example of one of the incidents is as follows: “Daphena, looking at Linda, makes a small grunt sound and then turns to look down. Linda drops her chin down, says ‘ohf’, and pouts slightly.” This incident was rated as having matched modality, duration, and rhythm, but Linda’s behaviour was more intense, giving emphasis to her affect attunement response.

In the analysed sample of interaction between Yvonne and Daphena, 12 incidents within 300 s of interaction were considered to be affect attunement. The mean duration of these incidents was 2.2 s (range 1.1 - 5.8 s). As an example, one incident was described as following: “Daphena is sitting in a chair being assisted with her meal, she suddenly sits upright then her posture slumps down again, such as in a bobbing motion. Yvonne copies the body motion and verbalises ‘hh hh’ in a rising then falling intonation, pausing in her mealtime assistance of Daphena.” This incident was rated as having a marked degree of imitation, but, because of the addition of the vocalisation and emphasis of intensity, it was rated as an affect attunement.

The results of the frequency of ratings for amodal qualities are presented in Table 3.1. Average frequency of incidents of affect attunement was 1 every 25 s or 2.4 / min (252 s / 10 incidents for Linda and 300 s / 12 incidents for Yvonne) for both dyads.

In both dyads, DSW catching of the affect of Daphena was evident for all incidents. Daphena's changing behaviour in response to the DSW's attunement was never markedly present, but was somewhat present in five of Linda's incidents and two of Yvonne's incidents. Some degree of DSW commenting was present in six of Linda's incidents and 10 of Yvonne's incidents. A marked degree to mimicking was rated for five of Yvonne's incidents, and somewhat mimicking was rated on three of Yvonne's and five of Linda's incidents. Matching of amodal qualities between the DSWs and Daphena were frequently rated. Affect, duration, and intensity matching at either somewhat or marked degree was rated across all but two incidents. Rhythm matching, although occurring frequently, did not occur in three of the incidents across both participants.

Table 3.1
Frequency of Ratings of Amodal Qualities of Affect Attunement

Amodal Quality	DSW Participant (N)					
	Linda (10)			Yvonne (12)		
	Rating			Rating		
	Not at all	Somewhat	Markedly	Not at all	Somewhat	Markedly
Catching	0	2	8	0	3	9
Changing	5	5	0	10	2	0
Changing with effect	4	6	0	5	7	0
Comment	4	6	0	2	10	0
Mimicking	5	5	0	4	3	5
Affects person with PIMD	0	5	5	0	9	3
Affects DSW	0	2	8	1	5	6
Affects matching	0	4	6	0	9	3
Intensity person with PIMD	1	7	2	0	6	6
Intensity DSW	0	5	5	1	6	5
Intensity matching	0	4	6	1	6	5
Duration matching	0	4	6	1	3	8
Rhythm matching	1	6	3	2	4	6

Note. N = number of incidents of affect attunement.

The frequencies for the ratings of each modal quality are presented in Table 3.2. Daphena and Linda both used facial and postural modes in most of their incidents, with matching modalities present in eight incidents for facial expression and seven incidents for posture. Linda also used vocalisation in eight of the incidents, with Daphena vocalising in only two of the incidents. Posture was rated frequently in Yvonne's interactions, with both Yvonne and Daphena matching posture in seven incidents. Like Linda, Yvonne also frequently used vocalisation (10 incidents), but in this dyad's interaction, Daphena also used vocalisation in six of the incidents. Gestural modes were rated once only for Daphena across both interactions, and never for the DSWs.

Table 3.2
Frequency of Modal Qualities of Affect Attunement

Modal Quality	Dyad (N)					
	Linda (10)			Yvonne (12)		
	Daphena	Linda	Matching	Daphena	Yvonne	Matching
Facial	9	9	8	3	1	10
Vocal	2	8	4	6	10	6
Gestural	0	0	10	1	0	10
Postural	9	8	7	11	8	7

Note. N = number of incidents of affect attunement.

The qualities of Daphena's eliciting behaviour were examined in her interaction with Yvonne, using the BeTA's 4-point graded scale (0, 1, 2, 3), indicating degree of presence, with 0 indicating no presence, and 3 as markedly present. The frequency for each of the ratings is presented in Table 3.3. As an example, the incident between Yvonne and Daphena that was described at the beginning of the results was given the following ratings: loss 2, sudden 3, fall 0, risk 0, effort 1, attention 1, emotion 1, negative 0, striving 0, and effective action 1. These ratings indicated that Daphena's behaviour could be characterised by a sudden loss of motor control. Many of Daphena's behaviours to which Yvonne responded as affect attunement occurred suddenly and involved a seeming loss of motor control. These behaviours appeared to have a motoric-like quality, therefore a code of *idiosyncratic*, which was not an original code, was considered for the coding system.

Table 3.3
Frequency of Ratings of Behavioural Themes of Eliciting Behaviour

Theme	Rating			
	0	1	2	3
Loss	5	2	4	1
Sudden	3	2	1	6
Fall	12	0	0	0
Risk	12	0	0	0
Effort	1	10	1	0
Attention	2	9	0	1
Emotion	1	9	1	1
Negative	7	2	3	0
Strive	10	2	0	0
Effective action	1	6	4	1
Idiosyncratic	7	0	0	5

Across the 12 incidents of affect attunement in Yvonne's sample, 132 ratings across 11 themes were made. The most frequently used level of rating on the BeTA scale was 0 or not present, accounting for 46.2% (61) of the theme ratings made. The rating of 1 was made for 32.6% (43) of the ratings, showing that both the ratings of 0 and 1 accounted for 78.8% of ratings. Ratings of 2 and 3 were made 16 and 18 times, respectively.

Discussion

This trial of the AAP within an adult with PIMD/DSW dyad followed by a trial of the BeTA provided preliminary evidence of the presence of affect attunement. Furthermore, the results indicated that the AAP had face validity in that the key aspects of affect attunement were evident in the interactions between the adult with PIMD and DSWs. In particular, the results provided a description of incidents that (a) appeared to

be moments of connection between Daphena and her DSWs, and (b) could be quantified to enable the description of affect attunement in these interactions.

The results of this trial could be used to guide changes to the AAP and the BeTA that may increase both the face validity and construct validity of the tool. For example, given that Catching was coded as somewhat or markedly present for all incidents, and that a criteria for identifying an incident was the DSW responding to a behaviour of the person with PIMD, it appears that this is a redundant category. Similarly, affects on the part of the DSW and person with PIMD are required for an incident of affect attunement; hence these could be removed from future coding given their redundancy. Other amodal categories received a spread of ratings and appeared to be useful for describing affect attunement.

Several categories across modality and behavioural themes were rarely or never rated as present (e.g., gestures and the falling theme). Although these were not present at all in this sample, the heterogeneity of people with PIMD and the lack of redundancy of these items suggest that these items be maintained in the coding system, despite the low ratings.

A final recommended change to the coding system that appeared warranted from the preliminary findings was a reduction in the number of rating levels for the BeTA. In this study, the most frequently used levels were 0 and 1, with 2 and 3 rarely being used. As a result, changing to a three-point graded scale with 0 representing not present, 1 representing somewhat present, and 2 representing markedly present appeared warranted. These changes would also be consistent with the 3-point scale used throughout the rest of the coding system.

Given the results of this preliminary study, a new coding system was developed that incorporated the AAP and the BeTA and the changes that were indicated. The new

coding form (see appendix B) and manual was called the Affect Attunement Behaviour Coding (AABC). The creation of the AABC involved drawing together the work of Jonsson and colleagues, and background information on affect attunement and operational definitions. The manual was also based on Haft's affect attunement coding manual (Haft, 1989) and the publications of Stern (Stern, 1985; Stern, et al., 1985).

In conclusion, it appeared from this preliminary study that the coding of affect attunement using the system derived from Jonsson, based on the work of Stern, has face validity for the description of interactions between adults with PIMD and their DSWs. The next step was to examine the reliability of the newly developed AABC.

Study 2: Reliability

In addition to the tool being valid, it is important that the items in the AABC can be reliably recorded. Portney and Watkins (1999) reported that researchers often have decided to use only one rater to avoid establishing inter-rater reliability, however this practice compromises the strength of generalisability of outcomes. With one rater, there is a high chance that individual bias may influence the scoring (Sharpe & Koperwas, 2003). Hence, examining reliability, using multiple raters, was considered important to the rigour of this study.

According to Cordes (1994), examining the reliability of a tool involves addressing a number of considerations, including: operational definitions of variables, the quality of data collected, the nature of the qualities being described (e.g., presence/absence, onset and offset of behaviours), the degree to which numbers gained faithfully represent what they are meant to represent, the type and extent of training provided to people using the tool, and the ability for multiple people or multiple viewers to report the same true numbers. In this section of the preliminary study, the AABC manual and coding sheet were refined to aid accurate rating. Various procedural

methods were trialled to determine the method that would provide reliable descriptions of affect attunement in dyads of adults with PIMD and DSWs.

Multiple raters have been recommended in literature to reduce measurement error related to use of only one rater (Yoder, Short-Meyerson, & Tapp, 2004). The preferred form of assessing reliability across multiple raters has been through simultaneous observation and independent rating of a sample of data (Portney & Watkins, 1999). Yoder et al. (2004) stated that this form of inter-rater agreement is particularly important during the training phase of data collection. In using multiple independent raters, Cordes (1994) suggested that all raters provide ratings for entire data sets until consistency is achieved, with consistency being determined according to mathematical calculations.

Reliability can be calculated mathematically using different indices depending on data type. In this study, the data were categorical in nature, and hence, methods appropriate to this type of data were percentage agreement (point-by-point) and Cohen's kappa calculations (Jones, Johnson, Butler, & Main, 1983). Percentage agreement (number of agreements divided by agreements plus disagreements, multiplied by 100) has been the most commonly reported index of agreement, however it has been found not to control for chance agreement (Bakeman & Gottman, 1997; Sharpe & Koperwas, 2003; Watkins & Pacheco, 2000; Yoder, et al., 2004). Cohen's kappa and its variants (e.g., weighted kappa and bias adjusted kappa) are calculations of agreement after correcting for chance agreement (Jones, et al., 1983). Kappa has been argued to be more complicated to calculate and less simple to interpret than percentage agreements (Cordes, 1994; Watkins & Pacheco, 2000), however it has been reported frequently to be a more rigorous measure of inter-rater reliability (Cissna, Garvin, & Kennedy, 1990). Percentage agreements was used for the preliminary study as an initial measure of the

extent to which two raters agreed when coding a data sample. Although varying across studies, at least 80% agreement has been frequently reported as an acceptable level of agreement for data coded from video-taped samples (Kopenhaver Haidet, Tate, Divirgilio-Thomas, Kolanowski, & Happ, 2009).

Reliability in Studies of People with Disabilities

Reliability, as highlighted previously, has been argued to be influenced by many factors, including the complexity of the data examined and number of codes used (Kazdin, 1977). The complexity of the task of coding the communication of people with disabilities has been noted by several researchers and attributed to different causes. In particular, the behaviour of people with multiple disabilities has been reported to be less readable than the behaviour of people without disabilities (Dunst & Lowe, 1988; Wilder, 2008). Wilder (2008), for example, reported that the readability was reduced particularly for children who used very short duration behaviours (i.e., less than 1 s) and for children with particular characteristics, such as passivity.

Rather than viewing low levels of reliability as a threat to the rigour of research, Nicholas, Geers, and Rollins (1999) proposed that they might reflect the ambiguity of some people's communicative behaviours. They examined the intentionality and communicative functions of deaf and hearing children, and found higher levels of coder agreement for those children that were hearing (71%) than for those who were deaf (61%). Rather than attributing this finding to coder error, they suggested that the reduced agreement reflected the poorer ability of the child to communicate in the wider world. Furthermore, they suggested that using consensus coding to overcome poor levels of agreement would lead to lack of acknowledgement of the ambiguous communication that would occur on a daily basis.

Other researchers have attributed coding difficulties to lack of operational criteria for describing behaviours of populations who receive limited research attention. For example, Iacono et al. (1998) noted difficulties in determining which behaviours could be considered to be communicative in children who had severe and multiple disabilities, given that published criteria did not take into account the inability of these children to demonstrate key indicators. Contributing to this difficulty was the lack of published criteria for pre-intentional communicative acts, which were found to be produced frequently by these children. As a result, they chose to use a consensus coding method for recording communicative acts as a means of creating such criteria.

Consensus between two raters has been used in a few studies on communication in which difficulties in gaining independent reliability have been evident. For example, Shriberg, Kwiatkowski, and Hoffman (1984) suggested that, in the context of transcribing speech sounds, consensus could be used as a way of reducing errors of measurement. It is evident from the literature, that consensus rating can be done in one of two ways: (a) both raters conduct the scoring together, discussing disagreements and reaching a consensus (as done by Iacono, et al., 1998); or (b) both raters conduct the scoring independently, then compare and discuss discrepancies to then reach a consensus (as done by Shriberg, et al., 1984).

However, in addition to Nicholas et al.'s (1999) argument that consensus coding fails to recognise inherent ambiguity, several researchers have also raised methodological concerns about using consensus coding. Consensus procedures can be influenced by systematic changes in scores, thereby resulting in a bias (e.g., a weaker rater frequently changing his/her rating or systematically adapting ratings to match that of the other rater) (Cordes, 1994; Shriberg, et al., 1984). A further problem reported by Shriberg et al. (1984) is the lack documented rules or processes to reach consensus. In

their study, they used a set of consensus rules derived from a normative study to guide the transcribers in making decisions (e.g., if one transcriber stated that a sound was correct and the other transcriber said it was a distortion, the consensus rule was to mark it as correct). However, such rigorous methods cannot be used when precedence for decisions has not been previously set.

Reliability of Items of the AABC

The AABC consists of varying data types. Bakeman and Gottman (1997) differentiated between behavioural codes, in which codes are recorded whenever a behaviour corresponding to that code occurs, and rating scales, in which levels of behaviours are determined. The AABC contains items for coding presence and items for rating the extent to which behaviours have particular characteristics (Yoder, et al., 2004). Several researchers have also differentiated between socially based and physical codes (Bakeman & Gottman, 1997; Sharpe & Koperwas, 2003). According to Bakeman and Gottman (1997), physically based codes have a clear origin in physiology and are generally clearly identifiable, whereas socially based codes require observers to use social processes or cultural judgements to categorize behaviours. A few items of the AABC relate to physical-based codes (e.g., selection of modalities), in which behavioural actions are coded. However, the majority of items are socially based, requiring the raters to make some degree of inference about the behaviours of the people being observed (Sharpe & Koperwas, 2003). The presence of socially based codes increases the complexity of the AABC.

In light of the importance of reliability and consideration of difficulties encountered by previous researchers examining communication of people with multiple disabilities, the aim of the current preliminary study was to determine the most appropriate and feasible method of achieving reliable coding in the larger study. Figure

3.1 summarises the methods of reliability described in the previous section that were trialled in this study. The vertical axis represents the least to most optimal methods, based on review of the literature, with the least preferred lowest on the axis and most preferred highest on the axis. For example, for identification of potential incidents, the least preferred procedure was to use one rater (consistent with the validity study described in the previous section), followed by two raters deciding on incidents through an agreement or consensus procedure.

The optimal procedure for identifying potential incidents was two independent raters identifying incidents, with these raters demonstrating at least 80% agreement. The second continuum was for rating the qualities of the incidents of affect attunement. The optimal procedure was to have two independent raters achieve agreement of at least 80% for each quality. According to Yoder et al. (2004), when there are two or more observers, typically only 20% of the sample is coded by both for calculation of reliability. The next preferred option was to have independent rating of all incidents followed by a discussion of disagreements by both raters and development of a third consensus rating. The third preferred option was to have a shared consensus rating completed by two raters on all incidents. Finally, and least preferred, was rating done by one rater alone, with no comparison ratings.

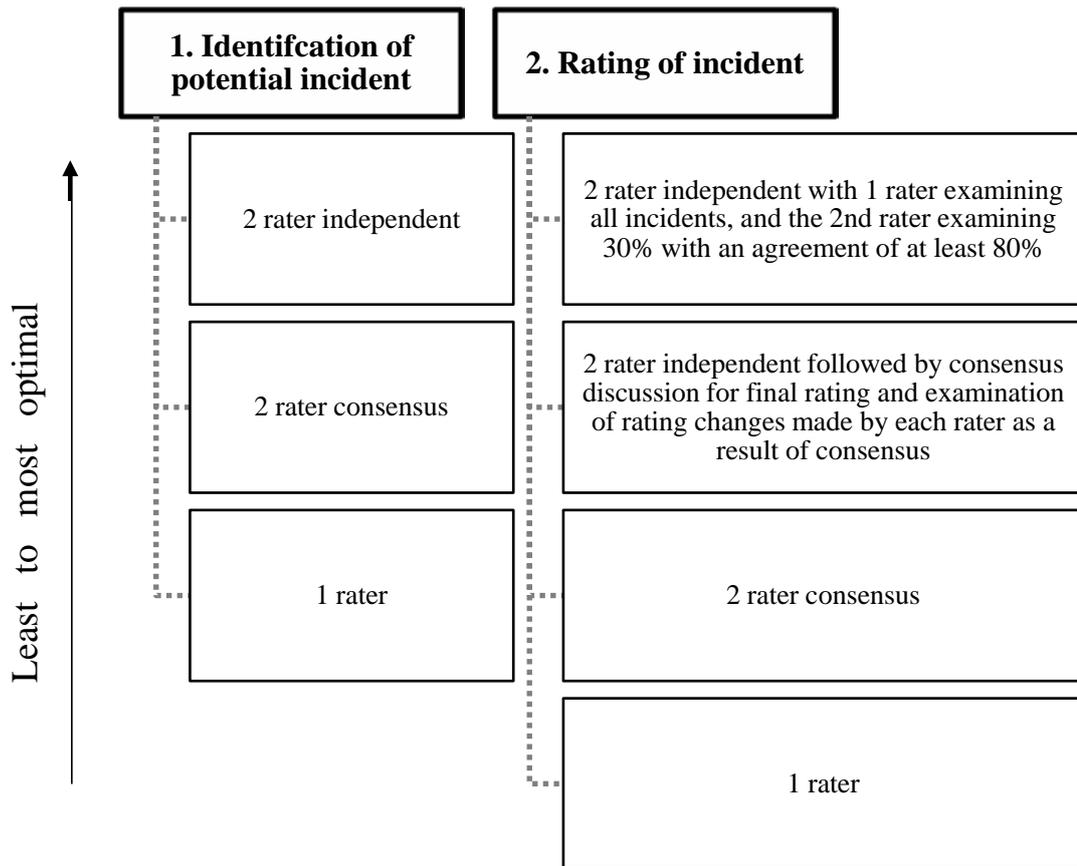


Figure 3.1. Options for rating procedure.

Each of the procedures were examined in the trials.

Method

Participants. This phase of the study involved Daphena, Linda, Yvonne, and one additional DSW, Alma, who had worked with Daphena for more than 15 years. Two further video-recordings of interactions were obtained for this part of the study. One of the video-recordings was of Jackie and her DSW interacting in day service context. Jackie was a woman with Rett syndrome, who was in her 20s, who had PIMD. She did not use any formal communication methods and was in a wheelchair. Kevin, also from the same day service, was video-recorded interacting with a different DSW during a mealtime. Kevin had cerebral palsy, and was reported to use some gestures

inconsistently (e.g., raising his eyes as a form of agreement). Both additional participants had next-of-kin provide consent for the video-recording for this part of the study, and both DSWs provided consent on their own behalf.

Raters. In addition to the chief researcher (SF), two research assistants were employed at different periods (according to availability) to be involved in reliability and refinement of the coding system. Both were postgraduate research students with an interest in ID. Rater HW was completing a Professional Doctorate in Psychology. Rater JH, who had a Bachelor of Applied Science (Disability) (Honours), was completing a Doctorate of Philosophy with a focus on people with ID.

Training of raters. The training of the raters involved two parts. The first part was preparatory reading to enable familiarisation with the construct of affect attunement, as neither rater had previous experience with or knowledge of affect attunement. The preparatory reading included the draft AABC manual, Stern et al.'s (1985) article on coding affect attunement, and Jonsson and Clinton's (2006) article on the BeTA. Secondly, each rater discussed the construct and its qualities with the chief researcher and engaged in approximately 4 hours of shared coding. The shared coding involved extensive discussion and revisiting the manual to ensure that ratings were made in ways that were consistent with the operational definitions.

Procedure. Four coding sessions were conducted over a 9 month period, with each coding session taking 4 to 6 hrs. The first three sessions involved the chief researcher (SF) and research assistant HW, and the fourth session involved SF and research assistant JH. The purpose of the coding sessions was to investigate rating procedures for coding, with a particular focus on inter-rater reliability. Across the four coding sessions, the procedures were trialled in order to determine the best procedural

method to use in the main study. In addition, changes were made to the manual based on discussions during the coding.

Results

The process of shared coding of 5 video-recorded interactions, across 4 coding sessions (ranging for 4 to 6 hrs duration each) over 9 months provided the opportunity to discuss and refine the codes and their definitions. Table 3.4 provides a summary of the changes made to the coding system and manual, and levels of agreement attained by the researcher and research assistants.

Table 3.4

Summary of Changes to Coding System and Manual, and Agreement during Study Two

Date / Raters	Sample and observational technique	Notes on agreement	Procedural implications	Changes made to coding manual & form
17/01/2008 SF & HW	Linda floor-play video: Incident identified by consensus, coded independently, then discussed.	Six incidents identified. Agreement for each coding dimension varied from three out of six to agreement on all. The lowest agreement was on the <i>catching, changing, modality of DSW, and duration ratings</i> . The latter two items were resolved through discussion. Issues around duration were related to judgements of onset and offset of incident.	Support for 2 rater consensus identification. Support for 2 rater consensus rating of qualities. Poor support for independent coding.	Consensus reached that <i>Affects in the incident</i> was redundant, hence removed. <i>Catching and changing</i> changed to <i>yes/no</i> codings. Manual refined to clarify operational definitions.
14/03/2008 SF & HW	Alma foot-spa video: Independent identification of acts, then discussed.	Five acts identified: Two of the acts identified by both raters, three acts identified by only one rater.	Poor support for 2 rater independent identifications.	None
	Yvonne floor-play video: Independent identification of acts.	Six acts identified: Four of the acts identified by both raters, two acts identified by only one rater.		None

Date / Raters	Sample and observational technique	Notes on agreement	Procedural implications	Changes made to coding manual & form
9/07/2008 SF & HW	Kevin video: Shared identification, individual coding, then discussed.	Two acts: Differences in independent coding were resolved in discussion. Discrepancy in rating <i>effective action</i> – determine whether a goal is held by the person with a disability.	Support for shared identification. Support for 2 rater independent coding followed by consensus coding.	None
	Kevin video: Shared identification and consensus coding.	Two acts: Coding by discussion felt much easier than the independent coding and consensus was reached very quickly.	Support for consensus coding.	None
08/08/2008 SF & JH	Kevin video: Independent identification and coding.	Kevin video: 15 acts identified, four identified by both raters.	Poor support for independent identification.	None
	Jackie video: Independent identification and coding.	Jackie video: Four acts identified, two identified by both raters. Across the six events coded by both raters, agreement ranged from 0-100% on dimensions. There was no agreement on the matching of shape. Agreement was also low on duration codings and coding of the eliciting behaviour, in particular for <i>loss</i> , <i>sudden</i> , and <i>attention</i> .	Poor support for independent coding of qualities.	None

Discussion

In refining the coding system, an extensive process of trial and modification of the system was completed over several months. Changes were made to the manual and the coding form to enhance clarity. Furthermore, various procedures for inter-rater reliability (e.g., independent, consensus) were trialled to enable a decision to be made regarding procedures for the main study to ensure rigour. The final decision for the procedure of identification of potential acts of affect attunement, followed by the decision of the procedure of rating of qualities of incidents, was determined.

Firstly, procedures for identification of potential incidents are discussed. One-rater identification was used in the validity study and independent identification of incidents was trialled in the reliability study. Across the trials, 30 incidents were identified, however only 12 of the incidents were identified by both raters independently. In contrast, when a shared identification approach was used, consensus was quickly attained, suggesting that a consensus approach would provide better identification of incidents. This consensus approach is consistent with Jonsson et al.'s (2001) procedure, in which pairs of psychologists began the rating by initially noting all possible instances of affect attunement or imitation prior to independent rating of qualities.

Secondly, various procedures for rating the qualities of affect attunement were trialled. One-rater identification was used in the validity study. In the current trial, independent rating, independent followed by consensus for disagreements, and complete consensus rater were trialled. Support was not found for the use of independent rating because it resulted in varying levels of agreement across the different qualities, with many not reaching acceptable levels (less than 80%). However, it was noted that discussions following independent rating often resulted quickly in consensus

agreements. Conducting the rating entirely through consensus discussion (i.e., two rater consensus) was the most efficient means of rating and was preferable to a single rater in terms of reducing the potential for bias. However, the two rater independent, followed by consensus procedure, allowed for the benefits of full consensus rating, while enabling the continuous monitoring of inter-rater agreement across different qualities on original independent ratings. In addition, this method allowed for systematic shifts in ratings of each rater to be monitored by comparing the independent ratings to the consensus rating. This procedure of independent followed by consensus discussion for items of disagreement was consistent with the procedure used by Jonsson et al. (2001) for AAP ratings. The procedure differed, however, in regards to the BeTA ratings, in which Jonsson and Clinton (2006) used consensus ratings for 10 dyads (in development of their manual) and independent ratings for 17 dyads.

The final optimal method of rating was determined to be shared identification of incidents, followed by independent rating by two raters, and finally, discussion and a third rating through consensus by the two raters. The independent rating of the incidents allowed for continued monitoring of levels of reliability, whilst the consensus rating was felt to be the most accurate coding, using the discussed opinions of both raters. Transparency could also be achieved by providing comparison of independent to consensus ratings.

Final Coding System

Following the process of refinement, the final coding system, manual, and method was developed (Appendix C). As a result of this process, the model of affect attunement as described by Jonsson and colleagues (Jonsson & Clinton, 2006; Jonsson, et al., 2001) and Stern (1985) to capture mother-infant affect attunement was modified

to capture affect attunement in interactions between adults with PIMD and DSWs (Fig. 3.2).

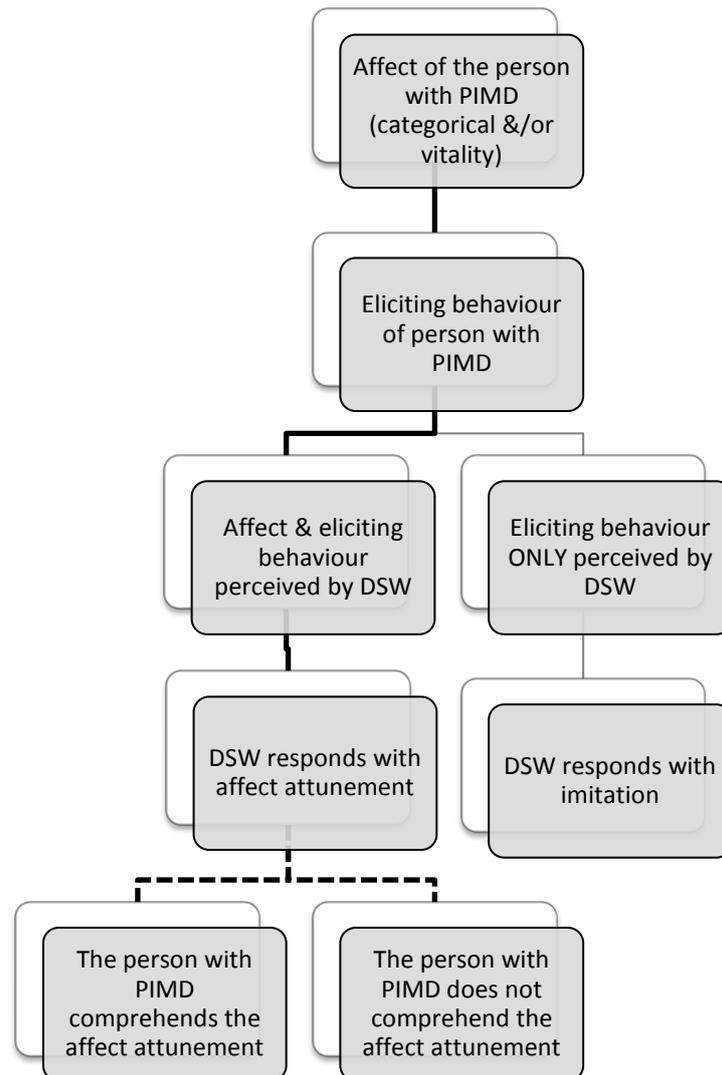


Figure 3.2. Model of affect attunement in interactions between adults with PIMD and DSWs.

Summary

The AAP and BeTA, combined to create the AABC, guided the exploration of an area of the interaction that, to-date, has not been explored in this group. The coding captured a DSW behaviour that was responsive to the person with PIMD. The eliciting behaviours of the person with PIMD were ones that have not been explored in previous research of people with PIMD. Methods for conducting the coding were trialled and an

optimal method decided. As a result of this process, the AABC and the method for coding and determining reliability were used in the larger study that examined the nature of affect attunement within interactions between adults with PIMD and their DSWs.

CHAPTER FOUR

METHOD

Ethical Considerations

Ethics approval was granted through the Monash University Standing Committee on Ethics in Research Involving Humans. Further approval was gained from the Scope Human Research Ethics Committee, specifically for participation of people residing and working in services provided by Scope Victoria, a large non-government organization. See Appendix D for both approval letters.

Design

The design of this study was observational. Video-recordings of natural interactions between dyad participants were conducted, and the videos coded for the presence of affect attunement using the developed coding system. The nature of affect attunement was analysed using descriptive statistics and measures of association as a means of searching for relationships amongst variables.

Participants

The research involved two participant types in dyads. A person with a PIMD was required along with a DSW. Twenty-30 dyads were sought for the study. This range was selected based on the need to balance the requirement for sufficient numbers to complete statistics of association, with the issue of people with PIMD being from a small incidence population. Small numbers are not uncommon in observational research on people with PIMD, which have ranged from 3 to 20 people (e.g., Clegg, et al., 1991b; Hiemstra, Vlaskamp, & Wiersma, 2007; Petry & Maes, 2006; Vlaskamp, et al., 2003), with the exception of a larger study in Sweden, in which population registers were used to contact participants (Granlund, Terneby, & Olsson, 1992b), and some studies in the United States, based in schools for children with disabilities (Guess,

Roberts, Siegel-Causey, & Rues, 1995; Mar & Sall, 1999). In Victoria and Tasmania, the total population of people with PIMD is not known, and no registers are available for ascertainment studies. The target number of participants was also influenced by past studies of affect attunement between mother-infant dyads, which have ranged from 10 (Stern, et al., 1985) to 39 (Jonsson, et al., 2001) dyads.

Selection Criteria

The selection criteria for this study included adults (aged over 18 years) with PIMD, residing in a residential group home with other people with a disability, receiving 24 hour support. Participants had to have a profound intellectual and multiple disabilities, as described by having at least four of the five qualities: (a) major sensory impairment, (b) severe motor difficulties, (c) absence of verbal skills, (d) dependence on others to meet basic daily needs, and (e) apparent lack of engagement with the environment. Presence of these qualities was determined through a combination of strategies, comprising a judgement by the person who provided proxy consent, as recorded on the consent form, discussion with the residential House Supervisor, and observation of the person at an initial meeting. Consent for the person with PIMD was sought from the person's next-of-kin, legally appointed guardian, or person deemed responsible for their daily care.

The criteria for the residential DSW was that s/he had worked with the person with PIMD for at least 12 months, and was therefore familiar with the person. The DSW provided consent on his/her own behalf.

Recruitment and Consent Procedures

Recruitment for this study involved three steps: (a) support from a residential service, (b) recruitment of a person with a PIMD, and (c) recruitment of a DSW who supported the person with a PIMD. The first step of contacting the manager of disability

accommodation services (government and non-government) was done by letter. The letter informed the manager of the project aims and invited him/her to contact the researcher by phone. Letters were sent to 35 non-government disability services across Victoria and Tasmania, and to eight Victorian government service regions. A follow-up phone call was made approximately one week after the letter was sent. The organisation was then able to indicate in writing if there was interest in being involved in the study. Several organisations indicated that they did not support people with PIMD, and a few organisations indicated that, despite supporting people with PIMD, they were unable to commit to the study. Explanatory statement and consent form packages (see Appendix E) were sent to 19 organisations, with a total of 88 consent forms being distributed by the organisations.

Consent forms were completed and sent to the researcher from 11 different organisations. Discussion with organisations that had received consent forms, but did not have any participants return forms indicated a variety of responses to a request for their reasons for non-return. These included that the person with PIMD's next-of-kin did not wish his/her family member to participate, a senior member, upon reading the information, felt that there were no suitable participants, or reasons were not stated.

Of the 26 consent forms received on behalf of people with PIMD, three were for participation of individuals deemed unsuitable for the study: one adult was still residing in his/her family home, and two were deemed not to have PIMD. For one other person, from Tasmania, consent was received after data collection was completed in that state.

Upon receipt of proxy consent forms, the researcher contacted the residence in which the adult with PIMD lived (as per details provided on the consent form) and asked to speak to the House Supervisor. The researcher explained the study and

forwarded participant explanatory statements and consent forms (see Appendix F) for distribution to DSWs. A consenting DSW was found for each person with PIMD.

Description of Participants with PIMD

In order to determine if the criteria for having a PIMD had been met, two procedures were used. The researcher viewed the consent form that had been completed on behalf of the person, and contacted the consenting person by telephone to elicit a short description of the person with a disability. Secondly, the researcher confirmed the criteria when meeting the person with PIMD at the time of data collection. One of the participants (participant 6) was excluded from the study as both the person providing consent on behalf of the person and the researcher agreed that the person did not have at least four out of the five characteristics. There appeared to be a reluctance to report that people did not engage with their environment, with 33% of people providing consent on behalf of the person with PIMD reporting that the person did not have difficulties in this area. However, observation by the researcher confirmed that these people did have difficulties, in that they were not alert to people coming in and out of their immediate environment and their behaviours was largely self-engaged unless somebody else initiated an interaction with the person. Finally, 21 people were judged to have at least four of the five characteristics of PIMD by the researcher.

Age and gender. The participants with PIMD were aged between 24 and 55 years (mean = 37 years). Twelve of the participants were male and 9 were female.

Health profile. The health profile of the participants is presented in Table 4.1. The profile was determined by asking the DSWs mostly closed answer questions about the person; for the question about the person's diagnosis, an open question was used. The DSWs consulted client files and medication packs whenever possible in answering questions.

Other than ID, the main diagnosis was reported to be cerebral palsy in 42.9% of people. Several participants' were reported to have uncontrolled epilepsy from an early age. Specific syndromes (e.g., Down syndrome, Congenital Rubella syndrome, and Rett syndrome) were reported for five participants. For a further five participants, DSWs did not know the diagnosis. Twenty-eight per cent of the participants had scoliosis.

Additionally, health was rated as either good, sometimes unwell, or unwell most of the time. Two-thirds of the DSWs reported that the person they supported had good health; the remainder reported that the person was sometimes unwell (28.6%) or unwell most of the time (4.8%). However, 81% of participants were on a regular medication regimen, with the most common medication types being anticonvulsants (61.9%), laxatives (47.6%), and reflux medication (47.6%). Several of the participants were taking four different types of anticonvulsants simultaneously (e.g., Epilum, Rivotril, Keppra, Dilantin). A quarter of the participants had epilepsy that was well controlled, and two people had monthly seizures. One-third of the participants were reported to have weekly or daily seizures.

Vision and hearing were rated on 3-point scales. For vision the choices were: (a) sees well (may wear glasses), (b) vision problems limit making eye contact over 2 metres away, and (c) little or no useful vision. Hearing was rated as: (a) hears normal conversation level voices (may uses hearing aid), (b) hears only loud voice, and (c) little or no useful hearing. Sensory impairments were reported for 62% of the participants, with vision impairments reported more frequently than hearing impairments.

Mobility was rated by selecting the statement that best describes the person's mobility, with the five choices being: (a) able to walk around easily, (b) able to walk independently but can be unsteady and may need supervision, (c) requires support of staff member to walk, (d) unable to walk but can assist with transfers, and (e) unable to

walk or help with transfers. Over half of the participants were completely dependent on support from DSWs in regards to mobility and were unable to assist at all when they were being transferred in hoists. Two participants could provide some assistance in transfers by turning or lifting body parts. Supported walking was possible for 28.6% of participants, with one participant being able to walk, albeit unsteadily, and one participant walked easily.

Communication was also rated through selection of the statement that best described the person, with the following five options: (a) communicates through short sentences or picture sequences, (b) communicates through single words or pictures, (c) communicates through gestures or basic signs, (d) communicates through looking at or reaching to things, and (e) communicates through body language and facial expression only. None of the participants were reported to use verbal skills in any modality. Many (52.4%) were able to look at or reach to items, a behaviour which was reportedly used unintentionally to communicate, and two participants were reported to be able to use routine gestures. The remaining participants were reported to communicate using facial expression and body language.

Table 4.1
Demographics of Participants with PIMD

	Gender	Age (yrs)	Main Diagnosis (in addition to ID)	Epilepsy frequency	Health rating	Vision	Hearing	Medication Types	Mobility	Communication
1	Male	38	Cerebral Palsy	None	Good	Little or no useful vision	Normal	Antipsychotic, Laxative, Muscle relaxant, Reflux, Vitamins & Minerals	Unable to help with transfers at all	Body language & facial expression
2	Female	39	Unknown	Weekly	Good	Little or no useful vision	Normal	Anticonvulsants, Laxative, Supplement	Unable to help with transfers at all	Body language & facial expression
3	Male	37	Epilepsy	Weekly	Good	Sees well	Normal	Anticonvulsants, Hypolipidaemic agent, Laxative, Reflux	Unable to help with transfers at all	Looking or reaching
4	Female	24	Epilepsy	None (controlled)	Good	Sees well	Normal	Anticonvulsant, Laxatives, Vitamins	Requires support to walk	Looking or reaching

	Gender	Age (yrs)	Main Diagnosis (in addition to ID)	Epilepsy frequency	Health rating	Vision	Hearing	Medication Types	Mobility	Communication
5	Male	31	Cerebral Palsy	Weekly	Sometimes unwell	Vision problems limiting looking > 2 m	Hears loud sounds only	Anticonvulsant, Muscle relaxant, Narcotic Analgesic, Reflux	Unable to help with transfers at all	Body language & facial expression
7	Female	47	Down's syndrome	None (controlled)	Good	Sees well	Normal	Anticonvulsant, Reflux, Thyroid agent, Vitamin	Unable to help with transfers at all	Gestures & signs
8	Female	29	Rett syndrome	Monthly	Sometimes unwell	Vision problems limiting looking > 2 m	Normal	Anticonvulsant, Laxative, Vitamin & Mineral	Unable to help with transfers at all	Body language & facial expression
9	Male	38	Unknown	Weekly	Good	Little or no useful vision	Normal	Anticonvulsant, Vitamin & Mineral	Walk can be unsteady	Looking or reaching
10	Male	37	Unknown	Weekly	Good	Sees well	Normal	Anticonvulsant	Requires support to walk	Gestures & signs
11	Male	40	Tuberous sclerosis	None (controlled)	Sometimes unwell	Sees well	Normal	Anti-anxiety, Anticonvulsant, Laxative, Reflux	Walks easily	Looking or reaching

	Gender	Age (yrs)	Main Diagnosis (in addition to ID)	Epilepsy frequency	Health rating	Vision	Hearing	Medication Types	Mobility	Communication
12	Male	36	Congenital Rubella syndrome	None	Good	Vision problems limiting looking > 2 m	Hears loud sounds only	Antianxiety, Analgesic	Requires support to walk	Looking or reaching
13	Male	30	Cerebral Palsy	None	Sometimes unwell	Sees well	Normal	Antihistamine, Laxative	Requires support to walk	Looking or reaching
14	Male	44	Cerebral Palsy	None	Unwell most of the time	Little or no useful vision	Normal	Antianxiety, Analgesic, Laxative, Reflux, Vitamin & Minerals,	Unable to help with transfers at all	Body language & facial expression
15	Female	48	Cerebral Palsy	None (controlled)	Sometimes unwell	Little or no useful vision	Normal	Anticonvulsants, Antinauseants, Reflux	Unable to walk but can help with transfers	Looking or reaching
16	Female	33	Unknown	None	Good	Sees well	Normal	Reflux, Thyroid agent	Requires support to walk	Looking or reaching

	Gender	Age (yrs)	Main Diagnosis (in addition to ID)	Epilepsy frequency	Health rating	Vision	Hearing	Medication Types	Mobility	Communication
17	Male	33	Cerebral Palsy	None	Good	Sees well	Normal	Laxative, Ulcer	Unable to walk but can assist with transfers	Looking or reaching
18	Female	33	Cerebral Palsy	Monthly	Good	Little or no useful vision	Normal	Analgesic, Anticonvulsants, Laxative	Unable to help with transfers at all	Body language & facial expression
19	Female	39	Prader Willi	None	Good	Vision problems limiting looking > 2 m	Normal	Antidepressant	Requires support to walk	Looking or reaching
20	Male	55	Cerebral Palsy	None (controlled)	Sometimes unwell	Little or no useful vision	Normal	Anticonvulsant, Vitamin & Mineral	Unable to help with transfers at all	Looking or reaching
21	Female	36	Cerebral Palsy	Weekly	Good	Little or no useful vision	Normal	Anticonvulsant, Hormone, Reflux	Unable to help with transfers at all	Body language & facial expression

	Gender	Age (yrs)	Main Diagnosis (in addition to ID)	Epilepsy frequency	Health rating	Vision	Hearing	Medication Types	Mobility	Communication
22	Male	34	Cerebral Palsy	Weekly	Good	Little or no useful vision	Little of no useful hearing	Laxative, Reflux, Vitamin & Minerals	Unable to help with transfers at all	Body language & facial expression

Note. All data is as reported by DSW, and hence may represent varying degrees of accuracy

Adaptive behaviour levels. Two assessments were administered to describe adaptive behaviour levels: Vineland Adaptive Behaviour Scales (VABS) – Interview Edition (Sparrow, Balla, & Cicchetti, 1984) and the Scales of Independent Behavior – Revised, Early Development Form (SIB-R EDF) (Bruininks, Woodcock, Weatherman, & Hill, 1996). VABS raw scores and age equivalent scores were recorded. A floor effect was found for the majority of participants when calculating standard score (below 20); therefore this score was not used in any analysis.

Figure 4.1 shows the adaptive behaviour age equivalence in months for all participants across sub-domains and composite scores on the VABS, and the total age equivalence on the SIB-R EDF. The boxes contain 50% of the cases, and the whiskers protruding show the smallest and largest scores. Outlying scores for participants 4 and 12 are also shown. With the exception of the daily living skills sub-domain, all median age equivalence scores were under 12 months. The lowest scores were in the socialization domain with a mean of 3.0 months ($SD= 3.34$).

Correlations between the age equivalence scores as assessed on the VABS and SIB-R EDF were also examined across all participants. Using Pearson's correlation coefficient, a significant and large correlation was obtained, $r(19) = .88, p < .000$.

Inter-rater reliability of the VABS scores was assessed, with a second rater listening to recordings of the five VABS interviews. Intraclass correlation coefficients (two way mixed model with measures of consistency) were used to examine correlation amongst domain scores. The coefficients with 95% confidence intervals were: communication domain 0.92 (0.23-0.99), daily living domain 0.93 (0.35–0.99), socialization domain 0.77 (–1.19–0.98), and gross motor domain 0.99 (.91-1.00). All of these correlation coefficients are considered to be excellent agreements (Cicchetti & Sparrow, 1981).

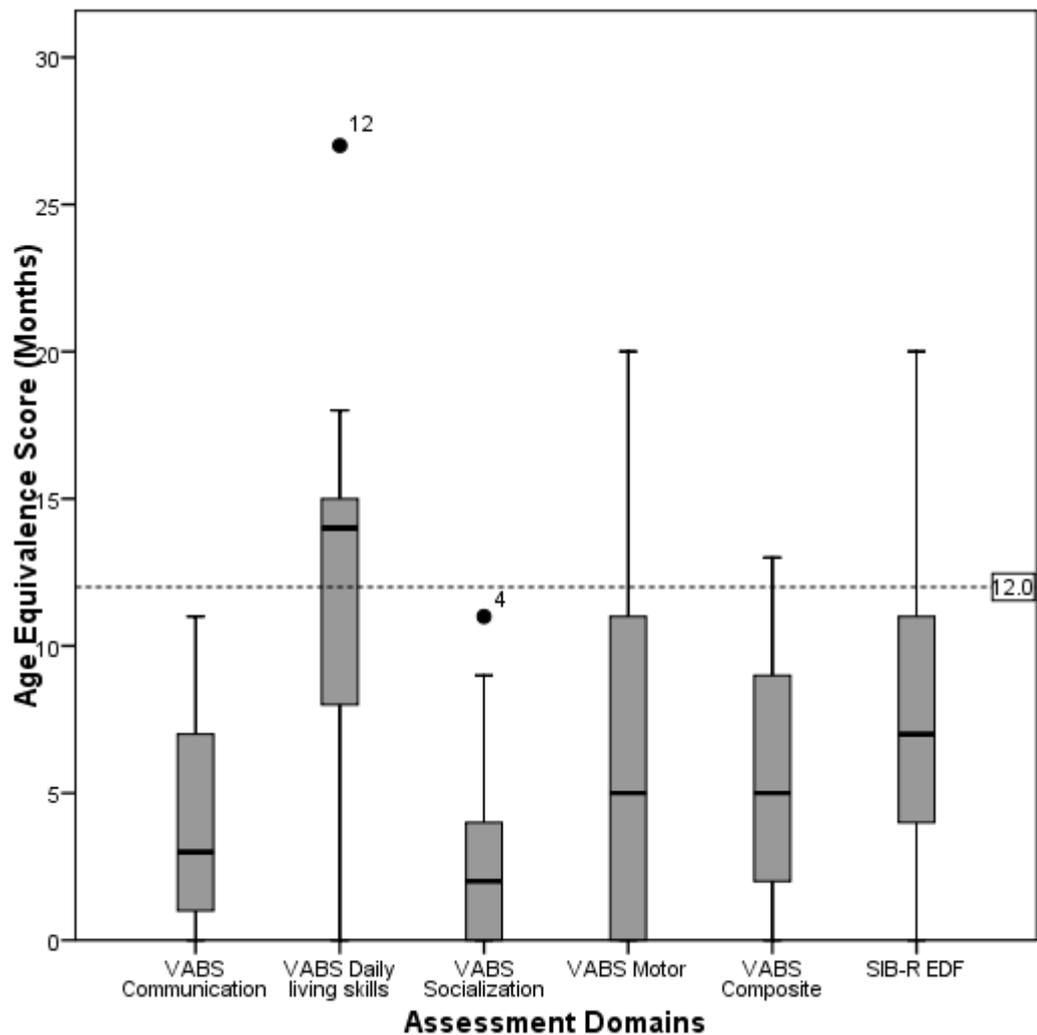


Figure 4.1. Adaptive behaviour age equivalence (months).

Description of DSWs

There were 21 DSWs, 18 who were female and three were male. The DSWs were aged from 31 to 64 years (mean = 48 years). Five of the DSW participants had Year 10 level of high school education. The remaining DSWs had either completed or were currently doing a Certificate IV level Technical and Further Education study in disability. All but two of the DSWs were parents, with many (47.6%) being grandparents. The majority (76.2%) of DSWs were born in Australia. The remaining 5 DSWs were born in the United Kingdom or New Zealand.

The DSWs had from 9 months to 30 years of experience in working with people with disabilities (mean = 10 yrs). The DSWs had worked with their dyad participant from 8 months to 16 years (mean = 4 years, 3 months).

Procedures

Each consenting DSW was contacted by phone to arrange an appointment for data collection. The DSW was asked to make a time that would be best for him/her and the person with PIMD to be “just spending time together” in the person’s residence.

At this appointment, the project was explained again to each participating DSW. Little interaction occurred between the researcher and the person with PIMD in order to minimise the potential for the researcher’s interaction style influencing the interaction of the DSW. Time was spent to build rapport between the DSW and the researcher through informal conversation and engagement with all of the people in the house, and then the order of events was explained.

Data collection began with a short interview (less than 5 mins) addressing demographic questions relating to the person with PIMD and then relating to the DSW (see Appendix F). The questions relating to the person with PIMD included brief categorical information about the person’s age, gender, diagnosis, general health, presence of epilepsy, medication, hearing, vision, hearing, mobility, and communication. The questions about the DSW included his/her age, highest level of education, parental status, country of birth, length of time working with people with disabilities, and length of time working with the participant with PIMD.

The researcher then explained that she would be video-recording an interaction in a place chosen by the DSW for approximately 20 min. Observations were recorded on a JVC™ GZ-MG275AA hard disc camcorder, placed on a small table-top camera stand. The researcher explained that she would set the camera on a stand in order to

capture both participants, leave the room during the interaction, and return intermittently to ensure that the camera was still running. Positioning the camera in a single place was sufficient for the majority of the participants, as they did not have independent mobility. However, for the three participants who were mobile during the recording, the camera was hand-held by the researcher who followed the person, hence for these participants she was present through the time of recording. Guidelines followed by the researcher for completing the video data collection are in appendix C3.

Following the video recording of the interaction, the DSW was asked to answer further questions. The researcher explained to the DSW that there were few tools available for describing skills of people with PIMD, and therefore the researcher would be using two tools to obtain further information about the person with PIMD. The DSW was asked permission to audio-record the interview for the VABS, for the purpose of “another person checking if they would answer the same thing if they were filling out the form.” All DSWs consented to the audio-recording. All audio recordings were made on a Panasonic™ RR-US395 digital voice recorder. Immediately following this interview, the DSW completed the SIB-R EDF.

All data collection occurred between November 2008 and April 2009.

Data Management

Document Data

Demographic data collected during the interviews were entered into an SPSS Statistics (Version 17.0) datum sheet. Sub-scale raw scores and age equivalencies, from the VABS and the SIB-R EDF, were also entered into a SPSS datum sheet.

Video-Recorded Data

The video-recordings were converted into MPEG-4 format and then transferred into NVivo (“NVivo qualitative data analysis software (Version 8.0.264.0 SP3)

[Computer software]," 2008). NVivo is a qualitative data management software program that can be used to view and code video data. NVivo was selected because it enabled organisation of and playing of multiple video samples, and had easy to use controls for pausing and selecting small (1/10th s) time sequences for analysis through repeated viewing.

Coding of Video-Recordings

Coding of the video-recordings followed the method outlined in the AABC Manual (see appendix C). The manual was developed throughout the preliminary study as outlined in Chapter 3. In summary: (a) the video was viewed in its entirety by two raters simultaneously; (b) a 10 min segment was selected by both raters in consensus for analysis (usually after 5 min had proceeded and the DSW and person with PIMD appeared settled in the interaction); (c) the segment was played and then paused when either of the raters believed she saw a potential incident of affect attunement; (d) the incident was selected and the raters independently completed a coding form; and (e) the raters completed a third consensus coding form through discussion of their independent coding forms and review of the video incident. These steps were repeated across the 10 min segment for each of the 21 dyads. The data from the coding were entered into a SPSS datum sheet.

Inter-rater Reliability and Consensus Coding

Inter-rater reliability of coding conducted independently was determined by comparing the two raters coding for percentage agreement, Kappa and Weighted Kappa (adjusted for degree of disagreement), Bias Adjusted Kappa, and Prevalence and Bias Adjusted Kappa (Byrt, Bishop, & Carlin, 1993) (Table 4.2). Percentage agreement was determined for each quality by dividing the number of agreements by the total number of incidents and then multiplying by 100. Weighted Kappa analyses were completed

using StatsDirect statistical software ("StatsDirect (Version 2.7.7) [Computer software,") and Bias Adjusted Kappa, and Prevalence and Bias Adjusted Kappa were completed using the spreadsheet Diagnostic and Agreement Statistics[®] (Mackinnon, 2000).

Agreement was examined for each category, as opposed to presenting only a single global reliability score, in line with recommendation by Cissna et al (1990) for data that are highly subjective. The percentage agreement ranged from 59% to 100% across items ($M = 0.82$). Cohen's kappa ranged from 0.18 to 1 ($M = 0.50$, $SD = 0.20$). Weighted Kappa was slightly lower, ranging from 0.18 to 0.95 ($M = 0.52$, $SD = 0.18$). Hence, the Kappa scores range from slight to almost perfect agreement (Landis & Koch, 1977). Twelve of the 32 items had a kappa above 0.61, indicating a substantial to almost perfect agreement, and 8 items scored a moderate agreement. The remaining items had between slight and fair levels of agreement.

Table 4.2:

Inter-rater Reliability of Independently Rated Incidents (Prior to Consensus Rating)

Item	Percentage agreement	K		Weighted κ		BAK	PABAK
		κ	Sig	K	Sig		
Changing (chang)	82.8	0.32	0.01			0.32	0.66
Comment (comm.)	81.3	0.61	0.00			0.61	0.63
Intensity PIMD (intPIMD)	85.9	0.68	0.00			0.68	0.72
Intensity DSW (intDSW)	81.3	0.30	0.01			0.29	0.63
Intensity matching (intMATCH)	81.3	0.58	0.00	0.55	0.00		
Duration PIMD (durPIMD)	79.7	0.66	0.00	0.68	0.00		
Duration DSW (durDSW)	68.8	0.47	0.00	0.55	0.00		
Duration matching (durMATCH)	70.3	0.39	0.00	0.40	0.00		
Rhythm matching (rhyMATCH)	60.9	0.37	0.00	0.41	0.00		
Shape matching (shapMATCH)	65.6	0.24	0.01	0.27	0.00		
Modality of person with PIMD							
- Facial (modPfac)	81.3	0.59	0.00			0.58	0.63
- Vocal (modPvoc)	95.3	0.91	0.00			0.91	0.91
- Gestural (modPgest)	94.8	0.95	0.00			0.94	0.97
- Postural (modPpost)	84.4	0.64	0.00			0.64	0.69
- Other (modPother)	100	1	0.00			1	1
Modality of DSW							
- Facial (modDfac)	81.3	0.62	0.00			0.62	0.62
- Vocal (modDvoc)	90.6	0.61	0.00			0.61	0.81
- Gestural (modDgest)	89.1	0.60	0.00			0.60	0.78
- Postural (modDpost)	87.5	0.75	0.00			0.75	0.75
- Other (modDother)	100	- ^a					
Modality matching (modMATCH)	59.4	0.39	0.00	0.44	0.00		
Affect attunement (AA)	59.4	0.18	0.16			0.17	0.19

Imitation (IMI)	75	0.36	0.00			0.33	0.50
Loss of control (loss)	96.9	0.73	0.00			0.73	0.94
Suddenness (sudd)	93.8	0.66	0.00	0.69	0.00		
Fall	100	- ^a					
Risk	93.8	0.48	0.00			0.47	0.86
Effort	59.4	0.23	0.01	0.26	0.00		
Attention (atten)	65.6	0.44	0.00	0.51	0.00		
Emotion (emot)	73.4	0.52	0.00	0.56	0.00		
Negativity (neg)	93.8	0.30	0.01			0.30	0.88
Striving (stri)	93.8	0.30	0.02			0.30	0.88
Effective action (eff)	93.8	0.48	0.00	0.42	0.00		
Confidence	65.6	0.24	0.05			0.24	0.31

Note. BAK = Bias adjusted kappa, PABAK = Prevalence and bias adjusted kappa.

Weighted Kappas are only reported when more than 2 points on a three point scale were used by raters. BAK and PABAK are only reported on when 2 points on the scale were used.

^a constants due to no variability within the ratings for both raters.

Following independent rating by each of the two raters on each incident, the raters then compared their rating and developed a third consensus rating for each incident. The percentage agreement between the original coding by rater 1 and the consensus code, and the original coding by rater 2 and the consensus code were analysed. This comparison indicated the extent to which each rater changed her result as a result of the consensus process (Table 4.3). There was a statistically significant difference between the raters in terms of the percentage agreement between their respective original codes and those development through consensus, such that rater 1 ($M = 89.17$, $SD = 8.60$) was more likely to change codes than was rater 2 ($M = 92.24$, $SD = 6.06$), $t(33) = -3.76$, $p < .001$ (two-tailed).

Table 4.3
Percentage Agreement with Consensus Codes

Item	Percentage Agreement with Consensus	
	Rater 1	Rater 2
changing	89.1	93.8
comment	87.5	93.8
intPIMD	89.1	96.9
intDSW	85.9	95.3
intMATCH	84.4	93.8
durPIMD	90.6	89.1
durDSW	82.8	85.9
durMATCH	82.8	87.5
rhyMATCH	70.3	85.9
shapMATCH	78.1	85.9
modPfacial	92.2	89.1
modPvocal	96.9	98.4
modPgest	98.4	100
modPpost	92.2	92.2
modPother	100	100
modDfacial	89.1	92.2
modDvocal	96.9	93.8
modDgestu	93.8	95.3
modDpost	92.5	95.3
modDother	100	100
modMATCH	73.4	79.7
AA	76.6	82.8
Imitation	81.3	93.8
Loss	100	96.9
Sudd	93.8	100
Fall	100	100
Risk	98.4	95.3
Effort	75	82.8
Atten	79.7	82.8
Emot	84.4	87.5
Neg	96.9	96.9
Stri	98.4	95.3
Eff	96.9	96.9
confidence	84.4	81.4

In addition to examining agreement at an item level, the percentage agreement between coders was examined in relation to each dyad. Mean percentage agreement across items for individual dyads was from 73.33 to 83.34% (Table 4.4). The number of incidents for each dyad needs to be considered when looking at this table, as the loading of a disagreement is higher when fewer incidents are recorded. It is worthy to note, however, that agreement varied across dyads, suggesting that some dyads may have been easier to code in agreement than other dyads. For example, dyads 14 and 15 had the lowest agreements scores.

Table 4.4

Percentage Agreement for Items for Individual Dyads

Item	Dyad number (number of incidents)															
	1(5)	2(3)	3(3)	4(6)	5(1)	7(4)	8(6)	10(5)	14(5)	15(3)	17(7)	18(1)	19(2)	20(8)	21(3)	22(2)
changing	80	100	67	67	100	50	100	100	100	67	86	100	100	63	100	100
comment	100	100	67	100	100	75	83	60	60	67	57	100	100	88	100	100
intPIMD	100	67	100	100	100	75	63	60	80	67	86	100	100	88	100	100
intDSW	80	100	100	100	100	75	67	40	80	67	100	100	50	75	100	100
intMATCH	60	67	100	100	100	100	67	80	60	100	86	100	50	88	100	50
durPIMD	100	100	100	50	100	50	100	80	80	100	57	100	100	75	100	100
durDSW	100	100	33	33	0	100	100	80	60	100	43	100	50	50	100	100
durMATCH	100	100	67	50	100	50	100	100	20	100	57	100	50	50	100	100
rhyMATCH	100	100	33	50	100	50	63	60	20	67	86	0	50	50	33	100
shapMATCH	80	100	67	83	100	100	67	60	40	33	43	100	0	86	67	0
modPfacial	80	100	100	67	100	75	67	100	80	67	71	100	50	88	100	100
modPvocal	100	100	100	100	100	100	100	80	100	100	100	100	50	88	100	100
modPgest	100	100	100	100	100	100	100	100	100	100	86	100	100	100	100	100
modPpost	100	100	100	83	100	100	100	80	60	67	71	100	100	75	100	100
modPother	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100
modDfacial	80	100	100	67	100	75	100	60	60	67	86	100	100	88	67	100
modDvocal	100	100	67	100	100	75	100	80	100	100	71	100	50	100	100	100
modDgestu	100	100	100	100	100	100	100	100	60	67	86	100	100	63	100	100
modDpost	100	100	67	100	100	75	100	80	60	67	100	100	100	88	100	50
modDother	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100
modMATCH	100	100	33	50	100	50	50	60	40	67	29	0	50	63	100	100

AA	80	67	67	67	100	50	50	60	40	67	29	0	100	75	67	50
Imitation	100	67	100	67	100	50	83	80	60	33	71	100	50	100	33	100
Loss	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100	50
Sudd	100	100	100	100	100	100	100	80	100	67	100	100	100	75	100	100
Fall	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100
Risk	80	100	100	100	100	100	63	80	100	67	100	100	100	100	100	100
Effort	60	67	33	50	100	75	50	60	80	100	43	0	0	63	100	50
Atten	60	33	100	50	100	75	50	80	80	33	43	100	100	75	67	100
Emot	60	100	67	67	100	75	100	60	60	33	86	100	100	50	100	100
Neg	100	100	100	83	100	100	100	100	40	100	100	100	100	100	100	100
Stri	100	100	100	67	0	100	100	100	100	67	100	100	100	100	100	100
Eff	100	67	67	100	100	100	100	80	100	100	86	100	100	100	100	100
Mean total	90.91	91.97	82.88	80.33	93.94	81.82	85.55	80	73.33	76.88	77.55	87.88	78.79	81.94	91.94	89.39
Number of qualities below 75%	4	7	13	14	2	7	11	10	15	19	13	4	11	10	6	6

Analyses

A variety of methods were used to analyse the data. Predominantly, descriptive measures were used for the frequency of qualities. Cluster analysis, in line with the analysis completed by Jonsson and Clinton (2006), was considered. However, the technique was not suitable for use in the current study given the small number of dyads and incidents (Dolnicar, 2002). While there are no clear guidelines concerning the sample size and variable numbers to be used, Dolnicar (2002) has suggested a formula of at least 2^k , cases where k refers to the number of variables. In this case of 10 variables, a sample of 1024 would be needed. Additionally, the small number of incidents in this study, made it very difficult to discriminate legitimate case examples from outliers, and hence, methods such as Ward's analysis and k-means cluster of non-hierarchical cluster analysis would be unstable because of the influence of outliers (Garson, 2010). In these analyses, whether removal of cases as outliers has a drastic affect on final cluster solutions (Field, 2000). Furthermore, the nested nature of the incidents examined (i.e., the lack of independence of observations with many dyads contributing more than one incident of attunement) violates an assumption of cluster analysis (Garson, 2010). Given these considerations, frequency was the primary analysis of both single qualities and composites of qualities. Measures of association were used to examine relationships between the presence or absence of affect attunement and demographics.

CHAPTER FIVE

RESULTS

The nature of the eliciting behaviour of the person with PIMD is described alongside the DSW responses. The data analysed was the consensus coding completed by both coders using the AABC.

To illustrate the qualities, a single example of affect attunement is described in detail. This example enables demonstration of the analysis of each quality of affect attunement for a specific dyad, which is then followed by aggregate results for that quality across all participants. One example of affect attunement was selected from the entire set of 64 incidents using the following process: (a) incidents were selected if both coders had independently judged their coding for the incident to be very confident, resulting in 8 incidents; (b) incidents rating clear affect attunement and no imitation were selected from the 8 incidents, leaving 6 incidents; (c) one incident was selected from the remaining 6 incidents in which the face of both participants was easily visible. An incident by P20 and his DSW was selected to illustrate the use of affect attunement.

Example of Affect Attunement

P20 was a man in his 50s. He had cerebral palsy, a profound ID, and was blind in one eye (possibly caused from eye-poking behaviour). He had epilepsy, which was controlled by medication, and also took several mineral and vitamin supplements. P20's health was described as deteriorating and he was sometimes unwell. He was diagnosed with osteoporosis and he saw a neurologist in relation to hand tremors. P20 used to be able to stand with support, but at the time of participation was unable to assist at all in his transfers to and from his wheelchair. P20's primary form of communication was body language and facial expression, and he was reported to occasionally look or reach towards items. P20 frequently engaged in tapping his hand on his wheelchair and the

DSW would try to ascertain his mood by the intensity of the tapping alongside the sounds he made, including sighs and breathing patterns. He was described as being very nervous in character, but was reported to be calmer in quiet environments. On the Vineland Adaptive Behavior Scale (Sparrow, et al., 1984) he had an age equivalence of 2 months for communication and socialisation, 9 months for daily living skills, and 3 months for motor skills.

P20 was supported by D20. She was aged in her 60s and had three small grandchildren. She had worked with people with disability for 2 years, working with P20 during this time. Previously, she worked in another area of community service.

In the selected incident of affect attunement, P20 was seated in his wheelchair in his room with a relaxation CD playing in the background. D20 was seated on his bed and she engaged in drying his hands following an interaction involving him feeling warm water in a bucket. Throughout the incident D20 rubbed P20's right hand, which was rested on the right arm of his wheelchair, while his left hand rested on top of the towel sitting on his lap. Throughout the entire incident, she watched his face and slowly dried his right hand. The example begins 6 min 9.5 s into the recording.

Dyad 20 Example

P20's eyes and mouth are closed and his head is tilted upwards. He makes an audible inhalation through his nose and lowers his head over 0.5 s. As his head lowers, his eyes begin to open and gaze at D20. At 6min 9.9 s, D20 begins to make a gentle "mm" sound, which rises, then drops in pitch and volume 1 s later. Meanwhile, P20 takes another breath in, this time not audible, that starts with his chest rising and then the creases between his nose and cheek become more evident. At 6 min 10.5 s, his cheeks slightly puff out and his lips press together and pucker out slightly. He continues to hold his gaze at D20 and sticks his chin out slightly. His eyes then squint a little and

his mouth opens slightly. The creases around his mouth and cheeks suggest a smile directed at his DSW. She finishes her “mm” and his smile deepens, with more creases around his mouth and a slight opening and closing of his mouth and eyes. The incident of affect attunement lasts 1.8 s.

On the AABC, one coder described the incident as “P20 sniffs long bringing head down into a smile like facial expression. DSW goes ‘mmm’ in response.” The other coder described the incident as “P20 takes a deep breath in, brings his head down and exhales with a small smile, DSW response by saying ‘hmm...’”

Number of Incidents of Affect Attunement: Aggregate

It was found that most of the DSWs in the present study used affect attunement in interactions with adults with PIMD. In total, 64 incidents of affect attunement were identified in the interactions. Five DSWs did not use any incidents of affect attunement, hence the 64 incidents were used across 16 dyads. The number of incidents ranged from 0 to 8 incidents per dyad, with a mean of 3.05 ($SD = 2.52$), which equates to nearly 1 incident every 3 mins during the interactions. Excluding the participants not using any affect attunement, the mean was 4 ($SD = 2.10$).

Of the 64 incidents, 43.8% were rated as clear incidents of affect attunement with no imitation evident. Of the incidents of affect attunement rated as uncertain (42.2%), half were rated as not having any evidence of imitation, with the remaining rated as having some evidence of imitation. A few incidents (14.1%) were considered to be clear incidents of affect attunement alongside an uncertain presence of imitation.

The relationship between the rating of affect attunement (none, uncertain, or clear) and confidence in coding (not at all, uncertain, or very confident) was investigated using Spearman rho correlation coefficient. There was a small, positive correlation between the two variables, $r = .29$, $n = 64$, $p < .05$. No incidents were rated

as clear incidents of imitation. For the remainder of the results, all incidents were counted as incidents of affect attunement, regardless of being rated as clear or uncertain.

Catching, Changing, and Commenting

Each incident was rated for the degree of catching (i.e., DSW appearing to notice the affect display of the person with PIMD), changing (i.e., the appearance of the person with PIMD noticing the attunement of the DSW), and commenting (i.e., the DSW responding with a comment that is not recasting the person with PIMD's affect, but adding or responding).

Dyad 20 Example

The incident between P and D20 was rated as yes for catching, as the DSW perceived an affective expression by P20. Given that P20's smile emerged after the DSW's attunement behaviour of saying "mm," changing was rated as yes. The behaviour of the DSW was rated as somewhat commenting on P20's affective expression.

Aggregate

All of the incidents were rated yes according to the DSW catching the affect of the person with PIMD. In rating whether the person with PIMD's affect changed in reaction to the DSW, 81.3% of incidents were rated as no and 18.8% as yes (Table 5.1). The incidents rated as yes for a change of response in reaction to the DSW were across 6 participants (3 participants having 3 incidents of yes each, and 3 participants having 1 incident of yes each). All participants had incidents rated as no.

Table 5.1
Ratings of Changing

Dyad	Changing		Total
	No	Yes	
1	4	1	5
2	3	0	3
3	3	0	3
4	3	3	6
5	1	0	1
7	3	1	4
8	6	0	6
10	4	1	5
14	5	0	5
15	3	0	3
17	4	3	7
18	1	0	1
19	2	0	2
20	5	3	8
21	3	0	3
22	2	0	2
Total	52	12	64

The degree to which a reaction was a comment was rated not at all in 43.8% of incidents, somewhat in 56.3%, and no incidents were rated as a marked incident of comment.

Amodal Qualities of Affect Attunement: Duration, Intensity, Rhythm, and Shape

The amodal qualities of affect attunement refer to the qualities of duration, intensity, rhythm, and shape. The qualities were coded for both the DSW and person with PIMD; also coded was the relationship of the qualities for the DSW and person with PIMD (i.e., whether or not there was a match within each incident). The qualities were also measured in groups to see which qualities were used together most frequently

(i.e., whether particular qualities were used simultaneously, such as simultaneous use of marked intensity and very different beat).

Dyad 20 Example

The incident between P20 and D20 lasted 1.8 s. The behaviours of each participant overlapped, with P20's behaviour rated at slightly shorter, at 1 s, than the D20's 1-2 s. P20's behaviour (rated relative to the rest of his behaviour on the video) was rated as very intense, and his DSW's behaviour as intense, indicating a difference between the intensity of behaviours. The rhythm and beat for both participants was somewhat similar (see figure 5.1), with the DSW's vocalisation of "mmm" having a minim like beat (using basic music notation) and P20's inhalation being a minim with a crochet at the end. Both participants' behaviour had a slow rise and fall shape, but with different slopes suggesting that the shapes were somewhat similar. In summary, this incident was rated as somewhat different for each of the amodal qualities of duration, intensity, rhythm, and shape.

<p>RHYTHM AND BEAT OF THE BEHAVIOURS: Draw the beat of pPIMD behaviour</p>  <p>Matching of rhythm and beat:</p>	<p>Draw the beat of DSW behaviour</p>  <p>0. Not at all 1. Somewhat 2. Markedly</p>
<p>SHAPE OF THE BEHAVIOURS: Draw the shape of pPIMD behaviour</p>  <p>Matching of spatial shape:</p>	<p>Draw the shape of DSW behaviour</p>  <p>0. Not at all 1. Somewhat 2. Markedly</p>

Figure 5.1. Rating sheet of incident 50 showing beat and shape of the behaviour.

Aggregate Duration

The fixed duration of incidents was measured by selecting the time (to 1/10th s), beginning from the behaviour of the person with PIMD to the end of the DSW's attuned

response. The times ranged from 0.9 to 7.3 s (mean = 2.3, *SD* = 1.1). Eighty percent of incidents were less than 3 s in duration.

An estimation of each individual’s behaviour was recorded after the total incident was selected. The raters estimated whether the individual’s behaviour took less than 1 s, 1-2 s, or longer than 2 s (Table 5.2). In 5 incidents, the person with PIMD and DSW both used behaviours longer than 2 s. In 18 incidents, both people used behaviours that lasted from 1 to 2 s. Seventeen of the incidents involved the behaviours of both participants lasting less than 1 s. For the remaining incidents, ratings of duration differed across the DSW and participant with PIMD. The behaviour of the DSW was rated as 1-2 s and behaviour of the person with PIMD rated as 0-1 s on 14 occasions. The converse (0-1 s for the DSW behaviour and 1-2 s for person with PIMD) was evident on 4 occasions. Matching of duration, hence, was complete in 62.5% or incidents, partial in 35.9%, and for 1 incident there was no match in duration. Hence, in the majority of incidents, the duration of behaviours was under 2 s and was matched between participants.

Table 5.2
Estimated Duration Frequencies and Matching

Participant	<1s	1-2s	>2s
Person with PIMD	21	33	10
DSW	32	26	6
Matching	17	18	5

Aggregate Intensity

The intensity of the behaviour of the person with PIMD and the DSW were rated as no intensity, intense, and very intense (Table 5.3). Overall, 60.9% (39) of the incidents were rated as intense for both the DSW and person with PIMD’s behaviour, and in 3 incidents both participants’ behaviours were rated as very intense. In 17 of the

incidents, the intensity of the person with PIMD was rated very intense, with the DSWs' behaviour rated as intense. Conversely, the DSW behaviour was rated as very intense and that of the person with PIMD as intense in 5 incidents. Complete matching of intensity was rated for 65.6% of behaviours, with the remainder being partially matched. The majority of the behaviours were intense and were matched between participants.

Table 5.3
Intensity Frequencies and Matching

Participant	No Intensity	Intense	Very Intense
Person with PIMD	0	44	20
DSW	0	56	8
Matching	0	39	3

Aggregate Rhythm

As previously mentioned, the rhythm of participants' behaviours were rated using basic musical notation. A judgement was made as to whether the ratings for the person with PIMD and the DSW were matched, somewhat matched, or not matched at all. Matching of rhythm of behaviour was rated as markedly matched in 10.9% incidents, somewhat in 54.7%, and not at all in 34.4% of incidents. The rhythm or beat of the behaviours was therefore rated as completely matched less frequently than the ratings for the matching of duration and intensity.

Aggregate Shape

Finally, the shape of the behaviour was rated by drawing the impression of the shape. For example, some shape impressions were slow rising lines, others were rough sustaining lines. Matching of shape was rated as markedly in 7.8% incidents, somewhat in 81.3%, and not at all in 10.9% incidents. Hence, matching of shape was somewhat evident in most of the incidents of affect attunement.

Aggregate Composite of Amodal Qualities

The amodal qualities of intensity, duration, rhythm, and shape were examined simultaneously across all incidents. Table 5.4 shows the number of incidents with the same matching qualities, with 2 indicating complete match, 1 somewhat, and 0 no match. The most frequently occurring amodal profile was a marked match of intensity and duration, with some match in shape and rhythm (20%). Only 2 incidents were rated as having a complete match in all amodal qualities.

Table 5.4
Composite Amodal Qualities of Incidents

Number of incidents	Intensity	Duration	Shape	Rhythm
13	2	2	1	1
8	1	2	1	1
7	2	2	1	0
6	1	1	1	1
6	2	1	1	1
3	2	2	1	2
3	2	1	1	0
3	1	1	1	0
2	2	2	2	1
2	2	2	0	0
2	2	2	2	2
2	1	1	0	0
2	2	1	0	0
1	1	2	2	2
1	2	1	1	2
1	1	2	1	0
1	1	2	0	0
1	2	0	1	0

Note. 0 = no match, 1 = some match, 2 = markedly matched

Mode of Behaviours

The mode of the behaviours according to the use of facial expression, vocalisation, gesture, posture, and other by the DSW and person with PIMD were rated as present or absent (i.e., dichotomous).

Dyad 20 Example

In the incident between P20 and D20, very different modalities were used. P20's behaviour incorporated facial, postural, and other (the audible inhalation) qualities, whereas the DSW's behaviour was vocal only.

Aggregate

The most frequently used modes for the people with PIMD were facial expression (70.3%) and postural changes (75.0%). Vocal modes were used in 48.4% of incidents and gestural modes in 21.9%. In a small number of incidents (10.9%), the mode other was rated referring to audible breathing expressions. Clusters of modes were then examined. Unimodal behaviours were present in 18.8% of behaviours. The remaining behaviours involved clusters of modes used together (Table 5.5). The most frequently occurring cluster was that of facial, vocal, and postural behaviours (18.8%), followed by facial and postural (17.2%).

Table 5.5
Composite of Modalities for People with PIMD

Number of incidents	Facial	Vocal	Gestural	Postural	Other
12	1	1	0	1	0
11	1	0	0	1	0
6	0	1	0	1	0
5	1	0	1	1	0
5	0	1	0	0	0
4	1	0	0	1	1
3	1	1	0	0	0
3	1	1	1	1	0
3	1	0	0	0	0
3	1	0	1	0	0
3	0	0	0	1	0
2	0	0	0	1	1
1	0	0	1	1	0
1	0	0	1	0	0
1	1	1	1	0	0
1	0	1	0	1	1

Note. 0 = not present, 1 = present

The pattern of DSW usage of modes differed to that of the participants with PIMD, with the predominant mode being vocal (87.5%). Facial expression was rated to be present in 60.9% of incidents and postural changes in 54.7% of DSW behaviours. Gestural behaviours were rated as present in 17.2% of behaviours, and no ratings of other were made. The clustering of DSW modes was examined, with data presented in Table 5.6). The mode of other has been excluded because it was not present in the DSW behaviours. The most frequently occurring cluster was facial, vocal, and postural (23.4%). A unimodal behaviour of using just the vocal mode was present in 21.9% of behaviours.

Table 5.6
Composite of Modalities for DSWs

Number of incidents	Facial	Vocal	Gestural	Postural
15	1	1	0	1
14	0	1	0	0
9	1	1	0	0
7	0	1	0	1
7	1	0	0	1
4	1	1	1	1
3	1	1	0	0
2	0	1	1	0
2	0	1	1	1
1	1	0	0	0

Note. 0 = not present, 1 = present

The modes of both participants were then examined in regards to whether they were matching or not (Table 5.7). The following modes were matched as present in both participants' expressions: facial 48.4%, vocal 45.3%, gestural 9.4%, and postural 48.4%. Overall modality profiles (after removing the Other category) were matched for presence of modalities completely in 25.0% of incidents, part matched in 68.8%, and completely different in 6.3% of incidents.

Table 5.7
Frequency of Matching of Modalities Between Person with PIMD and DSW

Modality	Different		Same	
	Present for DSW only	Present for person with PIMD only	Absent modality	Present modality
Facial	8	14	11	31
Vocal	27	2	6	29
Gestural	5	8	45	6
Postural	4	17	12	31

Note. Other has been removed

Nature of Eliciting Behaviour

Each eliciting behaviour was coded according to the degree of presence (none, some, lots) of the following 10 qualities: loss, suddenness, falling, risk, effort, attention, emotion, negativity, striving, and effective action (see Table 5.8).

Table 5.8
Frequencies of Quality Ratings Across All Incidents

Quality Name	None	Some	Lots
Sudden	56	8	0
Fall	64	0	0
Loss	59	5	0
Risk	59	5	0
Effort	6	46	12
Attention	26	31	7
Emotion	35	26	3
Negative	60	4	0
Strive	60	4	0
Effective action	60	3	1

Dyad 20 Example

P20's behaviour in this incident was coded as showing lots of motor effort and some emotion. All other qualities were rated as none.

Aggregate

The most frequently occurring quality was effort, followed by attention, and then emotion. When these behaviours did occur, they were more likely to be present as some, rather than lots. Effort was present in 58 of the 64 (90.6%) incidents. The quality of falling was not evident in any of the incidents.

Aggregate Composite of Qualities of Eliciting Behaviour

The most frequently occurring composite profile was some presence of effort and attention with no other qualities (see Table 5.9). This was the composite of 8 (12.5%) of the eliciting behaviours across 5 people with PIMD (3 people used this

profile twice, and 2 used the profile once). The composite of some effort, attention, and emotion, in the absence of any of the other qualities, was present in 6 incidents, used by 5 people (one person using this profile twice). Five of the elicited behaviours had the composite of some effort and some emotion in the absence of other qualities, and they were used by 4 participants. Another 5 of the behaviours had the composite of only some effort in the absence of other qualities, and they were also used by four other people. The remaining 40 (62.5%) elicited behaviours were spread across composites that were used less than 4 times each, with 16 composites being used only once.

None of the participants used the same composite of qualities more than twice.

Table 5.9

Eliciting Behaviour Composites Frequencies

Freq	Participant number (freq)	Qualities of eliciting behaviour of the person with PIMD									
		Loss	Sudd	Fall	Risk	Effo	Atten	Emot	Neg	Stri	Effe
8	8 (2), 7 (2), 21 (2), 17 (1), 14 (1)	0	0	0	0	1	1	0	0	0	0
6	3 (2), 2 (1), 8 (1), 10 (1), 20 (1)	0	0	0	0	1	1	1	0	0	0
5	17 (2), 1 (1), 18 (1), 20 (1)	0	0	0	0	1	0	1	0	0	0
5	4 (2), 5 (1), 20 (1), 22 (1)	0	0	0	0	1	0	0	0	0	0
3	2 (1), 4 (1), 10 (1)	0	0	0	0	1	1	2	0	0	0
3	7 (1), 17 (1), 19 (1)	0	0	0	0	1	2	0	0	0	0
2	1 (2)	0	0	0	0	1	1	0	0	0	1
2	8 (2)	1	1	0	1	1	1	0	0	0	0
2	20 (2)	0	1	0	0	1	0	0	0	0	0
2	1 (1), 20 (1)	0	0	0	0	2	0	0	0	0	0
2	1 (1), 14 (1)	0	0	0	0	1	0	1	1	0	0
2	2 (1), 10 (1)	0	0	0	0	2	1	1	0	0	0
2	3 (1), 7 (1)	0	0	0	0	1	2	1	0	0	0
2	14 (1), 20 (1)	0	0	0	0	2	0	1	0	0	0
2	15 (1), 17 (1)	0	0	0	0	0	0	1	0	0	0
1	4 (1)	0	0	0	0	2	1	0	0	1	0
1	4 (1)	0	0	0	0	2	2	0	0	1	0
1	4 (1)	0	0	0	0	0	0	0	0	0	0
1	8 (1)	1	1	0	1	2	0	0	0	0	0
1	10 (1)	0	1	0	1	1	0	0	0	0	0

1	14 (1)	0	0	0	0	0	0	1	1	0	0
1	15 (1)	0	0	0	0	1	1	1	0	1	0
1	15 (1)	0	1	0	1	0	1	1	0	0	0
1	17 (1)	0	0	0	0	0	1	1	0	0	0
1	17 (1)	0	0	0	0	2	2	0	0	0	0
1	19 (1)	0	0	0	0	2	2	0	0	0	0
1	20 (1)	0	1	0	0	2	1	0	0	0	0
1	21 (1)	1	0	0	0	1	1	0	0	0	0
1	22 (1)	1	0	0	0	1	0	0	0	0	0

The following are examples of the four most frequently occurring composites. Each composite is labelled followed by examples of behaviours from 3 different participant dyads that have been randomly selected.

Effort and attention examples:

- P14 lying on his back, gazes intensely at DSW, with what looks like a smile on his face or calm look that is departure from grizzle, DSW moves into his face ~50 cm away and says "what?"
- P17 taps his finger to his mouth and DSW says "you thinking about it" and taps his finger
- P21 gazing at DSW drops head to right then raises it and DSW raises her eyebrows then nods down.

Effort, attention, and emotions example:

- P10 taps soft toy twice, then squashes and wiggles his hand into the toy, then DSW taps couch once and then taps again in quick succession
- DSW comes with chocolate and P3 slowly raises his hands and rubs them together, DSW approaching him says "hehehehe"
- P2 raises head back and smiles, increasing vocalisation and followed by a drop of head, DSW says "mm" with similar intonation and slight smile.

Effort and emotion example:

- DSW tickling P1's back, P1 starts tensing up and sitting upwards, with what might be a smile on face emerging, DSW saying "where's the spot, where's that spot?" and giggles and moves in slightly to his face
- P17 leans over chair arm makes a small "mm" sound and appears to smile, DSW says "yeah ehe eh"

- P20 breaths in and audible breath out and closes his mouth, DSW goes "oh: you like that".

Effort only example:

- P4 lets out long open mouth sigh and turns head forwards, DSW lets out an "oh what a sigh"
- P20 makes a little grunting sound and extends posture up then turns, DSW turns to him and says "it's good"
- P22 groaning sound as opening mouth for food, DSW quietly responds with an "oh".

Relationship between Incidents of Affect Attunement and Demographics

The relationship between the number of incidents used by each dyad and the dyad's demographic qualities were examined. Firstly, the number of incidents of affect attunement was assessed for normality. Skewness of .34, kurtosis of -.98, and a *SD* of 2.52, were found, all indicating that the data were not normally distributed (Pallant, 2007). Hence, continuous data were analysed using Spearman's measures of association (1-tailed) (Table 5.10). Nominal data were reduced to a smaller number of categories according to what would be meaningful clinically (e.g., the five mobility categories were reduced to two categories of some independent mobility and no mobility) and then eta was used to examine strength of association (Table 5.8). For both measures, Cohen's interpretations of strength of relationship were used: small $r=.10-.29$, medium $r=.30-.49$ and, large $r=.50-1.0$ (Pallant, 2007).

Table 5.10

Spearman's rho Correlations with Number of Incidents of Affect Attunement Used by a Dyad (n=21)

Variable	<i>P</i>
Age of person with PIMD	.120
Age of DSW	-.144
Time working with people with disabilities	-.292
Time working as dyad	-.278
VABS communication domain raw score	.283
VABS daily living skills domain raw score	-.273
VABS socialization domain raw score	.205
VABS motor domain raw score	-.344

Table 5.11

Eta Relationship with Number of Incidents of Affect Attunement

Variable	Eta value
Gender of person with PIMD (male/female)	.022
Gender of DSW (male/female)	.451
Epilepsy (none/rarely/frequently)	.262
Health (well/unwell)	.068
Vision (useful vision/little useful vision)	.101
Hearing (hears well/hearing problem)	.340
Mobility (some mobility/no mobility)	.454
Communication (some proactive communication / body language only)	.014
DSW parenting (children/grandchildren)	.174

Across the two tables, medium relationships were found between number of affect attunement incidents and VABS motor domain, DSW rated mobility level of the person with PIMD, DSW rated hearing level, and DSW gender. More frequent affect attunement was moderately related to poorer mobility, poorer hearing, and female DSWs. The remaining relationships were small or not present at all.

Dyads with No Affect Attunement

In five of the video-interactions of dyads, there was no evidence of affect attunement. Further description of these five dyads was undertaken to explore potential patterns in relation to when affect attunement may be unlikely to occur. This exploration was conducted by presenting demographic qualities of these dyads and narratives of the videos (Table 5.12). Four of the five people with PIMD who did not have affect attunement incidents had daily living and motor skills rated as above 13 months and less than 8 months for communication and sociability. Several people were described as showing reduced facial expression during the interaction. One of the participants was reported to have frequent distressed behaviours, with two other participants reported to quickly leave interactions when they were unhappy. One of the DSWs (D13) appeared to be very anxious during the interaction, frequently changing activities and engaging with the researcher rather than with the person with a disability. In two of the interactions, general attuned behaviours in the form of watching the person with a disability and pacing the interaction were evident, however no specific incidents of affect attunement could be found.

Table 5.12
Description of Dyads with No Affect Attunement

Dyad	PIMD gender	Diagnosis	VABS domain age equivalence (months)				DSW gender	Description of interaction
			Com	Dls	Soc	Mot		
9	Male	Unknown, epilepsy, vision impairment	1	14	7	17	Female	The dyad is seated next to each other with a box of musical plastic toys. P9 selects and manipulates the toys for less than 5 s each, however he has a neutral facial expression. D9 offers and extends on the toy play, and P9 accepts offered toys but does not change his facial expression or make eye contact. D9 uses varying intonation and facial expression to comment on P9's behaviour. She is generally attuned to P9, however specific instances of recasts are difficult to discriminate.
11	Male	Tuberous sclerosis , ID, epilepsy	3	16	0	20	Male	P11 is mobile and spends much of the interaction wandering from room to room. D11 follows him and occasionally sits next to him. A few instances of shared meaning are evident: P11 puts D11's hand on a cup to indicate pouring drink, D11 asks P11 to get out of bed by asking and tapping P's feet towards the edge of the bed. During the interview, D11 indicated that P11 has a lot of distressed behaviour. D11's behaviour during the interaction could be described as non-intrusive, calm, and interested but not provocative towards P11.

Dyad	PIMD gender	Diagnosis	VABS domain age equivalence (months)				DSW gender	Description of interaction
			Com	Dls	Soc	Mot		
12	Male	Congenital rubella syndrome (vision and hearing impairment), autism	7	27	2	16	Male	<p>P12 is seated at the kitchen table eating his breakfast. He picks up the toast and drink, serving himself. P12 intermittently rocks and flicks his left hand. D12 sits to his right side. D12's main focus throughout the interaction is a task of footy tipping. He puts two team icon cards on the table to P's right. P appears to perceive the cards intermittently (e.g., when he puts his cup down at his right side) and picks up the card closest to him, puts it on the pile near D12 and then picks up the other card similarly. D12 appears to interpret this as a choice; he comments on the <i>choice</i> made.</p> <p>P12's attention is primarily on his breakfast. His facial expression is largely neutral, however he smiles at times, but the cause of his smile is not evident. Nor is it caught by the D12.</p> <p>D12 described P12 as quite a loner who would leave the room if he was unhappy.</p>
13	Male	CP, ID, Scoliosis	4	10	2	5	Female	<p>D12 appears to be very anxious throughout the interaction. She engages with P12, however her engagements are quick commands to do another activity. Opportunities for affect attunement are evident (e.g., P12 stretches up to reach a bar for supported standing) however D12's response is usually to direct him to a new activity.</p>

Dyad	PIMD gender	Diagnosis	VABS domain age equivalence (months)				DSW gender	Description of interaction
			Com	Dls	Soc	Mot		
16	Female	Unknown	6	15	4	19	Female	A very intense interaction between D16 and P16 is evident. D16 appears to be constantly attuned to P16, watching her and offering activities that challenge her (e.g., holding a desired object just beyond P16's reach). The shared focus on objects is sustained throughout the interaction. P16 shows her interest by reaching, flicking, and maintaining proximity, but does not show smiling or eye contact behaviours. D16's facial expression, though intensely interested in P16, shows minimal changes, and no recasting of P16's expressions. D16 described P16 as somebody who would move away from an interaction if she was unhappy.

Note: VABS domains: Com = communication, Dls = daily living skills, Soc = socialisation, Mot = motor

CHAPTER SIX

DISCUSSION

This study began with a broad aim of describing the nature of interactions that occur between people with PIMD and their DSWs. In order to address this aim, the literature was reviewed and a gap in the area of intersubjectivity identified. One type of intersubjectivity, called affect attunement, focused specifically on sharing of feelings or affects. A method of examining the use of affect attunement in interactions between dyads was selected for describing interaction. The nature of interactions was examined through a coding system describing affective attunement, including the frequency, duration, intensity, shape, modalities, and nature of the behaviour of the person with PIMD that elicited an affective attunement response from the DSW. The discussion focuses on answering the following research questions:

1. Do DSWs use affect attunement in interactions with adults with people with PIMD?
2. How frequently is affect attunement used by DSWs in their interactions with people with PIMD?
3. What are the amodal and modal qualities of affect attunement used in the dyad?
4. What are the behaviours of the person with PIMD to which the DSW attunes?
5. What is the relationship between the disability support workers' gender, parenting experience, and length of time working with the person and their affect attunement?

The first four questions have been addressed in the sections on the descriptive data of affect attunement, and the fifth question in the section on the relationship between the DSW's demographics and affect attunement, and dyads with no affect attunement. The discussion concludes with the implications for clinical practice and research.

DSW use of Affect Attunement in Interactions with People with PIMD

The first two research questions addressed in this study were (1) *Do DSWs use affect attunement in interactions with adults with people with PIMD?* and (2) *How frequently is affect attunement used by DSWs in their interactions with people with PIMD?* These questions were addressed by describing the frequency with which affect attunement was observed in each dyad. It was found that DSWs do in fact engage in affect attunement, although this may not be true of all DSWs in that five did not display any incidents of affect attunement.

Across the 21 dyads, 16 DSWs displayed incidents of affect attunement at least once. During the 10 min video-recordings of dyads with incidents, from one to eight incidents occurred, with an average of four incidents, indicating an overall rate of one incident every 2 ½ mins during interactions. The results of this study, therefore, indicate that affect attunement does occur in interactions between people with PIMD and their DSWs. Given that no previous research has explored affect attunement in these dyads, comparison can be made only with mother-infant interaction literature. This rate is lower than the approximately 1 per min reported for mother-infant dyads (Jonsson, et al., 2001; Stern, 1985; Stern, et al., 1985). Reasons for the lower occurrence for the adults in this study may lie in the differences in modal and amodal qualities, and eliciting behaviours.

An issue from the current ratings, related to use of affect attunement, is whether the person with PIMD's affect changed in reaction to the DSW. The changing of behaviour relates to whether the adults with PIMD in this study satisfied Stern's (1985) third requirement for affect attunement: that is, the person perceived the attunement behaviour of the partner. Perception can be demonstrated by changing of behaviour, or as suggested by Stern et al. (1985) has been more frequently the case, the person shows

no visible evidence of the perception, despite other evidence suggesting perception of the mother's behaviour. Infant perception in the absence of overt response was explored in the perturbation studies by Stern (1985) and Stern et al. (1985) in which the mothers misattuned and attuned to behaviours of their 8-12-month old infants. Their findings that infants frequently pause and looked at the mother during misattunement and continued their activity when mothers were attuned suggested that the infants did perceive the misattunement to be outside what they expected. It would seem that attunement, done well, results in no perceivable response by the infant.

In the current study, in which perturbation was not employed, the coding of the changing went some way to examining whether the person with PIMD perceived the partner's attunement. The most subjective rating required when using the coding system was for changing, because it required the rater to ascribe some meaning to the behaviour of the person with PIMD (i.e., awareness of the DSW's behaviour). Coding changed reaction involved examining up to 3 s of video content following the incident and making a judgement as to whether the person with PIMD showed any signal of perceiving the behaviour of DSW. The finding that 81.3% of incidents were rated as the person with PIMD not showing signs of perceiving the DSW's attunement suggests that either attunement was perceived with no visible response from the person with PIMD, or alternatively, the person with PIMD did not perceive the behaviour at all. Furthermore, the finding that 18.8% of incidents were rated as the person showing signs of perceiving the behaviour of the DSW's response, or changed his/her behaviour immediately following the DSW's behaviour provides some evidence that the person with PIMD perceived the DSW's attunement behaviour.

Subsequently, two possibilities might explain the limited evidence of the person with PIMD changing in response to the attunement of the DSW: (1) the person with a

disability perceived the attunement, but continued the interaction undisturbed (as in Stern's perturbation studies); or (2) the person with PIMD did not perceive the attunement at all. In watching the videos, both possibilities, under different conditions, seemed plausible, but could not be verified by data. In some incidents, particularly those involving attention of the person with PIMD to the DSW, there was some indication of the person perceiving the attunement and moving on in the interaction. However, in other incidents involving people with lower levels of attention, alertness, and contingent behaviour, it appeared that the person with PIMD may not have perceived the DSW's behaviour at all. Of the 10 people with PIMD who showed no evidence of a changed response, five were judged as having little to no useful vision, which, if accurate, may have contributed to a lack of perception of the DSW's attunement.

A core question then arises from these possible explanations: if the person with PIMD does not perceive the attunement, can the incident be considered to be affect attunement, or would it be more appropriate to describe the interaction as something different. Other researchers have overlooked the perception, but maintained the use of the term affect attunement. Jonsson et al. (2001), for example, failed to explore the infant's perception of the mother's attunement and instead focused only on the mother's identification of the infant's state and her response of the same feeling. This attention to only the first two elements may, in part, explain their claim that affect attunement was used prior to 9 months of age. Stern (1985), on the other hand, argued that infants needed sufficient cognitive capacity to make an inference about the relation between the behaviours, which was not evident prior to 9 months. He saw this capacity, in addition to the need for the infant to be able to either see or hear the mother's behaviours, as essential for true affect attunement. In the current study, one participant may not have had the sensory abilities to see or hear the attunement, with the remaining participants

all having either hearing or vision skills sufficient to perceive close interaction.

However, what is not evident from the data is whether the participants had sufficient attention to the behaviour of the partner or cognitive skills to process the attunement. In light of the absence of evidence, it may be more accurate to consider the incidents as *pseudo-affect attunement*.

Qualities of Affect Attunement

The third research question was: *What are the amodal and modal qualities of affect attunement used in the dyad?* The incidents of affect attunement were described using the amodal qualities of duration, intensity, rhythm, and shape and modal qualities of vocal, facial, postural, and gestural. Some degree of matching and some degree of difference were evident across the incidents of affect attunement. This finding would appear positive, given some degree of matching is required for an incident to be called affect attunement, but total matching is more likely to suggest imitation (Jonsson, et al., 2001; Stern, 1985; Stern, et al., 1985).

According to the precise and estimated duration, incidents of affect attunement were found to be very short, at times fleeting, with most (80%) being less than 3 s. These durations contrast with those reported by Jonsson et al. (2001) of 1 – 2 s, with a median of 1 s. Consequently, the current incidents between adults with PIMD and DSWs were slower in duration, albeit still short in the context of the entire interaction sample. Similarly, the individual behaviours of the DSW and person with PIMD were also brief: for example, 32.8% of the person with PIMD behaviours and 50% of DSW behaviours were estimated as lasting less than 1 s. On the basis of this finding, it is suggested that the longer incident duration was more attributable to the person with PIMD, which may be explained by their slowed movement and reaction patterns (Hogg & Sebba, 1986; Utley, 1994). The finding that matching of duration between the adult

with PIMD and their DSW occurred in 62.5% of incidents was similar to that found by Stern et al. (1985): that is, matching of duration was found for 69.2% of the incidents in the mother-infant dyads.

A further frequent amodal quality evident in the affect attunement incidents was frequent matching of intensity, occurring completely in 65.6% of incidents, and partially in 44.4%. Given that the rating of incidents as intense represented the minimal intensity, the high frequency of intense ratings compared with fewer markedly intense ratings suggests that many of the incidents could be considered to be subtle. The subtlety of behaviours in addition to many often being difficult to read often have been provided as rationales for assessments and interventions designed to increase the awareness and responsivity of interaction partners to low intensity behaviours of people with PIMD (Barber, 2001; Siegel-Causey & Guess, 1989). In considering the duration and intensity together, it could be suggested that the behaviours of affect attunement could easily be overlooked as they are short in duration and subtle in intensity.

While duration and intensity were frequently matched, rhythm and shape were more often different across participants' behaviours. Both qualities of rhythm and shape were rated as being somewhat matched in more than half of the incidents (54.7% for rhythm and 81.3% for shape). Complete matching was rated for rhythm and shape in only few incidents (about 11% and 8% respectively). Whereas completely different ratings were made only once for duration and not at all for intensity, completely different ratings were made for rhythm for about a third, but for shape in only a small proportion (10.9%). These distinctions between high frequency matching for duration (69.2%) and intensity (61.1%), and lower frequency matching for rhythm (11.4%) and shape (37.9%) were also found by Stern et al. (1985) in his mother-infant dyads,

suggesting a similarity between the amodal characteristics of affect attunement across both dyad groups.

In light of the fact that the adults with PIMD did not use conventional or symbolic communication, it is not surprising that the modal qualities of their behaviours included mostly facial expression and postural changes in the affect attunement incidents (70.3% and 75.0%, respectively). The use of vocalisations (48.4%) reflected those used by Stern et al.'s (1985) infants (57.2%). In comparing across other modalities, fewer facial displays (47.2%) were observed in Stern et al.'s infants, and more gestural expressions (51%) compared to being present in 21.9% of person with PIMD incidents. In the current study, only 18.8% of the incidents were unimodal, with the remaining involving different clusters of modes, reflecting Stern et al.'s (1985) finding that infants use multiple modes more frequently than single modes. Clusters of facial, vocal, and postural were the most frequently used clusters, although these accounted for only 18.8% of incidents, followed by facial and postural modes (17.2%). It was not possible to determine how modes clustered together in the studies by from Stern et al. (1985) or Jonsson et al. (2001) .

In contrast, DSWs' affect attunement behaviours were predominately vocal in mode (87.5%), followed by high percentages of facial expressions (60.9%), then postural changes (54.7%). This trend appears similar to the behaviours of mothers in the study by Stern et al. (1985), who used vocalisation in 73.1% of incidents and facial displays in 46.2%. The use of unimodal expressions was more common in DSWs than in the people with PIMD (accounting for 23.4% of incidents). The single mode was usually vocalisation/speech, reflecting the DSW's primary use of vocal means for affect attunement. In coding these vocalisations, in particular through the coding of shape, it appeared that the tone of voice primarily signified the attunement, with the linguistic

content often supporting the message. It is possible that Stern's (2002) argument that it is the tone of voice used by the mother to which infants tune into first, is also true for the person with PIMD. The value of tone of voice over linguistic content challenges the basis of previous research that focuses on the number of information carrying words as an indicator of the quality of interaction (e.g., Bradshaw, 2001) and viewing verbal content purely from a linguistic reference (e.g., Healy & Walsh, 2007 who coded verbal acts as linguists, such as questions, instruction, corrections). To date, with the lack of microanalysis in interactions, there has been little research into the tonal qualities of DSW speech and subsequent responses of people with PIMD.

Use of the same modes by both dyad members occurred for a quarter of incidents, with remaining incidents containing a mixture of same and different modes. Similarly to findings in the current study, mixed modes were the most common ratings reported by Stern et al. (1985) at 48.2% of incidents. In contrast, only few of the incidents of DSWs in the current study comprised completely different modes (6.3%), while 38.3% of incidents of the mothers in Stern et al. (1985) comprised completely different modes. In the current study, the frequent use of facial, vocal, and postural modalities by both participant groups may account for the rarity of completely different modes being used, in contrast to Stern et al.'s (1985) infants who used gestures and head and body motions (i.e., posture) more frequently than their mothers. As reported by the DSWs and rated using the AABC, gestures were rarely used by the people with PIMD in this study, hence a modality that frequently distinguished the behaviours of mother and infants in dyads was not available to the dyads of the current study, accounting for some of difference in use of different mode attunements.

Behaviours to Which DSWs Attune

The fourth research question addressed in this study was: *What are the behaviours of the person with PIMD to which the DSW attunes?* DSWs in the present study attuned to a small range of behaviours of people with PIMD, as indicated on the AABC. Composite frequencies of qualities indicated that motor effort and attention were most often rated as markedly present. Similarly, qualities rated as somewhat present in the behaviour were also most frequently those of motor effort and attention, with the addition of emotion expression (such as a smile). Nevertheless, these behaviours, although occurring most frequently for people with PIMD than other behaviours, must be seen as part of the smaller overall number of affect attunement incidents that occurred for these dyads, compared to mother-infant dyads. It is possible that motor effort and attention, both behaviours documented as difficult for many people with PIMD (Munde, et al., 2009; van der Putten, Vlaskamp, Reynders, & Nakken, 2005), are the best of worst behaviours that can be demonstrated. Subsequently, with such limitations on behaviours, adults with PIMD may be eliciting fewer behaviours to which DSWs can respond using affect attunement, which may account for the lower frequency of affect attunement in these than in mother-infant dyads.

The behaviours occurring most rarely for eliciting an affect attunement response in these dyads were falling (never occurring), negativity, strive, and effective action. It is possible that falling behaviours, which in infants may occur frequently as they develop sitting and walking skills (Lee & Aronson, 1974), are rarely experienced by adults with PIMD, who are frequently in wheelchairs (Vlaskamp, 2005b) with harnesses and customisation for stability (Pope, 2007).

The relative passivity of many of the people with PIMD (Bunning, 1998; Vlaskamp, et al., 2003) might, in part, explain the lack of striving and effective action behaviours. Striving behaviours are frequently seen in infants as they reach for objects placed just out of their reach (McKenzie, Skouteris, Day, Hartman, & Yonas, 1993) and effective action is seen when objects are offered that require an infant to plan intentionally to access them, with expectation of effect. However, adults with PIMD may be much less active. Such passivity is likely to be associated with having physical impairments (Pope, 2007), vision impairments (limiting the motivation to reach out to objects) (Bigelow, 2003), learned helplessness (Basil, 1992), or medication side-effects or seizure activity. Alternatively, it may be due to a lack of scaffolding provided by the DSW to encourage the person with PIMD to reach or affect objects/people.

The rarity with which negativity was an eliciting behaviour may have been because the DSWs shaped the interaction to avoid negativity or did not tune into it using affect attunement during the observation. One of the DSWs who participated in the study by Forster (2006) commented on how much she got out of her interaction partner's expressions of negativity, and how it contributed to the person with a disability's personality. She stated that she loved the "big fight at dinner time... because she's so there' it is a time when Daphena says 'I'm still here, and I still know what I bloody well want.'" (Forster, 2006, p. 83). The valuing of negativity expressed by this DSW suggests that expressions of negative emotions do occur in the interactions, and may also be valued by other DSWs, despite its rarity in the current sample.

Although negativity-based affect attunement was rare, not all other eliciting behaviours were of positive valence; in fact more than half were rated as having no categorical affect (such as happiness) about them. The frequent lack of categorical

affect is consistent with findings by Stern (1985) and Stern et al. (1985), and Jonsson and Clinton (2006).

When examined as composites of simultaneous qualities, the following composites, in which the qualities were rated as somewhat (not marked) occurred most frequently: (a) effort and attention; (b) effort, attention, and emotions; (c) effort and emotion; and (d) effort only. The rating of these as somewhat further suggests that the behaviours were subtle, not large exuberant behaviours by the person with PIMD.

Cluster analysis of affect attunement incidents as a means of examining composites of behaviours, as conducted by Jonsson and Clinton (2006), was not possible in the current study due to violation of methodological assumptions (e.g., small sample size, lack of independence of incidents) (Garson, 2010). However, it is possible to explore the similarities and differences between their clusters and the composites found in the current study. Jonsson and Clinton's (2006) most frequently occurring clusters were labelled as pleasurable motoric behaviour, effect initiation, focusing, loss of balance, uncontrolled behaviour, and displeasure. Pleasurable motoric behaviour may be similar to the effort and emotion cluster that was frequent in the current study. Similarly, Jonsson and Clinton's (2006) focusing may be similar to the two most frequent composites involving attention in the current study. However, composites similar to effect initiation, loss of balance, and uncontrolled behaviour were rarely, if ever, seen in these interactions, a finding that could be explained by the rare use of effective action and falling behaviours.

Factors that Influence DSW use of Affect Attunement

The fifth and final research question addressed in this study was: *What is the relationship between the disability support workers' gender, parenting experience, and length of time working with the person and their affect attunement?* The relationship

between the number of incidents used by each dyad and the dyad's demographic qualities was examined to address the research question about the relationship between the DSW's gender, parenting experience, and length of time working with the person and their affect attunement.

There was no evidence of strong relationships between the number of incidents of affect attunement and the gender of the person with PIMD, health status of the person, and communication skill ratings made by the DSWs. A medium relationship was found between the gender of the DSW, with females being rated as showing more frequent incidents of affect attunement, but this finding should be interpreted with caution given the small number of male DSWs in the sample. While Jonsson and Clinton, and Jonsson et al. (2006; 2001) did examine the relationship of infant gender to frequency of affect attunement, they did not examine the differences between mothers and fathers, hence potential caregiver gender influences remain unknown. There was a small positive relationship between parenting experience and frequency of affect attunement, with those people who were grandparents using affect attunement more frequently than those people who were not parents at all. The finding of only a small relationship suggests that although most of the affect attunement research has been conducted in mother-infant settings, parenting status may have only a small influence on its use in general interactions. Medium relationships were found between DSW's length of time working with people with disabilities/time working with the dyad partner and the frequency of affect attunement, with DSWs who had been working with the person with PIMD longer using less affect attunement. This finding is somewhat concerning as it suggests that affect attunement use may decrease over time. On the other hand, such potential decrease over time in working as a DSW may point to other factors, such as workplace dissatisfaction or burn-out for long term staff members.

Medium relationships were also found between the number of incidents and both the DSW rated motor scale and VABS motor scores, with there being more frequent use of affect attunement with people with fewer motor abilities. This relationship may be attributed to DSWs interacting more actively with people who are in a fixed position in their wheelchairs, compared to people who can independently move away or toward interactions. In addition, supporting the inverse relationship of the impact of greater motor skills, there was a small relationship between affect attunement frequency and VABS daily living skills (i.e., affect attunement was used less with people with greater daily living skills). Furthermore, there was a medium relationship between frequency of affect attunement and hearing problems, and a small relationship with epilepsy. Together these findings suggest that the greater degree of impairment (i.e., less motor and daily living skills, and more hearing and epilepsy problems), the more frequent the use of affect attunement by DSWs: however, further direct evidence is needed. The small positive relationship between social and communication age equivalence scores, however, indicates the opposite in terms of greater skills being more strongly related to more frequent affect attunement. It is possible that there may be an interaction effect occurring, such that high social-communication scores alongside low daily living and mobility scores lead to more frequent affect attunement, and vice versa, however, it was not possible to test this hypothesis with the current data.

There were no evident relationships that might explain the absence of affect attunement in five dyads. . However, the absence of affect attunement gives rise to potential explanations. The first explanation relates to some DSWs possibly feeling exceedingly anxious about being video-recorded. This anxiety may have had an impact by reducing the DSW's ability to be receptive to the expressions of the other person, hence reducing affect attunement. Such disruption to being receptive to another person

could be similar to McCluskey's (2005) caregiver stance in goal corrected affect attunement, in which the caregiver is unable to psychologically meet the careseeker until she or he is fully centred and has a settled arousal system. Additionally, the presence of excessive anxiety may have some relationship to Haft and Slade's findings (Haft, 1989; Haft & Slade, 1989) that mothers rated as securely attached (as opposed to insecurely attached) demonstrated more attunement to their infant. The individual personality type, level of anxiety, and attachment status of the DSW may, hence, impact significantly on their interactions.

The second explanation relates to the arousal levels of the person with a disability and the DSW's possible attempts using minimal interaction to maintain the person's arousal level at a low level, avoiding provoking the person to either engage in challenging behaviour or move away from the interaction (Beadle-Brown, Roberts, & Mills, 2009; McDonnell, Reeves, Johnson, & Lane, 1998). This explanation of arousal management seems plausible for Dyads 11, 12, and 18, as the first participant had a history of distressed behaviours and the second and third frequently avoided interaction by moving away from people. Such explanations might have been explored by interviewing the DSWs and exploring their explanations for interactions, however this was not possible within the constraints of this study. Furthermore, challenging behaviour was not examined in this study.

Finally, in four of the five dyads there was a large difference between combined daily living and motor age equivalence scores – all above 13 months, and combined communication and social age equivalence scores - all below 8 months. It is possible that DSWs may use less affect attunement with people with PIMD who appear more able (i.e., able to walk or self-feed), irrespective of these people having significant social-communicative impairments.

Limitations of the Study

A methodological issue in this study was the lack of assessed level of ID, a problem evident across research involving people with PIMD in light of the lack of standardized tools for description of cognitive and communication skills that can be used with this group (Vlaskamp, 2005b). In order to provide detailed description of the participant group for comparison to other research, and assist in interpreting results, it was necessary to find a means of assessing participants' cognitive skills. However, current standardised tests of cognition are not appropriate for people with PIMD because they fail to reach baseline levels (Leyin, 2010) and their physical impairments impede valid estimations of cognitive functioning (Vlaskamp, 2005b). Assessments of adaptive behaviours, while not providing precise cognitive scores derived from performance on tasks, can be used to infer levels of intelligence through behavioural descriptions (Moss & Hogg, 1997).

Given the lack of an assessments appropriate for describing people with PIMD, two were selected, which have been used in intellectual disability research, that allowed for description of early developmental skills: the SIB Early Development Form (Bruininks, et al., 1996) and the VABS (Sparrow, et al., 1984). The VABS had many apparent advantages over the SIB for describing this population. The VABS allowed for more detailed participant description than the SIB Early Development Form. Despite the SIB Early Development Form focusing on early skills, many of the participants in this study reached their ceiling before 10 items, and some participants were unable to score on any of the items at all. Subsequently, the time to conduct this assessment was often quite brief and focused on the lack of skills of the person with PIMD.

In contrast, the interview form of the VABS provided respondents with the opportunity to describe the skills of the person in different domains (e.g., "tell me about

X's communication"). The discourse enabled the respondent to share with the researcher those skills that the person with PIMD was able to demonstrate, which may or may not have matched items within the VABS, as opposed to focusing solely on the person's limited ability. Subsequently, the VABS took up to 20 min to complete, but contributed to development of rapport between the researcher and participating DSW, and signalled greater interest in the person with PIMD. Despite the methodological differences between the VABS and the SIB Early Development Form, a large correlation ($r = .88, n = 21, p < .01$) was found between the age equivalence scores.

A further methodological issue regarding demographic data was accuracy of reporting. DSWs were asked to categorise the person with PIMD's general health, frequency of seizures, hearing, vision, mobility, and communication, in addition to reporting the medications that the person was taking and the purpose of the medication. All of the DSWs reported that they knew the person well, however this could not ensure accurate reporting. The accuracy of the information provided could have been affected by the DSW's knowledge about the person with PIMD. For example, all of the DSWs were able to produce a medication sheet for the supported person, but there was inconsistency in ability to report purpose of medication. Some DSWs reported that they were not expected to know the purpose of medications, whereas others reported detailed knowledge. The discrepancies in knowledge reflect, in part, the different training received by workers in the area of medication. In Tasmania, many DSWs attend a detailed medication administration program, which involves 2 days of workshops, supervised practice, and a 2 hour assessment in which basic knowledge of commonly used medications is required (e.g., State Enterprise Training, 2010). In contrast, Victorian Government DSWs receive 5 hours induction in medication, with little focus on the nature of the medications being administered (Department of Human Services

Victoria, 2010). The difference in the training was reflected in the answers of DSWs about medication functions. Lack of accuracy in reporting the health and skills of the person with PIMD might have impacted on the ability to examine relationships between the use of affect attunement, and the health and skill presentation of the person with a disability.

In addition, in regards to vision and hearing assessments, under-diagnosis of problems by DSWs has been well documented (Evenhuis, et al., 2001; Fellingner, et al., 2009; van den Broek, Janssen, van Ramshorst, & Deen, 2006). Functional vision and hearing statements, such as “able to make eye contact over two metres away,” were used in this study to try to overcome the lack of formal assessments, but the data should still be treated with caution.

Video-recording Observation

In using video-recording, a balance was needed between gaining the best data for the purposes of analysis, and causing the least intrusion so as to avoid disrupting or influencing the interaction. While multiple cameras and split-screen viewing would have optimised the quality of the video-recordings for the purpose of video-analysis of each participant (Resch, 1981), the resulting intrusiveness within the home settings may have disrupted the naturalness of the sample gained. Similarly, the method used by McCluskey (2005) of using a mirror behind one participant in order to be able to view faces of both participants would not have been feasible in the current study in which semi-reclining postures were adopted by participants with PIMD. In McCluskey’s study, participants sat upright and faced each other from a short distance, whereas, in the current study, some people were semi-reclined in wheelchairs or on beds and staff frequently moved in their position, while often being in direct physical contact with the person with PIMD.

Erickson (1992) suggested that when people know that they are being video-recorded and agree to the purpose and trust the researcher, then a video camera should provide no further obtrusion than that of a note pad or audio-recorder. Few participants with PIMD appeared to pay any attention to the camera. Still, the DSWs varied in their observable responses: some appeared to be at ease, while others demonstrated signs that could have been interpreted as indicators of anxiety (e.g., frequently engaging with the researcher or briefly leaving the room to get new objects to engage with), although confirmation of anxiety could not be obtained. Conducting a period of desensitization (spending more time with the dyad and video-recording on an earlier occasion without using that recording for analysis) may have contributed to a more realistic picture of the interaction, but would have added to the demands made on the DSW and person with PIMD.

Reliability of the AABC

Documented difficulties in coding this type of behaviour were borne out in the current study, resulting in a decision to use consensus coding as opposed to the more conventional independent coding. Two factors may have influenced the ability to achieve consistently good levels of reliability: (a) the subtlety of the behaviours, and (b) the new coding system and coding topic. Affect attunement incidents have previously been coded by a only few researchers (Haft & Slade, 1989; Jonsson, et al., 2001; Stern, et al., 1985), and this study represented a first attempt to code incidents in adults with PIMD. Subsequently, the coders may not have been accustomed to recognising the phenomenon in streams of behaviour, hence reducing reliability.

Nevertheless, when considering the independent coding completed prior to consensus coding, the reliability results were encouraging. Twenty of the 32 qualities on

the AABC did reach kappa levels of moderate and above, and a further 5 qualities reached this level when prevalence bias was adjusted.

The difficulties with reliability in the current study may suggest that the task of rating single incidents of affect attunement is too difficult and that there may be greater value in making global judgements of attunement. Several other researchers have taken this approach. McCluskey and colleagues (1997) had participants rate 30s segments of interaction on a 6-point scale for attuned, undecided, or not attuned. Damen (2007) rated lengthy interactions on a 7-point scale from very low affective mutuality to very high affective mutuality. Nevertheless, the value of microanalysis of incidents of affect attunement, as completed in the current study, was precise for the construct described by Stern (1985), particularly given the fleeting nature of incidents. Completing only global ratings may obscure the small incidents of affect attunement that do occur.

Theoretical Implications

Intersubjectivity and, in particular, the construct of affect attunement provides a new way of explaining, exploring, and perhaps understanding the nature of interaction between adults with PIMD and DSWs. Comparisons between mother-infant affect attunement (Haft, 1989; Haft & Slade, 1989; Jonsson & Clinton, 2006; Jonsson, et al., 2001; Stern, 1985; Stern, et al., 1985) and that between adults with PIMD and DSWs in the current study show that there are many striking similarities between the matching of modal and amodal qualities between participants. The observed similarity between the dyads goes some way to support the use of a developmental model when considering adults with PIMD. However, there were also differences that highlight the uniqueness of the communication of the adult with PIMD beyond that of chronological age and the extended time within a so-called developmental age.

It is perhaps not surprising that the adults with PIMD used fewer types of eliciting behaviours and many of these behaviours were very subtle, which may account for the lower frequency of affect attunement in the adult dyad. Adults with PIMD have constraints placed on them that typically developing infants do not. Adults with PIMD may have restricted movement because of both cerebral palsy and wheelchair harnessing (Pope, 2007), and they may have limited capacity to reach or use gestures. In addition, their level of alertness may also be reduced (Arthur, 2003). These, and other factors, may result in the use of fewer behaviours that can elicit attunement from an interaction partner. Therefore, while there is merit in using a developmental model to examine interactions of adults with PIMD, given the demonstrated similarities, there are constraints in skills and abilities that place limitations on the validity of transferring the developmental model to this population. Infant developmental theories, in particular contemporary theories of intersubjectivity, attachment, and emotional developmental (e.g., Fonagy, 2001; Reddy, 2008; Schore, 1994), have much to offer for guiding a theoretical understanding of people with PIMD. These theories, however, must be considered with an understanding of the context (physical and social) and abilities of the person with a disability, essentially building a new theoretical perspective unique to adults with PIMD.

Philosophical Implications

A philosophical implication of the current study is the generation of a new hypothesis to explain DSW interaction with people with PIMD. It is possible that DSWs need to feel connected to the person whom they support with a recognition of the person's inherent humanity. Such a connection may be necessary for validating the relationship. Affect attunement is a means of feeling connected (Stern, 1985; Stern, et al., 1985). For the DSW, in contrast to a mother, an important function of affect

attunement might not be to support development, but as a means of communion or a feeling of connection. It is possible that DSWs use affect attunement to sustain themselves in relationship with another person who has significant communication limitations. This is one of the several ways that they sustain themselves, another being the language that they use about the person, such as the language described by Bogdan and Taylor (1989, 1998) that carers use to define the humanness of the other person, and the need to report that the other person understands because the opposite expression threatens to invalidate the relationship, as described by Forster (2006). This hypothesis requires testing. Methods used by Stern et al. (1985) to investigate why mothers used affect attunement may be adopted in further studies examining interactions between DSWs and people with PIMD, however the tacit knowledge of the DSW may be difficult to put in a transferable form, such as rationalised words (Reinders, 2010).

Research Implications

While a key finding of the current study was the use of affect attunement in interactions between DSWs and adults with PIMD, the importance of its use was not explored. Stern (1985), through his work with mothers and infants, has suggested that interactions including affect attunement are better quality interactions, with positive outcomes for both dyad partners. In the adult context, McCluskey (2005) has examined, in research and clinical practice, the value of goal corrected empathic attunement between caregivers and careseekers. The positive implications of affect attunement for both infants and adults suggests that it may also have important implications for dyads of DSWs and adults with PIMD. Furthermore, should affect attunement be validated as a feature of good quality interactions, the subsequent implications for the quality of life for the person with PIMD could be examined.

The impact of using affect attunement on each person within the dyad would need to be examined, as positive outcomes for a DSW may not necessarily be assumed to equate with those outcomes for the person with PIMD, and vice versa. This is particularly an issue if it is a pseudo-affect attunement, in which the person with PIMD does not perceive the attunement at all. If the person with PIMD was not perceiving the corresponding behaviour, then the socio-emotional benefits hypothesized by Stern and others (Haft, 1989; Haft & Slade, 1989; Siegel, 1996; Stern, 1985; Stern, et al., 1985) could not be suggested to occur for adults with PIMD. However, the impact on the DSW who engages in the pseudo-affect attunement may still be significant. At this early stage it may be hypothesized that pseudo-affect attunement is, indeed, important for sustaining interactions with people with PIMD from the perspective of the DSW. Pseudo-affect attunement may give a sense to the DSW that there is communion between him/her and the person with PIMD, irrespective that the interaction may be mediated by the DSW tuning into the expression of the person with PIMD, rather than it being a reciprocated interaction. Benefits for staff in regards to emotions, morale and well-being, a construct that has usually only been examined in its negative valence in the context of distress and burnout (Hatton, et al., 2004), may provide an avenue for further exploration of interaction satisfaction. Replicating the strategy used by Stern and colleagues (Stern, 1985; Stern, et al., 1985) of asking mothers what they thought the function of using affect attunement was may be a way of exploring the function of affect attunement for DSWs in the context of their paid interactions with people with PIMD, and move some way towards understanding why some DSWs use it and some do not. Furthermore, exploring the attachment style and personality of DSWs, an area which has received scant attention in research (Willems, Embregts, Stams, & Moonen,

2010), may be an important consideration for future research on the use or lack of use of affect attunement.

In order to examine if/which people with PIMD perceive the attunement of their interaction partners, perturbation studies, as conducted by Stern and colleagues (Stern, 1985; Stern, et al., 1985), could be replicated with adults with PIMD. However, comparison of behaviours in contexts of attunement and misattunement may be more difficult if the person is demonstrating few or more inconsistent eliciting behaviours.

If affect attunement is seen to be a valued characteristic of interactions between DSWs and people with PIMD, researching the means for enhancing the use of it is warranted. In the current study, the construct was explained to participating DSWs immediately following video-recording. Several DSWs stated that they had never considered this as a way of communicating (i.e., recasting back to the person what they had already done), but could see how it might be a valuable way of being together. Perhaps, just bringing the concept to DSWs and stating it as a valid way of being together may be the first step towards enhancing its use in everyday practice. Conversely, more structured learning opportunities, such as those used by McCluskey (2005) may need to be developed to teach people how to observe and enhance the use of affect attunement.

Clinical Implications

Several clinical implications arise from the current study, with the finding that affect attunement does exist as a naturally occurring behaviour in dyads of DSWs and people with PIMD, and that it may be a valuable component of communication. Understanding affect attunement, its potential benefits, and developing an ability to see incidents of affect attunement may be a valuable new skill for clinicians who support adults with PIMD and their DSWs. One way of teaching clinicians about affect

attunement could be through sharing the AABC with them. However, given the time and expertise required to use it, clinicians may not be able to implement it in clinical assessment.

Nevertheless, learning about the theory of affect attunement and providing evidence that many DSWs do use it naturally may be of use in clinical practice. The results of the current study suggest that there is value in clinicians incorporating the construct into the observations of interaction. Incorporating affect into practice may involve a focus on looking for moments of affect attunement, or in simpler terms, moments in which the DSW is recasting the feelings of the person with PIMD. These moments could be highlighted as good practice, providing positive feedback to DSWs using affect attunement. Additionally, clinicians highlighting the value of this seemingly simple behaviour could serve to validate it in the minds of the DSW: that is, letting DSWs know that reflecting back the behaviour of the person with PIMD is a valid way of being with them, and indeed, that just spending time with a person is an important part of their role could have a positive influence on the interaction.

Intersubjectivity and the construct of affect attunement may also have implications for how engagement is conceptualised and how it is used by practitioners in their own direct work with people with PIMD. Reddy (2008), in the context of working with parents and infants, referred to the need for practitioners to use a second-person approach to understanding people, as opposed to a first- or third-person approach. A first-person understanding occurs when one person claims to know the mind of another through reference to his/her own mind. A third-person understanding comes from watching and judging meaning of the behaviours of another person from a distance. In contrast, a second-person understanding, according to Reddy, arises through engagement with another person, which then gives rise to relational understanding.

Although in the current study, a largely third-person approach has been used to describe the affect attunement of other people, it is suggested that the construct lends itself well to being used in a second-person approach. A second-person approach would require practitioners to engage in using affect attunement with clients with PIMD in order to better understand the person.

The construct of affect attunement and its presence in interactions between DSWs and people with PIMD may also have implications for currently used interventions. Stern's (1985) definition, as opposed to a general definition of tuning in or attuning, may be particularly useful. Several relational interventions incorporate a general construct of attunement to support interaction between people with disabilities and interaction partners. For example, Intensive Interaction (Hewett & Nind, 1998; Nind & Hewett, 1994, 2001, 2005) incorporates attunement as a general theme, focusing on the use of imitation of the behaviours of the person with a disability (Nind & Hewett, 1994, 2005). In addition, there are the video-feedback based interventions in which explicit reference to attunement has been made, but as a global phenomenon, rather than as isolated incidents of affect attunement. Such interventions include: (a) CONTACT and its modifications by the International Communication and Congenital Deafblindness Group (Janssen, Riksen-Walraven, van Dijk, & Ruijsenaars, 2010; Janssen & Rødbroe, 2007; Janssen, Riksen-Walraven, & Van Dijk, 2003b; Rødbroe & Janssen, 2006), which have been used largely with deaf-blind children; (b) Video Interaction Guidance (Kennedy & Sked, 2008), which has been used occasionally with people with disabilities but more widely in family interactions; and (c) Marte Meo (Aarts, 2008a, 2008b), which has been used with parents their children with disabilities. On the basis of the results of the current study, it is suggested that each of these interventions may be improved by examining affect attunement both from global and

specific incident perspectives, in which specific incidents of registering and recasting affect can be highlighted in videos. Such a focus in Intensive Interaction may be particularly useful if there are concerns that behaviours are being imitated only in the absence of responses that include an affective emphasis, needed to strengthen an emotional connection with a person (O'Neill, Jones, & Zeedyk, 2008).

A final clinical implication of affect attunement and, in particular, the findings regarding the frequent use of vitality affects as opposed to categorical affects, is the need for practitioners to look beyond categorical affects in interventions. A shift away from a simple agency focus on only expressions of like and dislike or want and don't want could be beneficial for two reasons. Firstly, by examining or attending to only like and dislike, an interaction around vitality affects is missed (e.g., interactions of striving, attending, or withering in energy). Secondly, in the like/dislike context, often there is a focus only on the like expression. If Stern's perspective that affect attunement is a way of validating and demonstrating that all expressions are shareable is accepted, then it may be argued that failing to tune into dislike expressions fails to show the person that those expressions are shareable and received. A narrow agency perspective severely limits the possibility and celebration of the intersubjectivity that can occur between an adult with PIMD and their DSW.

Conclusions

Affect attunement has been examined in mother-infant dyads for many years, and it has been suggested to be an indicator of the quality of interaction between two people. However, to date, the specific construct had not been examined in interactions between DSWs and people with PIMD.

In the current study, it was found that many of the DSWs did use affect attunement. This presence of affect attunement provides a new way of examining the

interaction between adults with PIMD and their DSWs focusing on a pre-existing skill, albeit probably a tacit skill.

The incidents seen in this study usually lasted less than 3 s and involved behaviours that were not markedly intense, hence were often subtle. The eliciting behaviour of the adult with PIMD usually involved some degree of motor effort and attention. Sometimes behaviours had a categorical affect (e.g., smile/pleasure), however, affects of vitality were more common. Many of the eliciting behaviours could be described as rather unremarkable motor actions (voluntary and involuntary). Focusing on the importance of these very subtle interactions provides a contrast to previous research on interactions focusing on the complexity of DSW speech or the use of objects in communication. In addition, the current research departs from a focus on inadequacy of DSW communication skills, instead focusing on skill or even a natural attitude that many of them do use in natural, untrained interactions.

Implications for clinical practice and research include a need to establish whether interactions containing affect attunement are, in fact, of better quality. If affect attunement is found to be part of improved quality of interactions, then the next necessary step is to investigate whether the frequency of use of affect attunement can be increased or taught in those DSWs not seeming to use it. The study provides a new way of examining interactions between DSWs and adults with PIMD with a focus on intersubjectivity that exists within the dyad. The study demonstrates a way that two people can share through very subtle interactions regardless of the level of communication impairment.

REFERENCES

- Aarts, M. (2008a). *Marte Meo: Basic manual* (S. Gogol & C. O'Donovan, Trans. 2nd ed.). Eindhoven, The Netherlands: Aarts Productions.
- Aarts, M. (2008b). *Marte Meo: Developmental support for children and adults with disabilities using Marte Meo* [4 DVD set]. Sydney, Australia: Department of Ageing, Disability & Home Care of the New South Wales Government.
- Abbeduto, L., Warren, S. F., & Conners, F. A. (2007). Language development in Down syndrome: From the prelinguistic period to the acquisition of literacy. *Mental Retardation and Developmental Disabilities Research Reviews*, *13*, 247-261. doi: 10.1002/mrdd.20158
- ACT Health, & Disability ACT. (2004). *The disability workforce*. Canberra, Australia: Retrieved from www.dhcs.act.gov.au/pubs/documents/Disability%20Workforce%20report_Final5.rtf.
- Adamson, L. B. (1996). *Communication development during infancy*. Boulder, CO: Westview Press.
- Advocacy Incorporated. (1997). Advocacy Incorporated handout materials, CS1 - legally adequate consent, from <http://www.advocacyinc.org/CS1.cfm>
- Ainsworth, M. D. S., Bell, S. M., & Stayton, D. J. (1978). *Patterns of attachment: A psychological study of the Strange Situation*. Hillsdale, NJ: Erlbaum.
- Arthur-Kelly, M., Bochner, S., Center, Y., & Mok, M. (2007). Socio-communicative perspectives on research and evidence-based practice in the education of students with profound and multiple disabilities. *Journal of Developmental and Physical Disabilities*, *19*, 161-176. doi: 10.1007/s10882-007-9045-9
- Arthur-Kelly, M., Foreman, P., Bennett, D., & Pascoe, S. (2008). Interaction, inclusion and students with profound and multiple disabilities: Towards an agenda for research and practice. *Journal of Research in Special Educational Needs*, *8*, 161-166. doi: 10.1111/j.1471-3802.2008.00114.x
- Arthur, M. (2003). Socio-communicative variables and behavior states in students with profound and multiple disabilities: Descriptive data from school settings. *Education and Training in Developmental Disabilities*, *38*, 200-219.
- Arthur, M. (2004). Patterns amongst behavior states, sociocommunicative, and activity variables in educational programs for students with profound and multiple

- disabilities. *Journal of Developmental and Physical Disabilities*, 16, 125-149.
doi: 10.1023/B:JODD.0000026611.24306.92
- Arvio, M., & Sillanpaa, M. (2003). Prevalence, aetiology and comorbidity of severe and profound intellectual disability in Finland. *Journal of Intellectual Disability Research*, 47, 108-112. doi: 10.1046/j.1365-2788.2003.00447.x
- Bakeman, R., & Gottman, J. M. (1997). *Observing interaction: An introduction to sequential analysis* (2nd ed.). Cambridge, England: Cambridge University Press.
- Bandura, A. (2001). Social cognitive theory: An agentic perspective. *Annual Review of Psychology*, 52, 1-26. doi: 10.1146/annurev.psych.52.1.1
- Barber, M. (2001). Affective Communication Assessment: An owners manual. *PMLD Link, Spring*.
- Barber, M. (2008). Using Intensive Interaction to add to the palette of interactive possibilities in teacher-pupil communication. *European Journal of Special Needs Education*, 23, 393 - 402. doi: 10.1080/08856250802387380
- Basil, C. (1992). Social interaction and learned helplessness in severely disabled children. *Augmentative and Alternative Communication*, 8, 188-199. doi: 10.1080/07434619212331276183
- Bates, E. (Ed.). (1979). *The emergence of symbols: Cognition and communication in infancy*. New York, NY: Academic Press.
- Bates, E., Camaioni, L., & Volterra, V. (1975). The acquisition of performatives prior to speech. *Merrill-Palmer Quarterly*, 21, 205-226.
- Beadle-Brown, J., Roberts, R., & Mills, R. (2009). Person-centred approaches to supporting children and adults with autism spectrum disorders. *Tizard Learning Disability Review*, 14, 18-26.
- Bedrosian, J. L., & Calculator, S. N. (1988). A misunderstood population. In S. N. Calculator & J. L. Bedrosian (Eds.), *Communication assessment and intervention for adults with mental retardation* (pp. 1-6). Boston, MA: College-Hill.
- Beebe, B., Knoblauch, S., Rustin, J., & Sorter, D. (2005a). Forms of intersubjectivity in infant research and adult treatment: A systems view. In B. Beebe, S. Knoblauch, J. Rustin & D. Sorter (Eds.), *Forms of intersubjectivity in infant research and adult treatment* (pp. 1-28). New York, NY: Other Press.

- Beebe, B., Knoblauch, S., Rustin, J., & Sorter, D. (2005b). Introduction. In B. Beebe, S. Knoblauch, J. Rustin & D. Sorter (Eds.), *Forms of intersubjectivity in infant research and adult treatment* (pp. xvi-xxviii). New York, NY: Other Press.
- Beebe, B., Rustin, J., Sorter, D., & Knoblauch, S. (2005). An expanded view of forms of intersubjectivity in infancy and their application to psychoanalysis. In B. Beebe, S. Knoblauch, J. Rustin & D. Sorter (Eds.), *Forms of intersubjectivity in infant research and adult treatment* (pp. 57-86). New York, NY: Other Press.
- Beebe, B., Sorter, D., Rustin, J., & Knoblauch, S. (2005). Forms of intersubjectivity in infant research: A comparison of Meltzoff, Trevarthen, and Stern. In B. Beebe, S. Knoblauch, J. Rustin & D. Sorter (Eds.), *Forms of intersubjectivity in infant research and adult treatment* (pp. 29-53). New York, NY: Other Press.
- Bigelow, A. (2003). The development of joint attention in blind infants. *Development and Psychopathology, 15*, 259-275. doi: 10.1017/S0954579403000142
- Bloomberg, K., West, D., & Iacono, T. A. (2003). PICTURE IT: An evaluation of a training program for carers of adults with severe and multiple disabilities. *Journal of Intellectual & Developmental Disability, 28*, 260-282. doi: 10.1080/1366825031000150964
- Bloomberg, K., West, D., & Johnson, H. (2004). *InterAAction: Strategies for intentional and unintentional communicators*. Box Hill, Australia: Communication Resource Centre.
- Bloomberg, K., West, D., Johnson, H., & Iacono, T. (2009). *Triple C: Checklist of Communication Competencies (Revised edition)*. Box Hill, Australia: Scope.
- Bogdan, R., & Taylor, S. J. (1989). Relationships with severely disabled people: The social construction of humanness. *Social Problems, 36*, 135-148. doi: 10.1525/sp.1989.36.2.03a00030
- Bogdan, R., & Taylor, S. J. (1998). The social construction of humanness: Relationships with people with severe retardation. In R. Bogdan & S. J. Taylor (Eds.), *Introduction to qualitative research methods: A guidebook and resource* (3rd ed., pp. 242-258). New York, NY: John Wiley & Sons.
- Boxall, K., & Ralph, S. (2009). Research ethics and the use of visual images in research with people with intellectual disability. *Journal of Intellectual & Developmental Disability, 34*, 45-54. doi: 10.1080/13668250802688306

- Bradshaw, J. (2001). Complexity of staff communication and reported level of understanding skills in adults with intellectual disability. *Journal of Intellectual Disability Research, 45*, 233-243. doi: 10.1046/j.1365-2788.2001.00318.x
- Brock, J. (2007). Language abilities in Williams syndrome: A critical review. *Development and Psychopathology, 19*, 97-127. doi: 10.1017/s095457940707006x
- Brodin, J. (2005). Diversity of aspects on play in children with profound multiple disabilities. *Early Child Development and Care, 175*, 635-646. doi: 10.1080/0300443042000266222
- Bruininks, R., Woodcock, R., Weatherman, R., & Hill, B. (1996). *SIB-R: Scales of Independent Behavior-revised*. Allen, TX: Riverside Publishing.
- Bruner, J. (1978). On prelinguistic prerequisites of speech. In R. N. Campbell & P. T. Smith (Eds.), *Recent advances in the psychology of language: Language development and mother-child interaction* (Vol. 4a, pp. 199-214). New York, NY: Plenum.
- Bunning, K. (1998). To engage or not to engage? Affecting the interactions of learning disabled adults. *International Journal of Language and Communication Disorders, 33*, 386-391. doi: 10.3109/13682829809179456
- Burford, B. (1988). Action cycles: Rhythmic actions for engagement with children and young adults with profound mental handicap. *European Journal of Special Needs Education, 3*, 189-206. doi: 10.1080/0885625880030402
- Byrt, T., Bishop, J., & Carlin, J. B. (1993). Bias, prevalence and kappa. *Journal of Clinical Epidemiology, 46*, 423-429. doi: 10.1016/0895-4356(93)90018-V
- Calculator, S. N. (1988). Exploring the language of adults with mental retardation. In S. N. Calculator & J. L. Bedrosian (Eds.), *Communication assessment and intervention for adults with mental retardation* (pp. 95-106). Boston, MA: College-Hill.
- Caldwell, P. (2006). Speaking the other's language: Imitation as a gateway to relationship. *Infant and Child Development, 15*, 275-282. doi: 10.1002/icd.456
- Campo, S. F., Sharpton, W. R., Thompson, B., & Sexton, D. (1997). Correlates of the quality of life of adults with severe or profound mental retardation. *Mental Retardation, 35*, 329-337. doi: 10.1352/0047-6765(1997)035<0329:COTQOL>2.0.CO;2

- Cannella, H. I., O'Reilly, M. F., & Lancioni, G. E. (2005). Choice and preference assessment research with people with severe to profound developmental disabilities: A review of the literature. *Research in Developmental Disabilities, 26*, 1-15. doi: 10.1016/j.ridd.2004.01.006
- Carnaby, S. (2004). People with profound and multiple learning disabilities: A review of research about their lives. London, England: Mencap.
- Carnaby, S., & Pawlyn, J. (2009). Profound intellectual and multiple disabilities: Meeting complex needs through complex means. In J. Pawlyn & S. Carnaby (Eds.), *Profound intellectual and multiple disabilities: Nursing complex needs* (pp. 348-353). Chichester, England: Wiley & Sons.
- Carter, M., & Iacono, T. (2002). Professional judgements of the intentionality of communicative acts. *Augmentative and Alternative Communication, 18*, 177-191. doi: 10.1080/07434610212331281261
- Cascella, P. W. (2004). Receptive communication abilities among adults with significant intellectual disability. *Journal of Intellectual & Developmental Disability, 29*, 70 - 78. doi: 10.1080/13668250410001662847
- Cicchetti, D., & Sparrow, S. (1981). Developing criteria for establishing inter-rater reliability of specific items in a given inventory. *American Journal of Mental Deficiency, 86*, 127-137.
- Cirrin, F. M., & Rowland, C. M. (1985). Communicative assessment of nonverbal youths with severe/profound mental retardation. *Mental Retardation, 23*, 52-62.
- Cissna, K. N., Garvin, B. J., & Kennedy, C. W. (1990). Reliability in coding social interaction: A study of confirmation. *Communication Reports, 3*, 58-69.
- Clegg, J. A., Standen, P. J., & Cromby, J. J. (1991a). The analysis of talk sessions between staff and adults with profound intellectual disability. *Australia and New Zealand Journal of Developmental Disabilities, 17*, 391-400.
- Clegg, J. A., Standen, P. J., & Cromby, J. J. (1991b). Interactions between adults with profound intellectual disability and staff. *Australia and New Zealand Journal of Developmental Disabilities, 17*, 377-389.
- Cooper, S.-A., Smiley, E., Finlayson, J., Jackson, A., Allan, L., Williamson, A., . . . Morrison, J. (2007). The prevalence, incidence, and factors predictive of mental ill-health in adults with profound intellectual disabilities. *Journal of Applied*

Research in Intellectual Disabilities, 20, 493-501. doi: 10.1111/j.1468-3148.2007.00401.x

- Cordes, A. K. (1994). The reliability of observational data: I. Theories and methods for Speech-Language Pathology. *Journal of Speech and Hearing Research*, 37, 264-278.
- Coupe O'Kane, J., & Goldbart, J. (1998). *Communication before speech: Development and assessment* (2nd ed.). London, England: David Fulton.
- Cummins, R. A. (2005). Issues in the systematic assessment of quality of life. In J. Hogg & A. Langa (Eds.), *Assessing adults with intellectual disabilities: A service provider's guide* (pp. 9-22). Malden, MA: Blackwell.
- Damen, S. (2007). "I feel what you mean!" *Affective attunement and tactile meaning negotiation in obtaining shared meaning*. MSc in Education (Communication and Congenital Deafblindness) Masters, University of Groningen, Groningen, Netherlands.
- Damen, S., Kef, S., Worm, C., Schuengel, C., & Janssen, M. J. (2008). The effect of CONTACT on the quality of interaction between persons with visual & intellectual disabilities & their caregivers. *Journal of Intellectual Disability Research*, 52, 771.
- Davis, P., Young, A., Cherry, H., Dahman, D., & Rehfeldt, R. (2004). Increasing the happiness of individuals with profound multiple disabilities: Replication and extension. *Journal of Applied Behavior Analysis*, 37, 531. doi: 10.1901/jaba.2004.37-531
- Dawkins, B. (2009). Valuing Tom: Will Valuing People Now change the lives of people with profound and multiple learning disabilities? *Tizard Learning Disability Review*, 14, 3-12.
- Dearn, L. (2010). Too much guardianship? Reflections on guardianship in Victoria 1988-2008. Melbourne, Australia.
- Dennis, R. (2002). Nonverbal narratives: Listening to people with severe intellectual disability. *Research and Practice for Persons with Severe Disabilities*, 27, 239-249. doi: 10.2511/rpsd.27.4.239
- Department of Health and Human Services, Disability Services, & Tasmania's Disability Advocacy Services. (2007). *The role of advocacy services in the*

Tasmanian disability sector. Hobart, Australia: Disability Services, Human Services Group.

Department of Human Services Victoria. (2010). Induction Retrieved 6th October, 2010, from

http://www.dhs.vic.gov.au/disability/improving_supports/learning_and_development/workforce_development_and_learning/certificate-iv-in-disability-for-disability-accommodation-staff-das/induction

Dillon, C. M., & Carr, J. E. (2007). Assessing indices of happiness and unhappiness in individuals with developmental disabilities: A review. *Behavioral Interventions*, 22, 229-244. doi: 10.1002/bin.240

Disability ACT. (2007). *A disability workforce strategy for the ACT disability sector*. Retrieved from

http://www.dhcs.act.gov.au/DisabilityACT/Publications/Executive_Summary_Disability_Workforce_Strategy.doc.

Dobson, S., Upadhyaya, S., Conyers, I., & Raghavan, R. (2002). Touch in the care of people with profound and complex needs: A review of the literature. *Journal of Intellectual Disabilities*, 6, 351-362. doi: 10.1177/146900470200600402

Dobson, S., Upadhyaya, S., & Stanley, D. (2002). Using an interdisciplinary approach to training to develop the quality of communication with adults with profound learning disabilities by care staff. *International Journal of Language and Communication Disorders*, 37, 41-57. doi: 10.1080/13682820110089362

Dollaghan, C., & Miller, J. (1986). Observational methods in the study of communicative competence. In R. L. Schiefelbusch (Ed.), *Language competence: Assessment and intervention*. San Diego, CA: College-Hill Press.

Dolnicar, S. (2002). A review of unquestioned standards in using cluster analysis for data-driven market segmentation. *Faculty of Commerce - Papers, Univeristy of Wollongong*. Retrieved from <http://ro.uow.edu.au/commpapers/273>

Duker, P. C., Boonekamp, J., ten Brummelhuis, Y., Hendrix, Y., Hermans, M., van Leeuwe, J., & Seys, D. (1989). Analysis of ward staff initiatives towards mentally retarded residents: Clues for intervention. *Journal of Mental Deficiency Research*, 33, 55-67.

- Dunst, C. J. (1978). A cognitive-social approach for assessment of early nonverbal communicative behavioral. *Communication Disorders Quarterly*, 2, 110-123. doi: 10.1177/152574017800200206
- Dunst, C. J., & Lowe, L. W. (1988). From reflex to symbol: Describing, explaining, and fostering communicative competence. *Augmentative and Alternative Communication*, 2, 11-18. doi: 10.1080/07434618612331273820
- Elgie, S., & Maguire, N. (2001). Intensive Interaction with a woman with multiple and profound disabilities: A case study. *Tizard Learning Disability Review*, 6, 18-24.
- Emerson, E. (2009a). Estimating future numbers of adults with profound multiple learning disabilities in England. *Tizard Learning Disability Review*, 14, 49-55.
- Emerson, E. (2009b). Estimating future numbers of adults with profound multiple learning disabilities in England. Lancaster, England: Centre for Disability Research (CeDR), Lancaster University.
- Erickson, F. (1992). Ethnographic microanalysis of interaction. In M. D. LeCompte, W. L. Millroy & J. Preissle (Eds.), *The handbook of qualitative research in education* (pp. 201-225). San Diego, CA: Academic Press.
- Espie, C. A., Paul, A., McFie, J., Amos, P., Hamilton, D., McColl, J. H., . . . Pardey, J. (1998). Sleep studies of adults with severe or profound mental retardation and epilepsy. *American Journal of Mental Retardation*, 103, 47-59. doi: 10.1352/0895-8017(1998)103<0047:SSOAWS>2.0.CO;2
- Evenhuis, H. M., Theunissen, M., Denkers, I., Verschuure, H., & Kemme, H. (2001). Prevalence of visual and hearing impairment in a Dutch institutionalized population with intellectual disability. *Journal of Intellectual Disability Research*, 45, 457-464. doi: 10.1046/j.1365-2788.2001.00350.x
- Transana (Version 2.20-Win). Wisconsin: Wisconsin Centre for Education Research. Retrieved from <http://www.transana.org/>
- Favell, J. E., Realon, R. E., & Sutton, K. A. (1996). Measuring and increasing the happiness of people with profound mental retardation and physical handicaps. *Behavioral Interventions*, 11, 47-58. doi: 10.1002/(SICI)1099-078X(199601)11:1<47::AID-BRT146>3.0.CO;2-P
- Felce, D., & Perry, J. (1995a). The extent of support for ordinary living provided in staffed housing: The relationship between staffing levels, resident

- characteristics, staff: resident interactions and resident activity patterns. *Social Science and Medicine*, 40, 799-810. doi: 10.1016/0277-9536(94)00152-J
- Felce, D., & Perry, J. (1995b). Quality of life: Its definition and measurement. *Research in Developmental Disabilities*, 16, 51-74. doi: 10.1016/0891-4222(94)00028-8
- Felce, D., & Repp, A. (1992). The behavioral and social ecology of community houses. *Research in Developmental Disabilities*, 13, 27-42. doi: 10.1016/0891-4222(92)90038-8
- Feldman, R., & Greenbaum, C. W. (1997). Affect regulation and synchrony in mother-infant play as precursors to the development of symbolic competence. *Infant Mental Health Journal*, 18, 4-23. doi: 10.1002/(SICI)1097-0355(199721)18:1<4::AID-IMHJ2>3.0.CO;2-R
- Fellinger, J., Holzinger, D., Dirmhirn, A., Dijk, J. v., & Goldberg, D. (2009). Failure to detect deaf-blindness in a population of people with intellectual disability. *Journal of Intellectual Disability Research*, 53, 874-881. doi: 10.1111/j.1365-2788.2009.01205.x
- Field, A. (2000). Postgraduate statistics: Cluster analysis Retrieved from <http://www.statisticshell.com/cluster.pdf>
- Firth, G. (2009). A dual aspect process model of Intensive Interaction. *British Journal of Learning Disabilities*, 37, 43-49. doi: 10.1111/j.1468-3156.2008.00505.x
- Firth, G., Elford, H., Leeming, C., & Crabbe, M. (2008). Intensive Interaction as a novel approach in social care: Care staff's views on the practice change process. *Journal of Applied Research in Intellectual Disabilities*, 21, 58-69. doi: 10.1111/j.1468-3148.2007.00369.x
- Fonagy, P. (2001). *Attachment theory and psychoanalysis*. New York, NY: Other Press.
- Foreman, P., Arthur-Kelly, M., & Pascoe, S. (2007). The impact of partner training on the communicative involvement of students with multiple and severe disability in special schools. *Journal of Intellectual & Developmental Disability*, 32, 233 - 247. doi: 10.1080/13668250701654417
- Fornefeld, B. (2008). *Individuals with PIMD as the forgotten fellow citizens*. Paper presented at the 13th IASSID World Congress, Cape Town, South Africa.
- Forster, S. L. (2006). *Communicative interactions between adults with profound intellectual disability and support workers: Part I*. Thesis Masters of Biomedical Science: Part 1, Monash University, Oakleigh, Australia.

- Forster, S. L., & Iacono, T. (2008). Disability support workers' experience of interaction with a person with profound intellectual disability. *Journal of Intellectual & Developmental Disability, 33*, 137-147. doi: 10.1080/13668250802094216
- Forster, S. L., & Taylor, M. (2006). Using Intensive Interaction: A case study. *ACQ, 8*, 12-15.
- Garson, G. D. (2010). Cluster analysis: Statnotes, from North Carolina State University Retrieved 4 June, 2010, from <http://faculty.chass.ncsu.edu/garson/PA765/cluster.htm>
- George, C., Kaplan, N., & Main, M. (1985). *The Adult Attachment Interview*. Unpublished manuscript, University of California, Berkeley, CA.
- Gittins, D., & Rose, N. (2008). An audit of adults with profound and multiple learning disabilities within a West Midlands Community Health Trust - implications for service development. *British Journal of Learning Disabilities, 36*, 38-47. doi: 10.1111/j.1468-3156.2007.00480.x
- Granlund, M. (1993). *Communicative competence in persons with profound mental retardation: Intervention focused on the social context*. Uppsala, Sweden: Uppsala University.
- Granlund, M., Björck-Åkesson, E., Brodin, J., & Olsson, C. (1995). Communication intervention for persons with profound disabilities: A Swedish perspective. *Augmentative and Alternative Communication, 11*, 49-59. doi: 10.1080/07434619512331277139
- Granlund, M., & Olsson, C. (1999). Efficacy of communication intervention for presymbolic communicators. *Augmentative and Alternative Communication, 15*, 25-37. doi: 10.1080/07434619912331278545
- Granlund, M., Terneby, J., & Olsson, C. (1992a). Creating communicative opportunities through a combined in-service training and supervision package. *European Journal of Special Needs Education, 7*, 229-252. doi: 10.1080/0885625920070304
- Granlund, M., Terneby, J., & Olsson, C. (1992b). Subject characteristics and the communicative environment of profoundly retarded adults. *Scandinavian Journal of Educational Research, 36*, 323-338. doi: 10.1080/0031383920360407
- Green, C. W., Gardner, S. M., Canipe, V. S., & Reid, D. H. (1994). Analyzing alertness among people with profound multiple disabilities: Implications for provision of

- training. *Journal of Applied Behavior Analysis*, 27, 519-531. doi: 10.1901/jaba.1994.27-519
- Green, M., & Cobb, L. (1991). Theories of communication development. In L. Sternberg (Ed.), *Functional communication: Analyzing the nonlinguistic skills of individuals with severe or profound handicaps* (pp. 1-17). New York, NY: Springer-Verlag.
- Grove, N., Bunning, K., Porter, J., & Morgan, M. (2000). *See What I Mean: Guidelines to aid understanding of communication by people with profound learning disabilities*. Kidderminster, England: BILD.
- Grove, N., Bunning, K., Porter, J., & Olsson, C. (1999). See what I mean: Interpreting the meaning of communication by people with severe and profound intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 12, 190-203. doi: 10.1111/j.1468-3148.1999.tb00076.x
- Guess, D., Mulligan-Ault, M., Roberts, S., Struth, J., Siegel-Causey, E., Thompson, B., . . . Guy, B. (1988). Implications of biobehavioral states for the education and treatment of students with the most profoundly handicapping conditions. *Journal of the Association for Persons with Severe Handicaps*, 13, 163-174.
- Guess, D., Roberts, S., Siegel-Causey, E., Ault, M., Guy, B., Thompson, B., & Rues, J. (1993). Analysis of behavior state conditions and associated environmental variables among students with profound handicaps. *American Journal of Mental Retardation*, 97, 634-653.
- Guess, D., Roberts, S., Siegel-Causey, E., & Rues, J. (1995). Replication and extended analysis of behavior state, environmental events, and related variables among individuals with profound disabilities. *American Journal of Mental Retardation*, 100, 36-51.
- Guess, D., & Siegel-Causey, D. (1995). Attractor dimensions of behavior state changes among individuals with profound disabilities. *American Journal on Mental Retardation*, 99, 642-663.
- Guy, B., Guess, D., & Mulligan, M. (1993). Classroom procedures for the measurement of behaviour state among students with profound disabilities. *Journal of the Association for Persons with Severe Handicaps*, 18, 52-60.

- Haft, W. L. (1989). *Affect attunement and maternal attachment: An observational study of the intergenerational transmission of mothers' internal representations of attachment*. Ph.D. thesis, City University of New York.
- Haft, W. L., & Slade, A. (1989). Affect attunement and maternal attachment: A pilot study. *Infant Mental Health Journal*, *10*, 157-172. doi: 10.1002/1097-0355(198923)10:3<157::AID-IMHJ2280100304>3.0.CO;2-3
- Häggeström, T., Jansson, L., & Norberg, A. (1998). Skilled carers' ways of understanding people with Alzheimer's disease. *Scholarly Inquiry for Nursing Practice*, *12*, 239.
- Haney, J. I., Wilson, J. W., & Halle, J. (1988). Adults with mental retardation: Who they are, where they are, and how their communicative needs can be met. In S. N. Calculator & J. L. Bedrosian (Eds.), *Communication assessment and intervention for adults with mental retardation* (pp. 69-94). Boston, MA: College-Hill.
- Hatton, C. (2004). Choice. In E. Emerson, C. Hatton, T. Thompson & T. Parmenter (Eds.), *International handbook of research in intellectual disabilities* (pp. 335-351). Chichester, England: Wiley.
- Hatton, C., Rose, J., & Rose, D. (2004). Researching staff. In E. Emerson, C. Hatton, T. Thompson & T. Parmenter (Eds.), *International handbook of research in intellectual disabilities* (pp. 581-605). Chichester, England: Wiley.
- Healy, D., & Walsh, P. N. (2007). Communication among nurses and adults with severe and profound intellectual disabilities: Predicted and observed strategies. *Journal of Intellectual Disabilities*, *11*, 127-141. doi: 10.1177/1744629507076927
- Hewett, D., & Nind, M. (Eds.). (1998). *Interaction in action: Reflections on the use of Intensive Interaction*. London, England: David Fulton.
- Hiemstra, S. J., Vlaskamp, C., & Wiersma, L. A. (2007). Individual focus in an activity centre: An observational study among persons with profound and multiple disabilities. *Education and Training in Developmental Disabilities*, *42*, 14-23.
- Hogg, J. (2007). Complex needs and complex solutions: The challenge of profound intellectual and multiple disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, *4*, 79-82. doi: 10.1111/j.1741-1130.2007.00103.x
- Hogg, J., Cavet, J., Lambe, L., & Smeddle, M. (2001). The use of 'Snoezelen' as multisensory stimulation with people with intellectual disabilities: A review of

- the research. *Research in Developmental Disabilities*, 22, 353-372. doi: 10.1016/S0891-4222(01)00077-4
- Hogg, J., Juhlberg, K., & Lambe, L. (2007). Policy, service pathways and mortality: A 10-year longitudinal study of people with profound intellectual and multiple disabilities. *Journal of Intellectual Disability Research*, 51, 366-376. doi: 10.1111/j.1365-2788.2006.00884.x
- Hogg, J., Reeves, D., Roberts, J., & Mudford, O. C. (2001). Consistency, context and confidence in judgements of affective communication in adults with profound intellectual and multiple disabilities. *Journal of Intellectual Disability Research*, 45, 18-29. doi: 10.1046/j.1365-2788.2001.00289.x
- Hogg, J., & Sebba, J. (1986). *Profound retardation and multiple impairment: Development and learning* (Vol. 1). Beckenham, Kent, England: Croom Hill.
- Hostyn, I., & Maes, B. (2009). Interaction between persons with profound intellectual and multiple disabilities and their partners: A literature review. *Journal of Intellectual & Developmental Disability*, 34, 296-312. doi: 10.3109/13668250903285648
- Iacono, T. (2006). Ethical challenges and complexities of including people with intellectual disability as participants in research. *Journal of Intellectual & Developmental Disability*, 31, 173-179. doi: 10.1080/13668250600876392
- Iacono, T. (2009). *Partners on the research journey – An ethics perspective (Keynote)*. Paper presented at the ASSID 44th Annual Conference: Power and Passion: Progress and Partnership.
- Iacono, T., Bloomberg, K., & West, D. (2005). A preliminary investigation into the internal consistency and construct validity of the Triple C: Checklist of Communicative Competencies. *Journal of Intellectual & Developmental Disability*, 30, 139-145. doi: 10.1080/13668250500204059
- Iacono, T., Carter, M., & Hook, J. (1998). Identification of intentional communication in with severe and multiple disabilities. *Augmentative and Alternative Communication*, 14, 102-114. doi: 10.1080/07434619812331278246
- Iacono, T., West, D., Bloomberg, K., & Johnson, H. (2009). Reliability and validity of the revised Triple C: Checklist of Communicative Competencies for adults with severe and multiple disabilities. *Journal of Intellectual Disability Research*, 53, 44-53. doi: 10.1111/j.1365-2788.2008.01121.x

- IASSID Special Interest Research Group: Profound Intellectual and Multiple Disabilities. (n.d.). Mission: Founding principles Retrieved 12 August, 2007, from <http://www.sirgpmid.be/index.php>
- Irvine, C. (2002). Preliminary findings of an informal longitudinal study into the research / practice interface: Noting the influence of extra trees in the wood rather than throwing the baby out with the bath-water. *Speech & Language Therapy in Practice*, 16-17.
- Ivancic, M. T., Barrett, G. T., Simonow, A., & Kimberly, A. (1997). A replication to increase happiness indices among some people with profound multiple disabilities. *Research in Developmental Disabilities*, 18, 79-89. doi: 10.1016/S0891-4222(96)00039-X
- Janssen, M., Riksen-Walraven, J., & Van Dijk, J. (2003a). Toward a diagnostic intervention model for fostering harmonious interactions between deaf-blind children and their educators. *Journal of Visual Impairment & Blindness*, 97.
- Janssen, M., Riksen-Walraven, J., van Dijk, J., & Ruijsenaars, W. (2010). Interaction coaching with mothers of children with congenital deaf-blindness at home: Applying the Diagnostic Intervention Model. *Journal of Visual Impairment & Blindness*, 104, 15-29.
- Janssen, M., & Rødbroe, I. (Eds.). (2007). *Communication and congenital deafblindness. II: Contact and social interaction* (Vol. I). Sint-Micheliësgestel, The Netherlands: VCDBF/Viataal.
- Janssen, M. J., Riksen-Walraven, J. M., & Van Dijk, J. P. M. (2003b). Contact: Effects of an intervention program to foster harmonious interactions between deaf-blind children and their educators. *Journal of Visual Impairment & Blindness*, 97, 215-229.
- Jefferson, G. (1984). Transcription notation. In J. Atkinson & J. Heritage (Eds.), *Structures of social action*. New York, NY: Cambridge University Press.
- Johnson, H., Douglas, J., Bigby, C., & Iacono, T. (2009). Maximizing community inclusion through mainstream communication services for adults with severe disabilities. *International Journal of Speech-Language Pathology*, 11, 180-190. doi: 10.1080/17549500902825265

- Jones, A. P., Johnson, L. A., Butler, M. C., & Main, D. S. (1983). Apples and oranges: An empirical comparison of commonly used indices of interrater agreement. *Academy of Management Journal*, *26*, 507-519. doi: 10.2307/256262
- Jones, F., Pring, T., & Grove, N. (2002). Developing communication in adults with profound and multiple learning difficulties using objects of reference. *International Journal of Language and Communication Disorders*, *37*, 173-184. doi: 10.1080/13682820110116875
- Jonsson, C.-O. (2001). *The Affect Attunement Protocol (AAP)*. Stockholm University. Stockholm, Sweden.
- Jonsson, C.-O., & Clinton, D. (2006). What do mothers attune to during interactions with their infants? *Infant and Child Development*, *15*, 387-402. doi: 10.1002/icd.466
- Jonsson, C.-O., Clinton, D., Fahrman, M., Mazzaglia, G., Novak, S., & Sorhus, K. (2001). How do mothers signal shared feeling states to their infants? An investigation of affect attunement and imitation during the first year of life. *Scandinavian Journal of Psychology*, *42*, 377-381. doi: 10.1111/1467-9450.00249
- Kangas, K. A., & Lloyd, L. L. (1988). Early cognitive skills as prerequisites to augmentative and alternative communication use: What are we waiting for? *Augmentative and Alternative Communication*, *4*, 211-221. doi: 10.1080/07434618812331274817
- Karlan, G. R., Ward, M., Pennington, G., & Granlund, M. (1985). *Early Social Communication Scale: Adapted for use with profoundly handicapped persons*. West Lafayette, IN: Purdue University.
- Kazdin, A. E. (1977). Artifact, bias, and complexity of assessment: ABCs of reliability. *Journal of Applied Behavior Analysis*, *10*, 141-150. doi: 10.1901/jaba.1977.10-141
- Kellett, M. (2005). Catherine's legacy: Social communication development for individuals with profound learning difficulties and fragile life expectancies. *British Journal of Special Education*, *32*, 116-121. doi: 10.1111/j.0952-3383.2005.00383.x

- Kellett, M., & Nind, M. (2001). Ethics in quasi-experimental research on people with severe learning disabilities: Dilemmas and compromises. *British Journal of Learning Disabilities*, 29, 51-55. doi: 10.1046/j.1468-3156.2001.00096.x
- Kellett, M., & Nind, M. (2003). *Implementing Intensive Interaction in schools: Guidance for practitioners, managers and coordinators*. London, England: David Fulton.
- Kennedy, H., & Sked, H. (2008). Video Interaction Guidance: A bridge to better interactions for individuals with communication impairments. In M. S. Zeedyk (Ed.), *Promoting social interaction for individuals with communicative impairments: Making contact* (pp. 139-154). London, England: Jessica Kingsley.
- Kiernan, C., & Reid, B. (1987). *Pre-Verbal Communication Schedule (PVCS)*. Windsor, England: NFER-Nelson.
- Kobe, F. H., Mulick, J. A., Rash, T. A., & Martin, J. (1994). Nonambulatory persons with profound mental retardation: Physical, developmental, and behavioral characteristics. *Research in Developmental Disabilities*, 15, 413-423. doi: 10.1016/0891-4222(94)90026-4
- Kopenhaver Haidet, K., Tate, J., Divirgilio-Thomas, D., Kolanowski, A., & Happ, M. B. (2009). Methods to improve reliability of video-recorded behavioral data. *Research in Nursing Health*, 32, 465-474. doi: 10.1002/nur.20334
- Lacey, P. (1995). The inner life of children with profound and multiple learning difficulties. In V. P. Varma (Ed.), *The inner life of children with special needs* (pp. 63-80). London, England: Whurr.
- Lancioni, G. E., O'Reilly, M. F., & Basili, G. (1999). Review of strategies for treating sleep problems in persons with severe or profound mental retardation or multiple handicaps. *American Journal on Mental Retardation*, 104, 170-186. doi: 10.1352/0895-8017(1999)104<0170:ROSFTS>2.0.CO;2
- Lancioni, G. E., O'Reilly, M. F., Singh, N. N., Oliva, D., & Groeneweg, J. (2002). Impact of stimulation versus microswitch-based programs on indices of happiness of people with profound multiple disabilities. *Research in Developmental Disabilities*, 23, 149-160. doi: 10.1016/S0891-4222(02)00092-6
- Lancioni, G. E., O'Reilly, M. F., Singh, N. N., Sigafos, J., Didden, R., Oliva, D., . . . Groeneweg, J. (2009). Persons with multiple disabilities accessing stimulation

- and requesting social contact via microswitch and VOCA devices: New research evaluation and social validation. *Research in Developmental Disabilities, 30*, 1084-1094. doi: 10.1016/j.ridd.2009.03.004
- Lancioni, G. E., O'Reilly, M. F., Singh, N. N., Sigafos, J., Oliva, D., Antonucci, M., . . . Basili, G. (2008). Microswitch-based programs for persons with multiple disabilities: An overview of some recent developments. *Perceptual and Motor Skills, 106*, 355-370. doi: 10.2466/PMS.106.2.355-370
- Lancioni, G. E., Singh, N. N., O'Reilly, M. F., Oliva, D., Smaldone, A., Tota, A., . . . Groeneweg, J. (2006). Assessing the effects of stimulation versus microswitch-based programmes on indices of happiness of students with multiple disabilities. *Journal of Intellectual Disability Research, 50*, 739-747. doi: 10.1111/j.1365-2788.2006.00839.x
- Lancioni, G. E., Singh, N. N., O'Reilly, M. F., Sigafos, J., Didden, R., Oliva, D., . . . Lamartire, M. L. (2007). Effects of microswitch-based programs on indices of happiness of students with multiple disabilities: A new research evaluation. *American Journal on Mental Retardation, 112*, 167-176. doi: 10.1352/0895-8017(2007)112[167:EOMPOI]2.0.CO;2
- Lancioni, G. E., Singh, N. N., O'Reilly, M. F., Sigafos, J., Oliva, D., & Baccani, S. (2007). Enabling students with multiple disabilities to request and choose among environmental stimuli through microswitch and computer technology. *Research in Developmental Disabilities, 28*, 50-58. doi: 10.1016/j.ridd.2005.12.001
- Lancioni, G. E., Tota, A., Smaldone, A., Singh, N. N., O'Reilly, M. F., Sigafos, J., . . . Montironi, G. (2007). Extending the evaluation of novel microswitch technology for small responses in children with profound multiple disabilities. *Assistive Technology, 19*, 11-16. doi: 10.1080/10400435.2007.10131861
- Landis, J. R., & Koch, G. G. (1977). The measurement of observer agreement for categorical data. *Biometrics, 33*, 159-174. doi: 10.2307/2529310
- Lavers-Preston, C. (2004). *Care staffs' experience and understanding of intensive interaction*. Doctorate of Clinical Psychology, Canterbury Christ Church University College, Canterbury, England.
- 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, 103-109. doi: 10.1111/j.1468-3156.2005.00374.x
- Lee, D., & Aronson, E. (1974). Visual proprioceptive control of standing in human infants. *Perception and Psychophysics*, 15, 529-532.
- Legerstee, M., Markova, G., & Fisher, T. (2007). The role of maternal affect attunement in dyadic and triadic communication. *Infant Behavior & Development*, 30, 296-306. doi: 10.1016/j.infbeh.2006.10.003
- Lewis, M., & Rosenblum, L. A. (Eds.). (1974). *The effect of the infant on its caregiver* (Vol. 1). New York, NY: John Wiley & Sons.
- Leyin, A. (2010). Learning disability classification: Time for re-appraisal? *Tizard Learning Disability Review*, 15, 33-44. doi: 10.5042/tldr.2010.0168
- Lovell, D. M., Jones, R. S. P., & Ephraim, G. (1998). The effect of intensive interaction on the sociability of a man with severe intellectual disabilities. *International Journal of Practical Approaches to Disability*, 22, 3-9.
- Lyons, G. (2003). *Life satisfaction for children with profound and multiple disabilities: Seeking eudaemonia*. PhD, The University of Newcastle, Newcastle, Australia.
- Lyons, G. (2005). The Life Satisfaction Matrix: An instrument and procedure for assessing the subjective quality of life of individuals with profound multiple disabilities. *Journal of Intellectual Disability Research*, 49, 766-769. doi: 10.1111/j.1365-2788.2005.00748.x
- Mackinnon, A. (2000). A spreadsheet for the calculation of comprehensive statistics for the assessment and diagnostic tests and inter-rater agreement. *Computers in Biology and Medicine*, 30, 127-134. doi: 10.1016/S0010-4825(00)00006-8
- Maes, B., Lambrechts, G., Hostyn, I., & Petry, K. (2007). Quality-enhancing interventions for people with profound intellectual and multiple disabilities: A review of the empirical research. *Journal of Intellectual & Developmental Disability*, 32, 163-178. doi: 10.1080/13668250701549427
- Mar, H. H., & Sall, N. (1999). Profiles of the expressive communication skills of children and adolescents with severe cognitive disabilities. *Education and Training in Mental Retardation and Developmental Disabilities*, 34, 77-89.
- Marquis, R., & Jackson, R. (2000). Quality of life and quality of service relationships: Experiences of people with disabilities. *Disability & Society*, 15, 411 - 425. doi: 10.1080/713661967

- McCluskey, U. (2005). *To be met as a person: The dynamics of attachment in professional encounters*. London, England: Karnac.
- McCluskey, U., Hooper, C.-A., & Miller, L. B. (1999). Goal-corrected empathic attunement: Developing and rating the concept within an attachment perspective. *Psychotherapy: Theory, Research, Practice, Training Spring*, 36, 80-90.
- McCluskey, U., Roger, D., & Nash, P. (1997). A preliminary study of the role of attunement in adult psychotherapy. *Human Relations* 50, 1261-1273. doi: 10.1177/001872679705001004
- McConkey, R., Morris, I., & Purcell, M. (1999). Communications between staff and adults with intellectual disabilities in naturally occurring settings. *Journal of Intellectual Disability Research*, 43, 194-205. doi: 10.1046/j.1365-2788.1999.00191.x
- McDonnell, A., Reeves, S., Johnson, A., & Lane, A. (1998). Managing challenging behaviour in an adult with learning disabilities: The use of low arousal approach. *Behavioural and Cognitive Psychotherapy*, 26, 163-171.
- McKenzie, B. E., Skouteris, H., Day, R. H., Hartman, B., & Yonas, A. (1993). Effective action by infants to contact objects by reaching and leaning. *Child Development*, 64, 415-429. doi: 10.1111/j.1467-8624.1993.tb02918.x
- McLean, J. E., & Snyder-McLean, L. (1987). Form and function of communicative behaviour among persons with severe developmental disabilities. *Australia and New Zealand Journal of Developmental Disabilities*, 13, 83-98. doi: 10.3109/13668258709023350
- McLean, L. K., Brady, N. C., McLean, J. E., & Behrens, G. A. (1999). Communications forms and functions of children and adults with severe mental retardation in community and institutional settings. *Journal of Speech, Language, and Hearing Research*, 42, 231-241.
- Meltzoff, A. N. (2007). 'Like me': A foundation for social cognition. *Developmental Science*, 10, 126-134. doi: 10.1111/j.1467-7687.2007.00574.x
- Meltzoff, A. N., & Moore, M. (1989). Imitation in newborn infants: Exploring the range of gestures imitated and the underlying mechanisms. *Developmental Psychology*, 25, 954-962. doi: 10.1037/0012-1649.25.6.954

- Meyers, C. E. (Ed.). (1978). *Quality of life in severely and profoundly mentally retarded people: Research foundations for improvement* (Vol. 3). Washington, DC: American Association on Mental Deficiency.
- Mirenda, P., Iacono, T., & Williams, R. (1990). Communication options for persons with severe and profound disabilities: State of the art and future directions. *Journal of the Association for Persons with Severe Handicaps*, *15*, 3-21.
- Moore, B., & Grant, G. W. B. (1976). On the nature and incidence of staff-patient interactions in hospitals for the mentally handicapped. *International Journal of Nursing Studies*, *13*, 69-81. doi: 10.1016/0020-7489(76)90016-X
- Moss, S., & Hogg, J. (1997). Estimating IQ from adaptive behaviour information in people with moderate or severe intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, *10*, 61-66. doi: 10.1111/j.1468-3148.1997.tb00007.x
- Mudford, O. C., Hogg, J., & Roberts, J. (1997). Interobserver agreement and disagreement in continuous recording exemplified by measurement of behavior state. *American Journal on Mental Retardation*, *102*, 54-66. doi: 10.1352/0895-8017(1997)102<0054:IAADIC>2.0.CO;2
- Mudford, O. C., Hogg, J., & Roberts, J. (1999). Behavior states: Now you see them, now you don't. *American Journal of Mental Retardation*, *104*, 385-391. doi: 10.1352/0895-8017(1999)104<0385:BSNYST>2.0.CO;2
- Munde, V. S., Vlaskamp, C., Ruijsenaars, A. J. J. M., & Nakken, H. (2009). Alertness in individuals with profound intellectual and multiple disabilities: A literature review. *Research in Developmental Disabilities*, *30*, 462-480. doi: 10.1016/j.ridd.2008.07.003
- Nagy, E. (2006). From imitation to conversation: The first dialogues with human neonates. *Infant and Child Development*, *15*, 223-232. doi: 10.1002/icd.460
- Nakken, H., & Vlaskamp, C. (2002). Joining forces: Supporting individuals with profound multiple learning disabilities. *Tizard Learning Disability Review*, *7*, 10-15.
- Nakken, H., & Vlaskamp, C. (2007). A need for a taxonomy for profound intellectual and multiple disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, *4*, 83-87. doi: 10.1111/j.1741-1130.2007.00104.x

- Neilson, A., Hogg, J., Malek, M., & Rowley, D. (2000). Impact of surgical and orthotic intervention on the quality of life of people with profound intellectual and multiple disabilities and their carers. *Journal of Applied Research in Intellectual Disabilities, 13*, 216-238. doi: 10.1046/j.1360-2322.2000.00023.x
- Nicholas, J. G., Geers, A. E., & Rollins, P. R. (1999). Inter-rater reliability as a reflection of ambiguity in the communication of deaf and normally-hearing children. *Journal of Communication Disorders, 32*, 121-134. doi: 10.1016/S0021-9924(99)00002-7
- Nind, M. (1996). Efficacy of Intensive Interaction: Developing sociability and communication in people with severe and complex learning difficulties using an approach based on caregiver-infant interaction. *European Journal of Special Needs Education, 11*, 48-66.
- Nind, M. (1999). Intensive Interaction and autism: A useful approach? *British Journal of Special Education, 26*, 96-102. doi: 10.1111/1467-8527.t01-1-00114
- Nind, M., & Hewett, D. (1994). *Access to communication: Developing the basics of communication with people with severe learning difficulties through Intensive Interaction*. London, England: David Fulton.
- Nind, M., & Hewett, D. (2001). *A practical guide to Intensive Interaction*. Kidderminster, England: British Institute of Learning Disabilities.
- Nind, M., & Hewett, D. (2005). *Access to communication: Developing basic communication with people with severe learning difficulties* (2 ed.). London, England: David Fulton.
- Nind, M., Kellett, M., & Hopkins, V. (2001). Teachers' talk styles: Communicating with learners with severe and complex learning difficulties. *Child Language Teaching and Therapy, 17*, 143. doi: 10.1191/026565901678225664
- NVivo qualitative data analysis software (Version 8.0.264.0 SP3) [Computer software]. Melbourne, Australia: QSR International.
- O'Neill, M. B., Jones, M. C., & Zeedyk, M. S. (2008). The use of imitation with children with autistic spectrum disorder: Foundations for shared communication. In M. S. Zeedyk (Ed.), *Promoting social interaction for individuals with communicative impairment* (pp. 51-65). London, England: Jessica Kingsley.
- Ogletree, B. T., Fischer, M. A., & Turowski, M. (1996). Assessment targets and protocols for nonsymbolic communicators with profound disabilities. *Focus on*

- Autism and Other Developmental Disabilities*, 11, 53-58. doi:
10.1177/108835769601100107
- Ogletree, B. T., Wetherby, A. M., & Westling, D. L. (1992). Profile of the prelinguistic intentional communicative behaviors of children with profound mental retardation. *American Journal on Mental Retardation*, 97, 186-196.
- Pallant, J. (2007). *SPSS survival manual: A step by step guide to data analysis using SPSS* (3rd ed.). Crows Nest, Australia: Allen & Unwin.
- Patja, K., Iivanainen, M., Vesala, H., & Oksanen, H. (2000). Life expectancy of people with intellectual disability: A 35-year follow-up study. *Journal of Intellectual Disability Research*, 44, 591-599. doi: 10.1046/j.1365-2788.2000.00280.x
- Pavlicevic, M. (1997). *Music therapy in context: Music, meaning and relationship*. London, England: Jessica Kingsley.
- Pavlicevic, M. (2002). Dynamic interplay in clinical improvisation. *Voices*, 2, 5-9.
- Petry, K., & Maes, B. (2006). Identifying expressions of pleasure and displeasure by persons with profound and multiple disabilities. *Journal of Intellectual & Developmental Disability*, 31, 28 - 38. doi: 10.1080/13668250500488678
- Petry, K., & Maes, B. (2007). Description of the support needs of people with profound multiple disabilities using the 2002 AAMR system: An overview of literature. *Education and Training in Developmental Disabilities*, 42, 130-143.
- Petry, K., Maes, B., & Vlaskamp, C. (2005). Domains of quality of life of people with profound multiple disabilities: The perspective of parents and direct support staff. *Journal of Applied Research in Intellectual Disabilities*, 18, 35-46. doi: 10.1111/j.1468-3148.2004.00209.x
- Petry, K., Maes, B., & Vlaskamp, C. (2007). Operationalizing quality of life for people with profound multiple disabilities: A Delphi study. *Journal of Intellectual Disability Research*, 51, 334-349. doi: 10.1111/j.1365-2788.2006.00882.x
- Piaget, J. (2003). *The psychology of intelligence* (M. Piercy & D. E. Berlyne, Trans.). London, England: Routledge. (Reprinted from: in English in 1950).
- Pianta, R. C. (1995). *Dyadic-level rating scales for parent-child interactions tasks*. University of Virginia.
- PMLD Network. (2001). Valuing people with profound and multiple disabilities: Response to "Valuing People" Retrieved November 24, 2004, from www.mencap.org.uk/download/vp_pmld.pdf

- Pope, P. M. (Ed.). (2007). *Severe and complex neurological disability: Management of the physical condition*. Edinburgh, Scotland: Butterworth-Heinemann.
- Porter, J., Ouvry, C., Morgan, M., & Downs, C. (2001). Interpreting the communication of people with profound and multiple learning difficulties. *British Journal of Learning Disability*, 29, 12-16. doi: 10.1046/j.1468-3156.2001.00083.x
- Portney, L. G., & Watkins, M. P. (1999). *Foundations of clinical research: Applications to practice*. Upper Saddle River, NJ: Prentice Hall
- Reddy, V. (2008). *How infants know minds*. Cambridge, MA: Harvard University Press.
- Reinders, H. (2010). The importance of tacit knowledge in practices of care. *Journal of Intellectual Disability Research*, 54, 28-37. doi: 10.1111/j.1365-2788.2009.01235.x
- Reinders, H. S. (2002). The good life for citizens with intellectual disability. *Journal of Intellectual Disability Research*, 46, 1-5. doi: 10.1046/j.1365-2788.2002.00386.x
- Reinders, H. S. (2008). *Receiving the gift of friendship: Profound disability, theological anthropology, and ethics*. Grand Rapids, MI: Wm. E. Eerdmans.
- Resch, R. C. (1981). Natural observational studies: Methodology and video-recording in spontaneous behavior settings. *Infant Mental Health Journal*, 2, 176-187. doi: 10.1002/1097-0355(198123)2:3<176::aid-imhj2280020306>3.0.co;2-2
- Richards, S. B., & Richards, R. Y. (1997). Implications for assessing biobehavioral states in individuals with profound disabilities. *Focus on Autism and Other Developmental Disabilities*, 12, 79-86. doi: 10.1177/108835769701200203
- Richards, S. B., & Sternberg, L. (1992). A preliminary analysis of environmental variables affecting the observed biobehavioural states of individuals with profound handicaps. *Journal of Intellectual Disability Research*, 36, 403-414. doi: 10.1111/j.1365-2788.1992.tb00558.x
- Rødbroe, I., & Janssen, M. (Eds.). (2006). *Communication and congenital deafblindness. I: Congenital deafblindness and the core principles of intervention* (Vol. I). St. Michielsgestel, The Netherlands: VCDBF/Viataal.
- Roemer, M., & van Dam, L. (2004). *Verstaanbaar Maken: Communicatie met mensen met een zeer ernstige verstandelijke (meervoudige) handicap: Inventarisatie en overdracht van ervaringskennis. (Making oneself understood. Communication with people with profound intellectual (multiple) disabilities: Inventory and*

- transfer of practical knowledge*). Maastricht, Netherlands: Universitaire pers Maastricht.
- Roemer, M., & van Dam, L. (2006). *Making oneself understood: Communication with people with profound intellectual (multiple) disabilities*. Paper presented at the IASSID Europe, Maastricht, Netherlands.
- Romski, M. A., & Sevcik, R. A. (1997). Augmentative and alternative communication for children with developmental disabilities. *Mental Retardation and Developmental Disabilities Research Reviews*, 3, 363-368. doi: 10.1002/(SICI)1098-2779(1997)3:4<363::AID-MRDD12>3.0.CO;2-T
- Rustin, J. (1997). Infancy, agency, and intersubjectivity: A view of therapeutic action. *Psychoanalytic Dialogues*, 71, 43-62. doi: 10.1080/10481889709539166
- Sacks, H., Schegloff, E. A., & Jefferson, G. (1974). A simplest systematics for the organization of turn-taking for conversation. *Language*, 50, 696-735. doi: 10.2307/412243
- Samuel, J., Nind, M., Volans, A., & Scriven, I. (2008). An evaluation of Intensive Interaction in community living settings for adults with profound intellectual disabilities. *Journal of Intellectual Disabilities*, 12, 111-126. doi: 10.1177/1744629508090983
- Samuel, J., & Pritchard, M. (2001). The ignored minority: Meeting the needs of people with profound learning disability. *Tizard Learning Disability Review*, 6, 34-44.
- Schlosser, R. W. (1999). Social validation of interventions in augmentative and alternative communication. *Augmentative and Alternative Communication*, 15, 234-247. doi: 10.1080/07434619912331278775
- Schore, A. (1994). *Affect regulation and the origin of the self: The neurobiology of emotional development*. Hillsdale, NJ: Lawrence Erlbaum.
- Seys, D., Duker, P., Salemink, W., & Franken-Wijnhoven, J. (1998). Resident behaviors and characteristics as determinants of quality of residential care: An observational study. *Research in Developmental Disabilities*, 19, 261-273. doi: 10.1016/S0891-4222(98)00007-9
- Seys, D. M., & Duker, P. C. (1986). Effects of a supervisory treatment package on staff-mentally retarded resident interactions. *American Journal of Mental Deficiency*, 90, 388-394.

- Sharpe, T., & Koperwas, J. (2003). *Behavior and sequential analyses*. Thousand Oaks, CA: Sage.
- Shriberg, L. D., Kwiatkowski, J., & Hoffmann, K. (1984). A procedure for phonetic transcription by consensus. *Journal of Speech and Hearing Research, 27*, 456-465.
- Siegel-Causey, E., & Guess, D. (1989). *Enhancing nonsymbolic communication interactions among learners with severe disabilities*. Baltimore, MD: Paul H. Brookes.
- Siegel, E. B., & Cress, C. J. (2002). Overview of the emergence of early AAC behaviours. In J. Reichle, D. R. Beukelman & J. C. Light (Eds.), *Exemplary practices for beginning communicators: implications for AAC* (pp. 25-57). Baltimore, MD: Paul H. Brookes.
- Siegel, N. (1996). *Affect attunement and infant-mother attachment*. Doctor of Philosophy, City University of New York, New York, NY.
- Simeonsson, R. J., Bailey, D. B., Huntington, G. S., & Brandon, L. (1991). Scaling and attainment of goals in family-focused early intervention. *Community Mental Health Journal, 27*, 77-83. doi: 10.1007/bf00752717
- Simonoff, E., Pickles, A., Chadwick, O., Gringras, P., Wood, N., Higgins, S., . . . Moore, A. (2006). The Croydon Assessment of Learning Study: Prevalence and educational identification of mild mental retardation. *Journal of Child Psychology and Psychiatry, 47*, 828-839. doi: 10.1111/j.1469-7610.2006.01630.x
- Singh, N. N., Lancioni, G. E., O'Reilly, M. F., Molina, E. J., Adkins, A. D., & Oliva, D. (2003). Self-determination during mealtimes through microswitch choice-making by an individual with complex multiple disabilities and profound mental retardation. *Journal of Positive Behavior Interventions, 5*, 209-215. doi: 10.1177/10983007030050040401
- Singh, N. N., Lancioni, G. E., Winton, A. S. W., Wahler, R. G., Singh, J., & Sage, M. (2004). Mindful caregiving increases happiness among individuals with profound multiple disabilities. *Research in Developmental Disabilities, 25*, 207-218. doi: 10.1016/j.ridd.2003.05.001
- Sparrow, S., Balla, D., & Cicchetti, D. (1984). *Vineland adaptive behavior scales*. Circle Pines, MN: American Guidance Service.

- State Enterprise Training. (2010). Medication administration program 2010 Retrieved 6th October, 2010, from <http://www.setraining.com.au/media/MedAdmin%20Program%202010.pdf>
- StatsDirect (Version 2.7.7) [Computer software] (Version 2.7.7) [Computer software]. Altrincham, England: StatsDirect. Retrieved from www.statsdirect.com
- Stern, D. (1985). *The interpersonal world of the infant: A view from psychoanalysis and developmental psychology*. New York, NY: Basic Books.
- Stern, D. N. (1977). *The first relationship: Infant and mother*. Cambridge, England: Harvard University Press.
- Stern, D. N. (2002). *The first relationship: Infant and mother (with a new introduction)*. London, England: Harvard University Press.
- Stern, D. N. (2004). *The present moment in psychotherapy and everyday life*. New York, NY: W.W. Norton & Company.
- Stern, D. N. (2005). Intersubjectivity. In E. S. Person, A. M. Cooper & G. O. Gabbard (Eds.), *The American Psychiatric Publishing textbook of psychoanalysis* (pp. 77-92). New York, NY: American Psychiatric Publishing.
- Stern, D. N., Hofer, L., Haft, W., & Dore, J. (1985). Affect attunement: The sharing of feeling states between mother and infant by means of inter-modal fluency. In T. M. Field & N. A. Fox (Eds.), *Social perceptions in infants* (pp. 249-268). Norwood, NJ: Ablex.
- Sundin, K., & Jansson, L. (2003). 'Understanding and being understood' as a creative caring phenomenon - in care of patients with stroke and aphasia. *Journal of Clinical Nursing*, 12, 107-116. doi: 10.1046/j.1365-2702.2003.00676.x
- Thomas, M., Felce, D., de Kock, U., Saxby, H., & Repp, A. (1986). The activity of staff and of severely and profoundly mentally handicapped adults in residential settings of different sizes. *British Journal of Mental Subnormality*, 32, 82-92.
- Thurman, S., Jones, J., & Tarleton, B. (2005). Without words - meaningful information for people with high individual communication needs. *British Journal of Learning Disabilities*, 33, 83-89. doi: 10.1111/j.1468-3156.2005.00342.x
- Tracy, J., Burbidge, M., Hanson, S., Moyle, J., Galea, J., & Iacono, T. (2008). Health & disability [kit]: Partnerships in action - Knowledge base. Melbourne, Australia: Monash University.

- Trevarthen, C. (1979). Communication and cooperation in early infancy: A description of primary intersubjectivity. In M. Bullowa (Ed.), *Before speech: The beginning of interpersonal communication* (pp. 321-348). Cambridge, England: Cambridge University Press.
- Trevarthen, C. (2008). Intuition for human communication. In M. S. Zeedyk (Ed.), *Promoting social interaction for individuals with communicative impairment: Making contact* (pp. 23-38). London, England: Jessica Kingsley.
- Trevarthen, C., & Aitken, K. J. (2001). Infant intersubjectivity: Research, theory, and clinical applications. *Journal of Child Psychology and Psychiatry*, 42, 3-48. doi: 10.1111/1469-7610.00701
- Utley, B. L. (1994). Providing support for sensory, postural, and movement needs. In L. Sternberg (Ed.), *Individuals with profound disabilities: Instructional and assistive strategies* (3rd ed., pp. 123-191). Austin, TX: Pro-Ed.
- van den Broek, E. G. C., Janssen, C. G. C., van Ramshorst, T., & Deen, L. (2006). Visual impairments in people with severe and profound multiple disabilities: An inventory of visual functioning. *Journal of Intellectual Disability Research*, 50, 470-475. doi: 10.1111/j.1365-2788.2006.00804.x
- van der Heide, D. C., van der Putten, A. A. J., van den Berg, P. B., Taxis, K., & Vlaskamp, C. (2009). The documentation of health problems in relation to prescribed medication in people with profound intellectual and multiple disabilities. *Journal of Intellectual Disability Research*, 53, 161-168. doi: 10.1111/j.1365-2788.2008.01141.x
- van der Putten, A., Vlaskamp, C., & Poppes, P. (2009). The content of support of persons with profound intellectual and multiple disabilities: An analysis of the number and content of goals in the educational programmes. *Journal of Applied Research in Intellectual Disabilities*, 22, 391-394. doi: 10.1111/j.1468-3148.2008.00469.x
- van der Putten, A., Vlaskamp, C., Reynders, K., & Nakken, H. (2005). Children with profound intellectual and multiple disabilities: The effects of functional movement activities. *Clinical Rehabilitation*, 19, 613-620. doi: 10.1191/0269215505cr899oa
- VICRAID, ACROD, & CIDA. (2003). Victorian disability NGO workforce analysis project. Melbourne, Australia.

- Victorian Department of Human Services. (2006). *Client Expenditure Recording System (CERS) policy and procedures manual*. Melbourne, Australia: Victorian Government Publishing Service Retrieved from http://www.dhs.vic.gov.au/_data/assets/pdf_file/0005/152789/cfm_cerspolicyp roceduresmanualfinal_pdf_0107_.pdf.
- Vlaskamp, C. (2005a). Assessing people with profound intellectual and multiple disabilities. In J. Hogg & A. Langa (Eds.), *Assessing adults with intellectual disabilities: A service providers' guide* (pp. 152-163). Oxford, England: Blackwell.
- Vlaskamp, C. (2005b). Interdisciplinary assessment of people with profound intellectual and multiple disabilities. In J. Hogg & A. Langa (Eds.), *Assessing adults with intellectual disabilities: A service providers' guide* (pp. 39-51). Oxford, England: Blackwell.
- Vlaskamp, C., de Geeter, K. I., Huijsmans, L. M., & Smit, I. H. (2003). Passive activities: The effectiveness of multisensory environments on the level of activity of individuals with profound multiple disabilities. *Journal of Applied Research in Intellectual Disabilities*, 16, 135-143. doi: 10.1046/j.1468-3148.2003.00156.x
- Vlaskamp, C., Hiemstra, S. J., & Wiersma, L. A. (2007). Becoming aware of what you know or need to know: Gathering client and context characteristics in day services for persons with profound intellectual and multiple disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 4, 97-103. doi: 10.1111/j.1741-1130.2007.00106.x
- Vlaskamp, C., & Zijlstra, R. (2004). Leisure time or killing time? An analysis of leisure provision for persons with profound intellectual and multiple disabilities (PIMD). *Journal of Intellectual Disability Research*, 48, 358.
- Ware, J. (2004). Ascertaining the views of people with profound and multiple learning disabilities. *British Journal of Learning Disabilities*, 32, 175-179. doi: 10.1111/j.1468-3156.2004.00316.x
- Ware, J. (2005). Profound and multiple learning difficulties. In A. Lewis & B. Norwich (Eds.), *Special teaching for special children? A pedagogies for inclusion* (pp. 67-80). Maidenhead, England: Open University Press.

- Warren, S. F., Brady, N. C., & Fey, M. E. (2004). Communication and language: Research design and measurement issues. In E. Emerson, C. Hatton, T. Thompson & T. Parmenter (Eds.), *International handbook of research in intellectual disabilities* (pp. 385-405). Chichester, England: Wiley.
- Watkins, M., & Pacheco, M. (2000). Interobserver agreement in behavioral research: Importance and calculation. *Journal of Behavioral Education, 10*, 205-212.
- Watson, J., & Fisher, A. (1997). Evaluating the effectiveness of Intensive Interactive teaching with pupils with profound and complex learning difficulties. *British Journal of Special Education, 24*, 80-87. doi: 10.1111/1467-8527.00020
- Watson, J., & Knight, C. (1991). An evaluation of Intensive Interactive teaching with pupils with very severe learning difficulties. *Child Language Teaching and Therapy, 7*, 310-325. doi: 10.1177/026565909100700306
- Wellesley, D., Hockey, K., Montgomery, P., & Stanley, F. (1992). Prevalence of intellectual handicap in Western Australia. *The Medical Journal of Australia, 156*, 94-102.
- Wetherby, A. M., & Prizant, B. M. (1989). The expression of communicative intent: Assessment guidelines. *Seminars in Speech and Language, 10*, 77-91. doi: 10.1055/s-0028-1082491
- Whitaker, S. (1989). Quality of life and people with a very profound handicap. *British Journal of Mental Subnormality, 35*, 3-7.
- Wilder, J. (2008). Video observations of dyadic interaction: Behaviour style of presymbolic children. *Scandinavian Journal of Disability Research, 10*, 104 - 124. doi: 10.1080/15017410801900390
- Willems, A. P. A. M., Embregts, P. J. C. M., Stams, G. J. J. M., & Moonen, X. M. H. (2010). The relation between intrapersonal and interpersonal staff behaviour towards clients with ID and challenging behaviour: A validation study of the Staff-Client Interactive Behaviour Inventory. *Journal of Intellectual Disability Research, 54*, 40-51. doi: 10.1111/j.1365-2788.2009.01226.x
- Wolff, P. H. (1965). The development of attention in young infants. *Annals of the New York Academy of Sciences, 118*, 815-830. doi: 10.1111/j.1749-6632.1965.tb40153.x

- Workforce Development and Learning. (2008). *Supporting people who have complex communication needs training manual*. Melbourne, Australia: Department of Human Services Victoria.
- World Health Organisation. (1996). *ICD-10 Guide for Mental Retardation*. Geneva, Switzerland: WHO.
- Yoder, P. (1987). Relationship between degree of infant handicap and clarity of infant cues. *American Journal of Mental Deficiency, 91*, 639-641.
- Yoder, P. J., Short-Meyerson, K., & Tapp, J. (2004). Measurement of behavior with a special emphasis on sequential analysis of behavior. In E. Emerson, C. Hatton, T. Thompson & T. Parmenter (Eds.), *The international handbook of applied research in intellectual disabilities* (pp. 179-199). Chichester, England: John Wiley & Sons.
- Zeedyk, M. (1996). Developmental accounts of intentionality: Toward integration. *Developmental Review, 16*, 416-461. doi: 10.1006/drev.1996.0018
- Zeedyk, M. S. (2006). From intersubjectivity to subjectivity: The transformative roles of emotional intimacy and imitation. *Infant and Child Development, 15*, 321-344. doi: 10.1002/icd.457
- Zeedyk, M. S., Caldwell, P., & Davies, C. E. (2009). How rapidly does Intensive Interaction promote social engagement for adults with profound learning disabilities? *European Journal of Special Needs Education, 24*, 119-137. doi: 10.1080/08856250902793545

APPENDICES

Appendix A: Affect Attunement Protocol original (Jonsson)

Appendix B: Initial AABC form

Appendix C: AABC Manual

Appendix D: Ethics Approval Letters (Monash University & Scope)

Appendix E: Information Inviting People with PIMD and DSWs to Participate in the Study (Consent Form and Explanatory Statements)

Appendix F: Demographic Questions for Participants

Appendix A: Affect Attunement Protocol (AAP) Original

The Affect Attunement Protocol

Carl-Otto Jonsson, Dep. of Psychology, Stockholm University, after Wendy L. Haft

INCIDENTS THAT MIGHT BE AFFECT ATTUNEMENT, IMITATION OR SOCIAL REFERENCING

Time on band at start of incident: Child no. Age: Scored by
Description of the incident: _____

Duration of the incident (from start of incident until the mother's reactions /attunement etc./ end)sec.

CATCHING (CA): Does the mother catch the affect of the child?

0. Not at all. 1. Somewhat. 2. Markedly

CHANGING (CH): Is the child's affect changed in the reaction of the mother?

0. Not at all. 1. Somewhat. 2. Markedly

CHANGING WITH EFFECT (CHE): Is the mother's reaction likely to change the affect of the infant?

0. Not at all. 1. Somewhat. 2. Markedly

COMMENT (CO): Is the mother's reaction a comment, not an affective reaction or imitation?

0. Not at all. 1. Somewhat. 2. Markedly

MIMICKING (MI): Is the infant's manifest reaction mimicked by the mother?

0. Not at all. 1. Somewhat. 2. Markedly

ARE THERE AFFECTS IN THE INCIDENT (AF)?

On the part of the child (AFC): 0. Not at all. 1. Somewhat. 2. Markedly

On the part of the mother (AFM): 0. Not at all. 1. Somewhat. 2. Markedly

Matching of affect between child and mother: 0. Not at all. 1. Somewhat. 2. Markedly

INTENSITY OF THE ACTION IN THE INCIDENT (INT)

On the part of the child (AFC): 0. Not at all. 1. Somewhat. 2. Markedly

On the part of the mother (AFM): 0. Not at all. 1. Somewhat. 2. Markedly

Matching of intensity between ch. and mo: 0. Not at all. 1. Somewhat. 2. Markedly

MATCHING OF THE DURATION OF THE ACTIONS OF CHILD AND MOTHER (DUR)

0. Not at all. 1. Somewhat. 2. Markedly

MATCHING OF RHYTHM AND FORM OF THE ACTIONS OF CHILD AND MOTHER

0. Not at all. 1. Somewhat. 2. Markedly

MODALITY OF REACTION

On the part of the child (MOC): A. Facial, B. Vocal, C. Gesture, D. Postural

On the part of the moth. (MOM): A. Facial, B. Vocal, C. Gesture, D. Postural

Matching of modality: 0. Quite different. 1. Partly similar. 2. Completely similar

EVALUATION

Affect attunement (AF) 0. Not at all 1. Uncertain 2. Clear

Imitation (IM) 0. Not at all 1. Uncertain 2. Clear

**Appendix B: Initial AABC Form Incorporating The Affect Attunement Protocol
(AAP) and Behavioural Themes in Affect Attunement (BeTA)**

Reproduced with permission from Carl-Otto Jonsson, Dep. of Psychology, Stockholm University, after Wendy L. Haft

INCIDENTS THAT MIGHT BE AFFECT ATTUNEMENT OR IMITATION

Time at start of incident: Time at end: Total: Partner: Sample: Scored by:
Description of the incident:

CATCHING: Does the DSW catch the affect of the pPIMD?

0. Not at all 1. Somewhat 2. Markedly

CHANGING Is the pPIMD's affect changed in the reaction of the DSW?

0. Not at all 1. Somewhat 2. Markedly

CHANGING WITH EFFECT: Is the DSW's reaction likely to change the affect of the pPIMD?

0. Not at all 1. Somewhat 2. Markedly

COMMENT: Is the DSW's reaction a comment, not an affective reaction or imitation?

0. Not at all 1. Somewhat 2. Markedly

MIMICKING: Is the pPIMD's manifest reaction mimicked by the DSW?

0. Not at all 1. Somewhat 2. Markedly

ARE THERE AFFECTS IN THE INCIDENT?

On the part of the pPIMD: 0. Not at all 1. Somewhat 2. Markedly

On the part of the DSW: 0. Not at all 1. Somewhat 2. Markedly

Matching of affect between pPIMD and DSW: 0. Not at all 1. Somewhat 2. Markedly

INTENSITY OF THE ACTION IN THE INCIDENT

On the part of the pPIMD: 0. Not at all 1. Somewhat 2. Markedly

On the part of the DSW: 0. Not at all 1. Somewhat 2. Markedly

Matching of intensity between pPIMD and DSW: 0. Not at all 1. Somewhat 2. Markedly

MATCHING OF THE DURATION OF THE ACTIONS OF PPIMD AND DSW

0. Not at all 1. Somewhat 2. Markedly

MATCHING OF RHYTHM AND FORM OF THE ACTIONS OF PPIMD AND DSW

0. Not at all 1. Somewhat 2. Markedly

MODALITY OF REACTION

On the part of the pPIMD: A. Facial B. Vocal C. Gesture D. Postural

On the part of the DSW: A. Facial B. Vocal C. Gesture D. Postural

Matching of modality: 0. Quite different. 1. Partly similar. 2. Completely similar

EVALUATION

Affect attunement: 0. Not at all 1. Uncertain 2. Clear

Imitation: 0. Not at all 1. Uncertain 2. Clear

	Loss	Sudd	Fall	Risk	Effort	Atten	Emot	Neg	Striv	Eff
Score (0,1,2,3)										

Appendix C: Affect Attunement and Behavioural Coding (AABC) Manual

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February 2009

This coding system has been adapted from several other coding systems devised by Haft (1989), Siegel (1996), and Jonsson and Clinton (2006). Advice and permission was sought directly from Jonsson (personal communication, July 13, 2007).

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Introduction to the System

This coding system was designed for researchers for identifying the use of affect attunement by disability support workers (DSWs) in their interactions with familiar adult interaction partners who have a profound intellectual and multiple disabilities (PIMD). It was also designed to describe the behaviours that the person with PIMD displays, to which the DSW show affect attunement in response.

Examining DSW affect attunement may aid in the description of what occurs in their interactions with adults who have PIMD. Specifically, it is important to establish which behaviours of the person with PIMD the DSW demonstrates attunement to, and the extent to which affect attunement is a behavioural pattern demonstrated by those with particular characteristics.

Definitions

Affect attunement. The performance of behaviours that express the quality of feeling of shared affect state without imitating the exact behavioural expression of the inner state (Stern, 1985). The behavioural modality will be same or different from the eliciting behaviour, however, clear affective emphasis must be present (Jonsson, et al., 2001). The process of affect attunement may be said to involve four phases: firstly, an affect (categorical or vitality) is demonstrated by one person; secondly, this affect is perceived by the interaction partner; thirdly the interaction partner re-casts the affect back to the person (using a same or different modality); and finally, the first person perceives this recast in relation to their own behaviour (Figure C1). Stern (2002) states by using affect attunement the “experience becomes a ‘we’ experience, not only a ‘me’ experience” (p. 14).

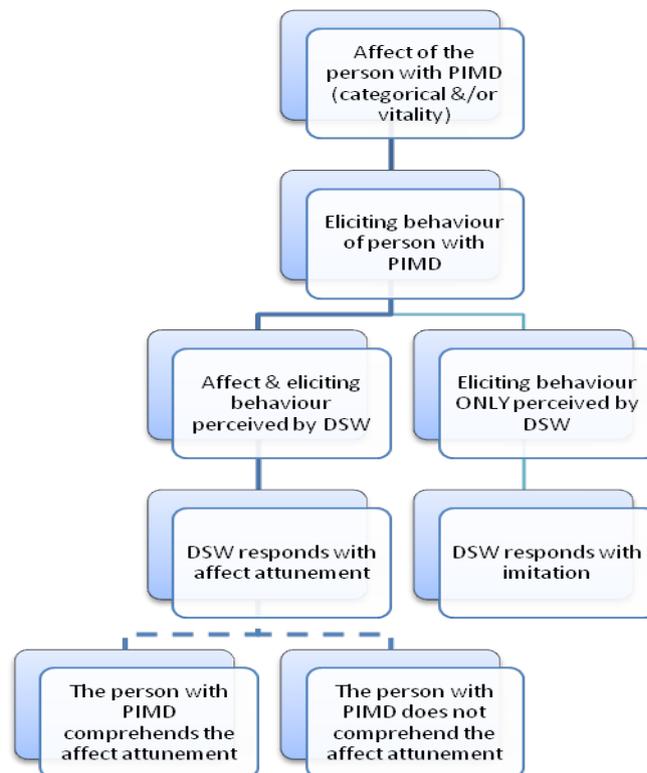


Figure C1. Model of affect attunement and imitation

Affect. A feeling or emotion. Stern (1985) refers to two different types of affect: categorical and vitality. Vitality affects may occur independently or with categorical

affects, such as a “rush” of anger. Stern uses the following illustration to aid in distinguishing the difference between vitality and categorical affects:

The expressiveness of vitality affects can be likened to that of a puppet show. The puppets have little or no capacity to express categories of affect by way of facial signals, and their repertoire of conventionalized gestural [sic] or postural affect signals is usually impoverished. It is from the way they move in general that we infer the different vitality affects from the activation contours they trace. Most often, the characters of different puppets are largely defined in terms of particular vitality affects; one may be lethargic, with drooping limbs and hanging head, another forceful, and still another jaunty. (Stern, 1985, p. 56)

Categorical affect. The discrete categories of happiness, sadness, fear, anger, disgust, surprise, interest, and shame, and their combinations, all of which have a level of intensity and a degree to which they are pleasant or unpleasant (Stern, 1985).

Amodal property. The properties of the behaviour: intensity, timing, and shape.

Eliciting behaviour. The behaviour, whether unintentional or intentional, that results in the interaction partner responding using affect attunement or imitation.

Gesture. For the purposes of this study, gestures refer to movements made by the hands. This may include behaviours such as reaching, clapping, or finger movements. Gestures need not be symbolic (i.e., actions used to represent an idea or concept, such as pointing to an object to indicate a desire for it).

Imitation. The mimicking of facial expressions, movements, and vocalisations, using the same modality as in the eliciting behaviour (Jonsson, et al., 2001).

Modality. The type of behaviour used, that is, vocalisation, facial expression, gesture, or postural change.

Properties of affect behaviours. Affect behaviours are composed of modality and amodal properties (Figure C2). The amodal properties can be applied to all of the modalities. That is, facial behaviours will have properties of intensity, timing, and shape, in the same way that a gestural behaviour has these properties. To Stern (1985), it is the amodal properties of the mother’s behaviour that the infant responds, not the modality per se. Therefore, if a mother matches the amodal properties of the infant’s behaviour, while perhaps using different modalities, the infant is able to perceive the similarity between the mother’s behaviour and its own. This may work similarly for adults with PIMD, however, further investigation is required.

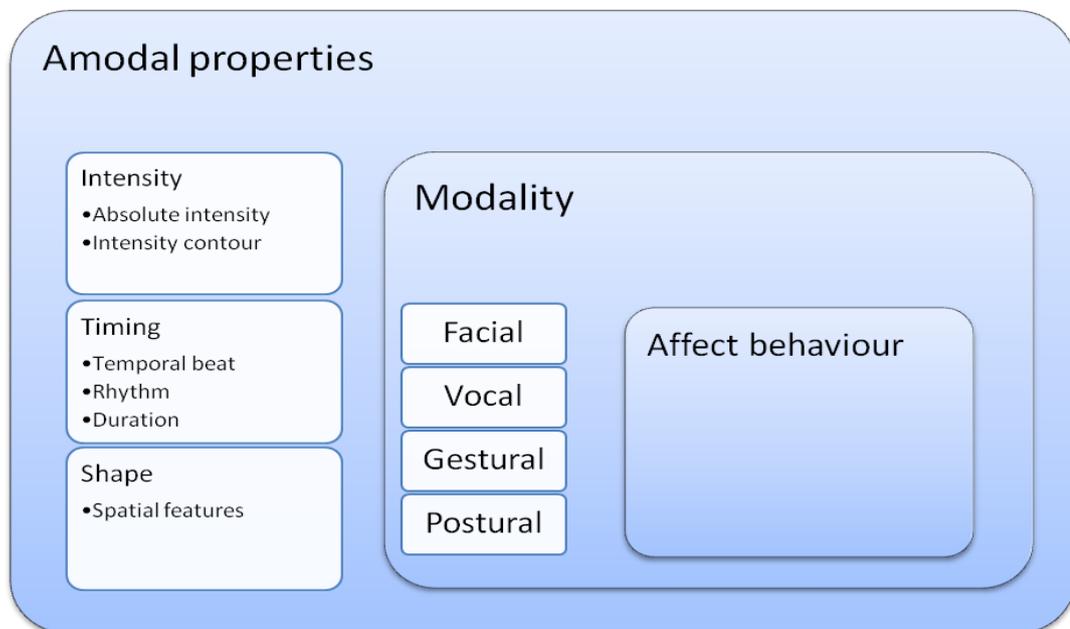


Figure 2: Affect behaviour is composed of modality and amodal properties.

Vitality affect. Stern (1985) used the term vitality affects to describe the forms of feelings involved with the vital processes of life (e.g., breathing, being hungry, or falling asleep). Vitality affects involve dynamic terms such as “surging”, “fleeting”, and “drawn out”, which capture the quality of an experience that is elicited through various motivational states, appetites, and tensions. Essentially, vitality affect refers to *how* a behaviour is performed, not *what* behaviour is performed.

Procedure

Sample Gathering

Codes are applied to videotaped segments of interactions between a DSW and person with PIMD. The video-recordings are made in a place selected by the DSW; usually this is in the person with PIMD's home. The DSW is instructed to interact "as usual" and is able to choose the circumstance which feel most comfortable (e.g., play, mealtimes, table top activity), provided that the experience involves him/herself and the person with PIMD, and does not involve intimate care (i.e., not a toileting routine or clothes changing routines). The dyad is video-recorded for 20 continuous minutes.

Getting good quality video. There are several strategies for obtaining optimum quality video.

- Use a tripod to ensure stable recordings.
- Capture both participants whole bodies where possible.
- Avoid moving the camera during the recording, unless necessary to capture the participants.
- Good lighting is important. You may need to ask participants to turn on the light in a room, or to close a curtain in order to ensure best visual recording. Having lights behind the person can put the person into silhouette, and dim lighting can make it difficult to discriminate facial expressions.

There may be times during video-recording when the video needs to be stopped. Reasons for this may include situations where the privacy of the participant may be compromised (e.g., if they lifted their clothing revealing their underwear) or the privacy of the other residents in the house is compromised (e.g., another resident's face appears on the camera). If another resident's voice / sounds appear on the camera, this is allowable, as is if they briefly pass by the camera or only their back is in view of the

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camera. If privacy is going to be compromised the lens of the camera should be covered for the duration of the disruption and then normal recording should proceed. In some circumstances the camera may need to be switched off.

Another reason for turning off the camera may be that the DSW feels that the interaction has ceased. If 15 minutes has already been captured, then the camera may be turned off. If 10 minutes has been recorded, ask the participant if they would be able to interact for 5 more minutes. If less than 10 minutes has been gathered, you may need to turn off the camera and ask them if you could do some more videoing later. If subsequent videos are a continuous 15 minutes, these should be used for coding.

Criteria for codeable video. For videos to be considered codeable the following criteria must be met:

1. The video must be 15 minutes of continuous recording of the DSW and person with PIMD.
2. Any pauses in the interaction (e.g., the DSW walking away to get a cup, leaving the room, or helping another resident) must not exceed 30 seconds.
3. The faces of both participants must be visible for the majority of the video.
4. The majority of the interaction must involve the DSW directing his/her attention to the person with PIMD (single comments to outside participants are allowable).
5. The auditory quality allows for hearing vocalisations and/or words of both participants.

Coding the Video

A 10 minute continuous segment of the sample is used for coding. Most of the time the coding will begin 3 minutes into the video and finish after 10 minutes of coding, however, there may be videos of which coding may begin earlier as the quality of the first minutes, and the ease of the DSW, are such that it would be valuable to begin the coding at this time.

The first stage in coding is viewing 15 minutes in its entirety. For the purposes of this study, coding is done by consensus by two raters seated together. The two raters should briefly discuss the video, describing the continuum of behaviours observed by both communication partners (e.g., describing what a very intense behaviour looked like for the person with PIMD, as opposed to no intensity). Following this discussion the raters watch the video, pausing it when either rater suspects seeing an incident of affective attunement. Both raters should then proceed independently through stage 2 – 5 of coding, followed by a discussion to create a third consensus rating form. Although it is possible to proceed through each step of the coding in a linear fashion (i.e., complete step 2 for the entire 15 minutes before proceeding to step 3), it is preferable to identify an incident, proceed through each step of coding for this incident, before moving onto the next incident. Each incident should be completed with a confidence rating: 0= not confident about the accuracy of the coding, 1= somewhat confident, 2= confident about the coding. If consensus could not be reached on any section of the coding of the incident, then 0 should be marked in confidence for the third consensus rating form.

Viewing the videos can be done using a range of software, depending on availability and comfort with the software. For this study, the videos were viewed using NVivo 8. This software was chosen because of its ease for importing the video, and managing multiple videos, and its ease for pausing and selecting small units of videos using audio timelines. The details for using NVivo can be seen in the appendix C3.

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The Affect Attunement and Behavioural Coding (AABC) form can be found in Appendix C1, and an example of a completed coding form in Appendix C2.

Stages of coding.

Coding Stages	Data Recorded
1. Preview	Nil
2. Incident of imitation / affect attunement	Time of incident / Description of incident
3. Discriminate imitation / affect attunement	Dimensions of incident
4. Eliciting behaviour	Coding (0-3) on 10 behavioural themes
5. Confidence	Coding (0-3) on confidence of coding

1. Preview. Raters begin by viewing the entire 15 min of interaction. This viewing enables the rater to observe the general interaction pattern. Nothing is written or scored during the first viewing.

2. Incident of Imitation / Affect Attunement. The recording is then played again from the beginning. The rater pauses the video when he/she sees an incident that may be either imitation or affect attunement. That is, the DSW acts within 2 seconds to a behaviour of the person with PIMD using a behaviour that appears imitate or recast the eliciting behaviour of the person with PIMD. This behaviour does not appear to be used to add further information to the eliciting behaviour or to answer the potentially communicative act, but to reflect back to the person their affect or behaviour. The time of the incident is recorded from the beginning of the eliciting behaviour by the person with PIMD to the end of the behavioural response by the DSW. Both times are recorded to the nearest 10th of a second on the AABC form.

The incident is then described using plain language, incorporating the eliciting behaviour of the person with PIMD and the responding behaviour of the DSW. The description should include the movements and sounds observed from the video, in addition to qualities of the behaviours (e.g., quick, slow, sudden).

3. Discriminate Imitation / Affect Attunement. The rater watches the incident again and answers the following questions for that specific incident. Most of the questions require the rater to answer either “not at all,” “somewhat,” or “markedly.” The rater may circle only one response for each question except for the modality of the reaction where as many observed are circled. It is possible to watch the incident several times, however, if the rater is needing to view it more than 4 times to address one question, this suggests a more conservative response of “somewhat” is indicated.

CATCHING: Does the DSW catch the affect of the person with PIMD? That is, does the DSW appear to notice that the person with PIMD has displayed an affect.

CHANGING: Is the person with PIMD’s affect changed in reaction to the DSW? That is, does the person with PIMD show any indication of having noticed that the DSW used an affective attunement response. The rater may need to watch the 2 seconds following the behaviour in order to ascertain whether the person’s affect has changed in reaction to the DSW or not.

COMMENT: Is the DSW’s reaction a comment, not an affective reaction or imitation? Comments are phrases said by DSW that aren’t recasting the person with PIMD’s expression (e.g., “well done!”). They might also be words naming objects that this person is attending to, asking questions, or reinforcing expressions.

INTENSITY OF THE BEHAVIOUR: Intensity refers to qualities such as loudness and forcefulness of the behaviour. Variation in intensity within the behaviours may also be observed through intensity contours, such as a build up, followed by an explosive behaviour, or a fading behaviour. When rating the intensity of the behaviours,

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consider the behaviour as relative to the individual's behaviour throughout the entire video. For example, for a person that provides minimal response, a raised eyebrow and moving forward may be considered to be very intense, or sustained gaze, may be considered to be intense, if the person usually shows no intensity in other behaviours. Similarly, the DSW's level of intensity should be rated in relation to their behaviour throughout the 15 minutes.

Is there matching of intensity between interacts (i.e., are they both using very intense behaviours, or one using intense and the other person very intense)? Matching of intensity is scored as: (0) 2 points different (i.e., one person's behaviour showed no intensity and the other person's was very intense); (1) 1 point different (i.e., one person with none and the other rated as intense, or one rated as intense and the other as very intense); or (2) both were rated at the same level of intensity. Intensity can be matched even when the modalities of the behaviours are different: for example, a sudden arm movement can be matched in intensity with a sudden vocalisation.

DURATION OF THE BEHAVIOURS: Duration refers to the length of time of the eliciting behaviour of the person with PIMD and affect attunement behaviour of the DSW. These behaviours may cross over in duration. Duration is rated as: less than one second, one to two seconds, or longer than two seconds. Matching of duration is scored as: (0) 2 points different (i.e., one person's behaviour is less than 1 second and the other person's is greater than 2 seconds); (1) 1 point different (i.e., one person with >1 and the other with 1-2 seconds, or one rated as 1-2 seconds that the other person as 2+ seconds); or (2) both were rated at the same duration.

RHYTHM AND BEAT OF THE BEHAVIOURS: Beat refers to a regular pulsation, whereas rhythm refers to a pattern of pulsations. These dimensions may be observed through a nodding of the head or a hand gesture, such as clapping. Use basic musical notation for recording the beat and rhythm of the behaviours. Use a crochet (♩)

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for a single beat, a minim (♩) for a longer beat, and quaver (♪) for a half beat. In determining the matching, the two people may use completely different beats, have beats that are somewhat similar, or use exactly the same beat.

SHAPE OF THE BEHAVIOURS: The shape of a behaviour refers to movements in space, such as the up and down move or side-to-side movement of a body part. Shape is a quality that can be difficult to describe. Use arrows and lines to capture the movement (e.g., a slow rising arrow, a side to side arrow, a quick drop downwards). Record whether participants are using markedly the same shape in their behaviours, a somewhat similar shape, or completely different shapes.

MODALITY OF BEHAVIOURS: The modality of the behaviours refers to how it was produced, such as facial, vocal, gestural, or other. Modalities may occur in isolation or simultaneously. Rate modalities of the person with PIMD and the DSW.

Matching of modality: The matching of modality refers to whether the two parties are doing the same behaviour with the same modality, such as both nodding their heads, or both sitting upright in their posture. If there is one difference in the modality (e.g., the person with a disability uses an arm movement gesture, but the DSW does not) circle 1 difference in modality. Circle 0 if there are two or more differences in modality used.

EVALUATION: The evaluation involves discriminating the behaviour of the DSW as either affect attunement or imitation. The incident is deemed to be affect attunement if there is matching in one or more of the amodal parameters, the use of the same or additional modalities, and there is clear affective emphasis. The incident is imitation only if the same modality is used and there is no clear affective emphasis.

4. Eliciting Behaviour. Watch the video again, this time focusing on the eliciting behaviour of the person with PIMD. Rate the behaviour on each of the 10 behavioural themes using the following graded scale:

0. Not present
1. Slightly present
2. Highly present

The behavioural themes are:

- A. *Loss*: Loss of control over actions: a drop in the control over/the regulation of the person's actions. The degree of loss of action control is assessed (e.g., inadvertently dropping an object or losing balance).
 0. no loss of action control
 1. some loss of action control
 2. entirely uncontrolled action (e.g., hiccup, dropping object)
- B. *Sudd*: Sudden or unexpected behaviour: surprise for the person with PIMD in their sudden behaviour (e.g., sneezing).
 0. no suddenness
 1. uncertain and some suddenness/surprise
 2. completely sudden (e.g., burp, or a sudden fall)
- C. *Fall*: Falling: The amount that the person falls, is assessed (e.g., person sits on the floor and tilts backward).
 0. no falling
 1. some body parts tilt or drop
 2. entire body/ torso falls
- D. *Risk*: Risk behaviour: Degree of risk, before pain discomforts or danger arise, for the child (e.g., engaging in a potentially harmful behaviour). Ouch behaviours.

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0. no risk
 1. some small risk of danger to him/herself (e.g., hits face with an object)
 2. clear risk of pain or discomfort
- E. *Effort*: Motor effort in actions and movements: The degree of motor effort in actions/movements (e.g., lifting one object with another or an effortful yawn). Reflexes don't require motor effort.
0. action requiring no effort
 1. some effort (e.g., stretching out arm)
 2. strong effort (e.g., powerful throw of an object)
- F. *Atten*: Attention and curiosity: Focusing attention on animate or inanimate object (e.g., focused gazing at an object or person). (Jonsson does not include interest in the mother, however for this coding gazing intently at the DSW will be considered to be attention).
0. no interest in objects or persons around
 1. some attention (e.g., shows some interest in an object offered by the DSW)
 2. strong attention (e.g., gazing at a picture, gazing at the camera)
- G. *Emot*: Affect: categorical emotional content (e.g., expressions of sadness, happiness, frustration).
0. no emotional stress observed
 1. some emotional stress observed
 2. strong and clear emotional stress
- H. *Neg*: Negative emotion: (e.g., for example sadness or anger).
0. no negative elements
 1. some negative emotion expressed
 2. obvious negative emotion expressed

Appendix C: AABC Manual

- I. *Str*: Striving: the person's movements display a striving expression, effort to achieve (e.g., stretching towards an object from an uncomfortable distance).
 - 0. no striving
 - 1. some striving to achieve
 - 2. strong striving to achieve
- J. *Eff*: Effective action: objective reach to fulfilment. Intentional behaviour with some expectation of effect. The element of “direction” in the action's standard is assessed (e.g., throwing an object or grasping another person).
 - 0. no action that the person is trying to achieve
 - 1. some objective that the person works towards, but not successfully
 - 2. has objective that is achieved by action

Each eliciting behaviour may have components of each theme. Three examples are provided here:

- (1) The person with PIMD startling in response to a banging door may rate as highly present on themes of loss of control and sudden behaviour, but not present on others themes.
- (2) The person with PIMD may push away an offered drink, simultaneously grimacing and turning away, and may rate moderately present on motor effort, moderately present affect and negative affect, and highly present effective action, because they have achieved the aim of pushing the drink away.
- (3) The person with PIMD may look at the DSW, raise his/her eyebrows, and smile, and may rate as slightly present on motor effort, highly present on attention, and highly present on affect.

Appendix C: AABC Manual

5. Confidence. Reflect on the level of confidence with which the coding for this incident were completed.

0. Not at all confident in the coding for this incident/no consensus could be reached
1. Somewhat confident with the coding for this incident
2. Confident with the coding for this incident.

Appendix C: AABC Manual

Appendix C2: Affect Attunement and Behavioural Coding Form - Completed Example

Sheridan Forster, Monash University (after Carl-Otto Jonsson)

Start time: 31.5 End time: 32.7 Total time: 1.2 Sample: 19_120308 Scored by: SF GKM

Description of the incident: Pop sound in the background. D suddenly raises her head, widening her eyes. Yv responds with raise of her head and sudden gasp in sound, she says "Go Swans!"

CATCHING: Does the DSW catch the affect of the person with PIMD?

2. No 1. Yes

CHANGING: Is the person with PIMD's affect changed in the reaction of the DSW?

1. No 1. Yes

COMMENT: Is the DSW's reaction a comment, not an affective reaction or imitation?

0. Not at all 1. Somewhat 2. Markedly

INTENSITY OF THE BEHAVIOUR:

Rate the intensity of the pPIMD behaviour 0. None 1. Intense 2. Very intense
 Rate the intensity of the DSW behaviour 0. None 1. Intense 2. Very intense
 Matching of intensity between interacts: 0. 2 pt diff 1. 1 pnt diff 2. Same intensity

DURATION OF THE BEHAVIOURS:

Duration of the pPIMD behaviour < 1 sec 1-2 sec >2 sec
 Duration of the DSW behaviour < 1 sec 1-2 sec >2 sec
 Matching of duration between interacts: 0. 2 pt diff 1. 1 pt diff 2. Same duration

RHYTHM AND BEAT OF THE BEHAVIOURS:

Draw the beat of pPIMD behaviour  Draw the beat of DSW behaviour 
 Matching of rhythm and beat: 0. Not at all 1. Somewhat 2. Markedly

SHAPE OF THE BEHAVIOURS:

Draw the shape of pPIMD behaviour  Draw the shape of DSW behaviour 
 Matching of spatial shape: 0. Not at all 1. Somewhat 2. Markedly

MODALITY OF REACTION

On the part of the person with PIMD: A. Facial B. Vocal C. Gesture D. Postural E. Other
 On the part of the DSW: A. Facial B. Vocal C. Gesture D. Postural E. Other
 Matching of modality: 0. 2+ diff 1. 1 diff in modality 2. Same

EVALUATION

Affect attunement: 0. Not at all 1. Uncertain 2. Clear
 Imitation: 0. Not at all 1. Uncertain 2. Clear

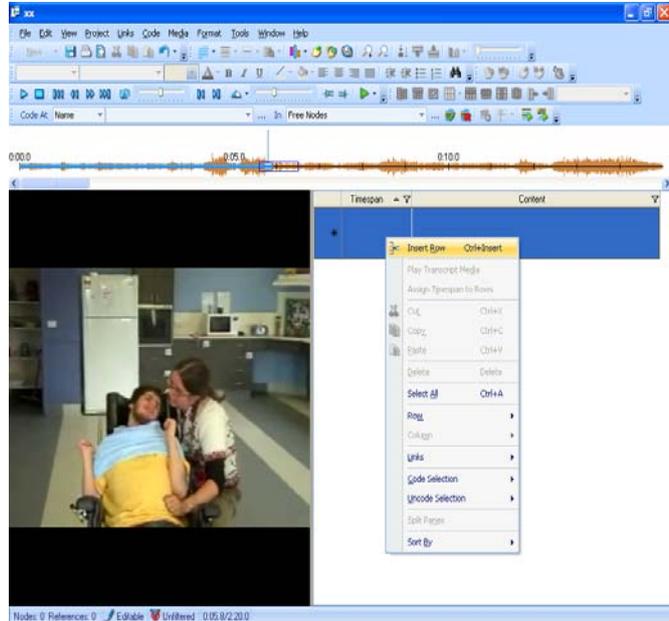
	Loss	Sudd	Fall	Risk	Effort	Atten	Emot	Neg	Striv	Eff
Score (0,1,2)	0	2	0	0	1	2	0	0	0	0

CONFIDENCE: How confident are you with the coding of this incident?

0. Not at all 1. Somewhat 2. Very confident

Appendix C3: Using NVivo 8 for Video Analysis

1. Import the video (Project – New Internal – Video), name the video, then click on Media – Import Media Content, and browse for your video
2. Double click on the video to open the video. You should be able to see a timeline, the video and the Timespan box.
3. Play the video.
4. To code the video, pause it near the incident. Click on the magnifier with the + to focus in on the timeline.
5. Select the incident on the timeline by using click and drag to select the required time. Then go to the Timespan boxes, right-click and select Insert Row. This will insert this time block into the Timespan, and make it easier for you to review the incident later.
6. To return to viewing the video use the magnifier – to view more of the timeline.
7. Continue steps 4-6 until complete.



References

- Haft, W. L. (1989). *Affect attunement and maternal attachment: An observational study of the intergenerational transmission of mothers' internal representations of attachment*. Ph.D. thesis, City University of New York.
- Jonsson, C.-O., & Clinton, D. (2006). What do mothers attune to during interactions with their infants? *Infant and Child Development*, *15*(4), 387-402. doi: 10.1002/icd.466
- Jonsson, C.-O., Clinton, D., Fahrman, M., Mazzaglia, G., Novak, S., & Sorhus, K. (2001). How do mothers signal shared feeling states to their infants? An investigation of affect attunement and imitation during the first year of life. *Scandinavian Journal of Psychology*, *42*(4), 377-381. doi: 10.1111/1467-9450.00249
- Siegel, N. (1996). *Affect attunement and infant-mother attachment*. Doctor of Philosophy, City University of New York, New York, NY.
- Stern, D. (1985). *The interpersonal world of the infant: A view from psychoanalysis and developmental psychology*. New York, NY: Basic Books.
- Stern, D. N. (2002). *The first relationship: Infant and mother (with a new introduction)*. London, England: Harvard University Press.

Appendix D: Ethics Approval Letters (Monash University & Scope)



Standing Committee on Ethics in Research Involving Humans (SCERH)
Research Office

Human Ethics Certificate of Approval

Date: 26 May 2008
Project Number: CF08/0973 - 2008000441
Project Title: Interactions between disability support workers and people with profound intellectual and multiple disabilities
Chief Investigator: Dr Teresa Iacono
Approved: From: 26 May 2008 to 26 May 2013

Terms of approval

1. The Chief investigator is responsible for ensuring that permission letters are obtained and a copy forwarded to SCERH before any data collection can occur at the specified organisation. **Failure to provide permission letters to SCERH before data collection commences is in breach of the National Statement on Ethical Conduct in Human Research and the Australian Code for the Responsible Conduct of Research.**
2. Approval is only valid whilst you hold a position at Monash University.
3. It is the responsibility of the Chief Investigator to ensure that all investigators are aware of the terms of approval and to ensure the project is conducted as approved by SCERH.
4. You should notify SCERH immediately of any serious or unexpected adverse effects on participants or unforeseen events affecting the ethical acceptability of the project.
5. The Explanatory Statement must be on Monash University letterhead and the Monash University complaints clause must contain your project number.
6. **Amendments to the approved project:** Requires the submission of a Request for Amendment form to SCERH and must not begin without written approval from SCERH. Substantial variations may require a new application.
7. **Future correspondence:** Please quote the project number and project title above in any further correspondence.
8. **Annual reports:** Continued approval of this project is dependent on the submission of an Annual Report. This is determined by the date of your letter of approval.
9. **Final report:** A Final Report should be provided at the conclusion of the project. SCERH should be notified if the project is discontinued before the expected date of completion.
10. **Monitoring:** Projects may be subject to an audit or any other form of monitoring by SCERH at any time.
11. **Retention and storage of data:** The Chief Investigator is responsible for the storage and retention of original data pertaining to a project for a minimum period of five years.

A handwritten signature in black ink, appearing to read "Ben Canny".

Professor Ben Canny
Chair, SCERH

Cc: Ms Sheridan Lee Forster;

Postal – Monash University, Vic 3800, Australia
Building 3E, Room 111, Clayton Campus, Wellington Road, Clayton
Telephone +61 3 9905 5490 Facsimile +61 3 9905 1420
Email scerh@adm.monash.edu.au www.monash.edu/research/ethics/human/index/html
ABN 12 377 614 012 CRICOS Provider #00008C



Scope (Vic) Ltd
ABN 63 004 280 871

830 Whitehorse Road
PO Box 608 Box Hill 3128

Tel (03) 9843 3000
Fax (03) 9843 2030
Email contact@scopevic.org.au

www.scopevic.org.au

27th January 2009

Ms Sheridan Forster
PhD Candidate
General Practice: Centre for Developmental Disability, Health Victoria
Monash University
Building 1, 270 Ferntree Gully Road
Notting Hill VIC 3168

Dear Ms Forster

RE: Scope 32/08 – Interactions between disability support workers and people with profound intellectual and multiple disabilities.

This letter is to advise formal approval for Project 32/08.

You are now free to proceed with the research in Scope from an ethics perspective.

If you are having any problems with contacting Regional Managers, please let me know.

Yours sincerely

A handwritten signature in blue ink that reads "Michael Bink".

Michael Bink
Head of Research & Community Development
Executive Officer, Scope Ethics Advisory Committee

HREC: EC00428
ORG: ORG0554

Chief Patron Professor David de Kretser, AO, Governor of Victoria
Patrons Mr. J.W.R. Pratt, AM & Mrs. L Pratt, Mr. V.R. Ruth & Mrs. E. Ruth

Member CP Australia
Donations of \$2 and over
are tax deductible

Appendix E: Explanatory Statements and Consent Forms

[University Letterhead]

09/02/09

Explanatory Statement

(For the person who can consent on behalf of a person with a disability)

Interactions between disability support workers and people with profound intellectual and multiple disabilities

This information sheet is for you to keep.

My name is Sheridan Forster and I am conducting a research project under the supervision of Dr. Teresa Iacono, Research Director, Centre for Developmental Disability Health Victoria, towards a Doctorate of Philosophy at Monash University. The research is part of my doctoral thesis.

Aim of the study

I am interested in interactions between disability support workers and people with profound intellectual and multiple disabilities living in residential services.

People with a profound intellectual and multiple disabilities will have at least 4 of the following characteristics:

- Major sensory impairment (e.g. hearing or vision)
- Severe motor difficulties
- Absence of verbal skills
- Dependence upon others to meet basic daily needs
- Apparent lack of engagement with the environment.

All these things can challenge interactions. Disability support workers are often the people that interact most with people living in residential services. There is very little research about what occurs in the everyday interactions between these two groups of people.

The aim of this research is to learn more about the interactions that occur between people with profound intellectual and multiple disabilities and their residential disability support workers. I want to find out what occurs when these two people are together interacting.

Why you have received this pamphlet

[Name of organisation] has sent this pamphlet on our behalf to the nearest relative or other person responsible for an adult with profound intellectual disability who they think may be suitable to participate in the study. People with profound intellectual

Appendix E: Consent

disability would not be able to fully understand this research, therefore we seek your permission to include this person in the study.

Who else is being asked to participate in the study?

After I have consent on behalf of the person with a profound intellectual and multiple disability, I will contact their House Supervisor to invite a disability worker to be involved in the study. Only disability support workers who have worked with the person for more than 12 months, and therefore knows that person well, will be invited to participate.

What does being in the study mean?

When I have received consent on behalf of the person with a disability and one of their disability support workers, I will contact the disability support worker to make an appointment to see them and the person with a disability at the residential house.

The research involves:

- asking questions about the person with a profound intellectual and multiple disability, such as the type of disability that the person has, the person's hearing and vision, and way of communicating
- a formal questionnaire with questions about what the person with a disability can do (e.g., how they eat, if they can pick up objects, and if they can make sounds).
- asking questions about the disability support worker, such as their age, whether they have children, and how long they have worked with the person with a disability
- a short video recording of the two people interacting together in a way that the support worker feels is typical of their daily interactions.

How much time will the research take?

The questions will take the disability support worker about 30 minutes to complete. The video recording will take about 30 minutes. Both the questions and video recording can be done on the same day.

Possible benefits

I hope that gaining a better understanding of what happens in interactions will contribute to improving services for people with profound intellectual and multiple disabilities. By knowing more about what happens in everyday interactions we may improve the quality of lives of people with disabilities through improved training and standards of support. However, there may not be any direct benefits to the person with profound intellectual and multiple disability as a result of being in this study.

Inconvenience/discomfort

The research will be done within a regular shift in the residential service. I hope that this will not disrupt the person's regular routine.

The disability support worker may also feel uncomfortable being video recorded.

Usually this discomfort reduces after a few minutes. Disability workers will be reassured that I am not looking at whether they do things correctly or incorrectly. Instead, I want to learn about the natural and everyday interactions between a disability worker and the person she or he supports.

Appendix E: Consent

I will not be recording the person receiving intimate care (e.g. being in the bathroom or getting changed).

Payment

There is no payment for being involved in this study.

Can I withdraw the person from the research?

Being in this study is voluntary and you are under no obligation to consent for the person to participate. If you do consent to participate, you may withdraw at any time simply by contacting one of the researchers.

Confidentiality

The questions asked to the disability support worker may be audio-taped. Video-recordings will be made of all participants. Participant names will not appear on written or multimedia recordings. Instead, codes will be given to each person. The list of names and codes will be kept separately to the information collected. Only the researchers will have access to the video- and audio-recordings. No names will be used in reporting of any of the information, therefore participation is confidential.

Storage of data

Storage of the data collected will adhere to the University regulations. All information in paper form will be kept on University premises in a locked cupboard/filing cabinet for 5 years. Electronic information (e.g., analyses of the interactions) will be stored in password protected files. This information will be accessed only by the researchers. A report of the study may be submitted for publication, but individual participants will not be identifiable in such a report.

Results

In doing this research, I will be writing a thesis, reports for research journals, and presenting the findings at conferences. If you would like to be informed of the overall research finding, please contact Sheridan Forster on 8575 2260 or sheridan.forster@med.monash.edu.au. The findings will be accessible for 2 years.

If you would like to contact the researchers about any aspect of this study, please contact the Chief Investigator:	If you have a complaint concerning the manner in which this research <CF08/0973> is being conducted, please contact:
Ms. Sheridan Forster Centre for Developmental Disability Health Victoria Tel: +61 3 8575 2260 Fax: +61 3 8575 2270 Email: sheridan.forster@med.monash.edu.au	Human Ethics Officer Standing Committee on Ethics in Research Involving Humans (SCERH) Building 3e Room 111 Research Office Monash University VIC 3800 Tel: +61 3 9905 2052 Fax: +61 3 9905 1420 Email: scerh@adm.monash.edu.au

Thank you.

Sheridan Forster

Consent Form

(For the person who can consent on behalf of a person with a disability)

Interactions between disability support workers and people with profound intellectual and multiple disabilities

NOTE: Signed written consent will remain with the Monash University researchers for their records.

<p>Does the person have a profound intellectual and multiple disability? (please select)</p> <ul style="list-style-type: none"><input type="checkbox"/> Major sensory impairment<input type="checkbox"/> Severe motor difficulties<input type="checkbox"/> Absence of verbal skills<input type="checkbox"/> Dependence upon others to meet basic daily needs<input type="checkbox"/> Apparent lack of engagement with the environment. <p>If the person demonstrates at least four of these characteristics, she or he is eligible for this research.</p>	<p>Who can provide consent on behalf of the person with an intellectual disability (please select the category that describes you)</p> <ul style="list-style-type: none"><input type="checkbox"/> Next-of-kin/ relative<input type="checkbox"/> Legal guardian<input type="checkbox"/> Person responsible for the individual
---	--

I agree that _____(insert full name of participant) may take part in the above Monash University research project. I have read the Explanatory Statement and any questions I had have been answered. I will keep the Explanatory Statement for my records.

I understand that agreeing to take part means that I am willing to allow _____(insert full name of participant) to:

- Have questions answered about them by their disability support worker
- Be video-recorded in 30 minutes of interaction with their disability support worker

Participant's name:

Phone Number of Residence of the Person with Disability:

Your name:

Your relationship to the person:

Your phone number:

Your address (if you would like to receive a copy of a summary of the research on completion):

.....

Your signature:

Date:

[University Letterhead]

10th December 2008

Explanatory Statement
(Disability Support Worker)

Interactions between disability support workers and people with profound intellectual and multiple disabilities

This information sheet is for you to keep.

My name is Sheridan Forster and I am conducting a research project under the supervision of Dr. Teresa Iacono, Research Director, Centre for Developmental Disability Health Victoria, towards a Doctorate of Philosophy at Monash University. The research is part of my doctoral thesis.

Aim of the study

I am interested in interactions between disability support workers and people with profound intellectual and multiple disabilities living in residential services.

People with a profound intellectual and multiple disabilities will have at least 4 of the following characteristics:

- Major sensory impairment (e.g. hearing or vision)
- Severe motor difficulties
- Absence of verbal skills
- Dependence upon others to meet basic daily needs
- Apparent lack of engagement with the environment.

All these things can challenge interactions. Disability support workers are often the people that interact most with people living in residential services. There is very little research about what occurs in the everyday interactions between these two groups of people.

The aim of this research is to learn more about the interactions that occur between people with profound intellectual and multiple disabilities and their residential disability support workers. I want to find out what occurs when these two people are together interacting.

Why you have received this pamphlet

_____ has provided consent for _____ to participate in this study. I have asked your House Supervisor to forward this pamphlet to you because you are a disability support for this person. I am looking for one disability support worker to participate with _____ in this study. I am looking for somebody who has worked with the person for at least 12 months.

If you would like to participate, please complete the enclosed consent form and return it using the reply paid envelope provided. I will only require one disability support

Appendix E: Consent

worker for each person with a disability, therefore will recruit the first worker who has worked with the person for the required period and returns a consent form.

When I have received consent on behalf of the person with a disability and one of their disability support workers, I will contact the disability support worker to make an appointment to see them and the person with a disability at the residence.

The research involves:

- asking questions about the person with a profound intellectual and multiple disability, such as the type of disability that the person has, the person's hearing and vision, and way of communicating
- a formal questionnaire with questions about what the person with a disability can do (e.g., how they eat, if they can pick up objects, and if they can make sounds).
- asking questions about the disability support worker, such as their age, whether they have children, and how long they have worked with the person with a disability
- a short video recording of the two people interacting together in a way that the support worker feels is typical of their daily interactions.

How much time will the research take?

The questions will take the disability support worker about 30 minutes to complete. The video recording will take about 30 minutes. Both the questions and video recording can be done on the same day.

Possible benefits

I hope that gaining a better understanding of what happens in interactions will contribute to improving services for people with profound intellectual and multiple disabilities. By knowing more about what happens in everyday interactions we may improve the quality of lives of people with disabilities, through improved training and standards of support. However, there may not be any direct benefits to the person with profound intellectual and multiple disability as a result of being in this study.

Inconvenience/discomfort

The research will be done within a regular shift in the residential service. I hope that this will not disrupt the person's regular routine.

The disability support worker may feel uncomfortable being video recorded. Usually this discomfort reduces after a few minutes. Please be assured that I am not looking at whether the support worker does things correctly or incorrectly. Instead, I want to learn about the natural and everyday interactions between a disability worker and the person she or he supports.

I will not be recording the person receiving intimate care (e.g. being in the bathroom or getting changed).

Payment

There is no payment for being involved in this study.

Being in the study is voluntary

Appendix E: Consent

Being in this study is voluntary and you are under no obligation to consent to participate. Although your employer has given permission for disability support workers to participate in the study, and for it to be conducted in work time, you are not obliged to participate. Your decision will not affect your employment or any current or future services received by the person with disability by the Centre for Developmental Disability Health Victoria. If you do consent to participate, you may withdraw at any time.

Confidentiality

The questions asked to the you may be audio-taped. Video-recordings will be made of all participants. Participant names will be not appear on written or multimedia recordings. Instead, codes will be given to each person. The list of names and codes will be kept separately to the information collected. Only the researchers will have access to the video- and audio-recordings. No names will be used in reporting of any of the information, therefore participation is confidential.

Storage of data

Storage of the data collected will adhere to the University regulations. All information in paper form will be kept on University premises in a locked cupboard/filing cabinet for 5 years. Electronic information (e.g., analyses of the interactions) will be stored in password protected files. This information will be accessed only by the researchers. A report of the study may be submitted for publication, but individual participants will not be identifiable in such a report.

Results

In doing this research, I will be writing a thesis, reports for research journals, and presenting the findings at conferences. If you would like to be informed of the overall research finding, please contact Sheridan Forster on 8575 2260 or sheridan.forster@med.monash.edu.au. The findings will be accessible for 2 years.

If you would like to contact the researchers about any aspect of this study, please contact the Chief Investigator:	If you have a complaint concerning the manner in which this research <CF08/0973> is being conducted, please contact:
Ms. Sheridan Forster Centre for Developmental Disability Health Victoria Tel: +61 3 8575 2260 Fax: +61 3 8575 2270 Email: sheridan.forster@med.monash.edu.au	Human Ethics Officer Standing Committee on Ethics in Research Involving Humans (SCERH) Building 3e Room 111 Research Office Monash University VIC 3800 Tel: +61 3 9905 2052 Fax: +61 3 9905 1420 Email: scerh@adm.monash.edu.au

Thank you
Sheridan Forster

Consent Form

(For the disability support worker)

Interactions between disability support workers and people with profound intellectual and multiple disabilities

NOTE: This consent form will remain with the Monash University researcher for their records

I agree to take part in the Monash University research project specified above. I have had the project explained to me, and I have read the Explanatory Statement, which I keep for my records. I understand that agreeing to take part means that I am willing to:

I agree to be interviewed by the researcher Yes No

I agree to allow the interview to be audio-taped (optional) Yes No

I agree to allow myself to be video-recorded for 30 minutes with the person who has a profound intellectual and multiple disability within a working shift at the residential service Yes No

I understand that my participation is voluntary, that I can choose not to participate in part or all of the project, and that I can withdraw at any stage of the project without being penalised or disadvantaged in any way.

I understand that any data that the researcher extracts from the interview and video-recordings for use in reports or published findings will not, under any circumstances, contain names or identifying characteristics.

I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party.

I understand that data from the interview, audio-tape, and video recording will be kept in a secure storage and accessible to the research team. I also understand that the data will be destroyed after a 5 year period unless I consent to it being used in future research.

Your name:

Your phone number (to arrange an appointment):

Name of person you support (for whom proxy consent has been provided):

Your address (if you would like to receive a copy of a summary of the research on completion):

.....

Your signature:

Date: ..

Appendix F: Demographic Questions

Demographic survey: Disability Support Worker

Research number:
Age:
Gender: M / F

For each item identified below, tick one box for each question except age group of children.
Write in the answer for country of birth and years of work.

What is your highest level of education?

- Some high school
- Year 10 high school
- Year 12 high school
- TAFE level course (e.g. Certificate IV in Community Services)
- Undergraduate university
- Postgraduate university
- Other (please specify): _____

Are you a parent?

- No
- Yes

If yes, what is the age group of your children (circle all that apply)

- Pre-school
- Primary school
- Secondary school
- Adult
- Adult children and grandchildren

Country of birth (if not Australia, years in Australia): _____

Length of time working with people with disabilities as a disability support worker: _____

Length of time working with the person with a disability involved in this study: _____

Appendix F: Demographic Questions

Demographic survey: Participant with a disability

Research number: Age: Gender: M / F

For each item identified below, tick one box for each question except medication where as many as is appropriate should be ticked and described.

What is the person's formal diagnosis?

Does the person have epilepsy?

- No
- Has controlled epilepsy (no seizures in last year)
- Less than monthly seizures
- Monthly seizures
- Weekly seizures or more often

Overall, how would you rate the health of the person

- Good
- Sometimes unwell
- Unwell most of the time

Is the person on any medication (what is the name of the medication)?

- None
- For health problem: _____
- For mood, anxiety, sleep, or behaviour: _____
- For epilepsy, seizures: _____
- Other: _____
- Unknown: _____

In your opinion, which best describes the vision of the person?

- Sees well (may wear glasses)
- Vision problems limit making eye contact over 2 metres away (may wear glasses)
- Little or no useful vision (even with glasses)

In your opinion, which best describes the person's hearing?

- Hears normal conversation level voices (may use hearing aid)
- Hears only loud voice (may use hearing aid)
- Little or no useful hearing (even with hearing aid)

Which statement best describes the person's mobility?

- Able to walk around easily
- Able to walk independently but can be unsteady and may need supervision
- Requires support of staff member to walk
- Unable to walk but can assist with transfers
- Unable to walk or help with transfers

Which statement best describes the person's way of communicating?

- Communicates through short sentences or picture sequences
- Communicates through single words or pictures
- Communicates through gestures (e.g. pointing 1 metre away) or basic signs (e.g. toilet)
- Communicates through looking at or reaching to things
- Communicates through body language and facial expression only

Appendix G: Conference Papers About This Research

- Forster, S., & Iacono, T. (2008). *Interactions between disability support workers and people with PIMD: Different coding perspectives*. Paper presented at the 13th IASSID World Congress, Cape Town, South Africa.
- Forster, S., & Iacono, T. (2008). *What's happening in interactions between disability support workers and people with profound intellectual and multiple disabilities: Different coding perspectives*. Paper presented at the ASSID 43rdth Annual Conference: Principles, policies & practices: The search for evidence, Melbourne, Australia.
- Forster, S., & Iacono, T. (2009). *Interactions between disability support workers and adults with PIMD: Affect attunement*. Paper presented at the 2nd Young Researcher Colloquium of the IASSID special interest research group on persons with profound intellectual and multiple disabilities, Cologne, Germany.
- Forster, S., & Iacono, T. (2009). *The power in moments of connection: Interactions between disability support workers and adults with profound intellectual and multiple disabilities*. Paper presented at the 2nd Asia-Pacific IASSID Regional Conference, Singapore.
- Forster, S., & Iacono, T. (2009). *The power in moments of connection: Interactions between disability support workers and adults with profound intellectual and multiple disabilities*. Paper presented at the AGOSCI Biennial Conference, Canberra, Australia.
- Forster, S., & Iacono, T. (2010). *Affective attunement between disability support workers and adults with profound intellectual disability*. Paper presented at the ASSID 45th Annual Conference: Seeking excellence, Brisbane, Australia.
- Forster, S., & Iacono, T. (2010). *It's communication Jim, but not as we know: Coding nonsymbolic based interaction*. Poster presented at the Speech Pathology Australia National Conference: Participation 2010, Melbourne, Australia.