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Title	Reconciling communication repertoires: a classic grounded theory of navigating interactions involving persons with severe/ profound intellectual disability
Authors	Martin, Anne-Marie
Publication date	2020-03-16
Original Citation	Martin, A-M. 2020. Reconciling communication repertoires: a classic grounded theory of navigating interactions involving persons with severe/profound intellectual disability. PhD Thesis, University College Cork.
Type of publication	Doctoral thesis
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Download date	2026-10-31 02:31:13
Item downloaded from	https://hdl.handle.net/10468/10556

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Reconciling Communication Repertoires

A Classic Grounded Theory of Navigating Interactions Involving Persons with Severe/Profound Intellectual Disability

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March 2020

Contents

List of Tables ..... **vii**

List of Figures ..... **viii**

List of Appendices ..... **ix**

Glossary of Abbreviations ..... **x**

Authors Declaration ..... **xii**

Acknowledgements ..... **xiii**

Abstract ..... **xv**

Chapter 1 Introduction **1**

1.1 Introduction 1

1.2 One Cannot Not Communicate 1

1.3 Person Centredness 3

1.4 Previous Research 3

1.5 Sequential Overview of Thesis 5

1.6 Summary 7

Chapter 2 Background **8**

2.1 Introduction 8

2.2 Interpersonal Communication 8

2.3 Intellectual Disability 11

2.4 Severe/Profound Intellectual Disability 13

2.5 Severe/Profound Intellectual Disability and Communication 16

2.6 Communication Partners Perspectives 18

2.7 Communication as a Right 20

2.8 Severe/Profound Intellectual Disability, Communication and Quality of Life 24

2.9 International and National Policy Driving the Rights Agenda 26

2.10 The Irish Legislative Landscape 30

2.11 Implementation and Progression of Policies and Strategies 32

2.12 Conclusion 34

Chapter 3 Research Methodology 37

3.1 Introduction 37

3.2 Study Aim 38

3.3 Paradigms for Research 39

3.4 Ontology and Epistemology 40

3.4.1 Realism 41

3.4.2 Relativism 44

3.5 Methodology 49

3.6 Grounded Theory 50

3.6.1 Development of Grounded Theory 50

3.6.2 Adopting a Grounded Theory Methodology 55

3.7 Philosophical Assumptions of this Study 56

3.8 Conclusion 57

Chapter 4 Method 58

4.1 Introduction 58
4.2 Why Classic Grounded Theory? 58
4.3 Aim and Objectives 59
4.4 Ethical Considerations....61
4.4.1 Beneficence and Non-Maleficence 62
4.4.2 Autonomy.... 66
4.4.3 Justice.... 69
4.4.4 Ethical approval.... 70
4.5 Access and Gate-Keeping....70
4.6 Sampling, Data Collection and Data Analysis....72
4.7 Sampling....72
4.7.1 Theoretical Sampling.... 73
4.7.2 Gaining Trust and Acceptance 77
4.8 Data Collection....79
4.8.1 Observations 80
4.8.2 Interviews.... 85
4.8.3 Saturation.... 87
4.8.4 Data Management 88
4.9 Data Analysis....89
4.9.1 Memoing 90
4.9.2 Substantive Coding.... 92
4.9.3 Theoretical Coding 100

4.10 Ensuring Quality 104
4.10.1 Fit, Work, Relevance, Modifiability 105
4.10.2 Methodological Quality Assurance 106
4.10.3 Responding to Threats to Quality 107
4.11 Role of the Researcher 108
4.11.1 Staying Open 109
4.11.2 Theoretical Pacing 110
4.11.3 Being Theoretically Sensitive 111
4.12 Conclusion 112
Chapter 5 Theory of Reconciling Communication Repertoires 114
5.1 Introduction 114
5.2 Overview of the Theory of Reconciling Communication Repertoires 115
5.3 Reconciling Communication Repertoires 119
5.4 Economising Effort 122
5.4.1 Interference Appeal vs. Probable Outcome 123
5.4.2 Complexity of Interaction vs. Probable Outcome 124
5.4.3 Time Demands vs. Probable Outcome 124
5.5 Stage 1: Motivation to Interact 125
5.6 Stage 2: Connection Establishment 127
5.6.1 Opportunity Seeking 127
5.6.2 Attention Grabbing 129
5.7 Connection Maintenance 131

5.8 Stage 3: Reciprocally Engaging.....134
5.8.1 Activity Sharing..... 134
5.8.2 Conversing..... 137
5.9 Stage 4: Navigating Understanding.....142
5.9.1 Experiencing Understanding..... 142
5.9.2 Appraising Understanding..... 145
5.10 Stage 5: Confusion Resolution 146
5.10.1 Revising 147
5.10.2 Repeating 148
5.10.3 Acquiescing 148
5.10.4 Resigning 149
5.11 Conclusion 150
Chapter 6 Discussion 153
6.1 Introduction 153
6.2 The Integrative Review 154
6.2.1 Stage 1: Problem Identification..... 156
6.2.2 Stage 2: Literature Search 158
6.2.3 Stage 3: Data Evaluation 160
6.2.4 Stage 4: Data Analysis 162
6.2.5 Stage 5: Presentation-Reporting the Conclusions 162
6.3 The Theory of Reconciling Communication Repertoires and Existing Knowledge.....162

6.3.1 Communication Repertoires 163

6.3.2 Motivation to Interact 170

6.3.3 Connectedness 174

6.3.4 Reciprocal Engaging 179

6.3.5 Understanding 186

6.3.6 Confusion Resolution 195

6.4 Conclusion 202

Chapter 7 Implications and Conclusions 205

7.1 Introduction 205

7.2 Practice Implications 206

7.3 Policy Implications 208

7.4 Management Implications 209

7.5 Education Implications 210

7.6 Research Implications 212

7.7 Strengths and Limitations 214

7.8 Dissemination Plan 216

7.9 Conclusion 219

References 222

Appendices 271

List of Tables

Table 4.1 Observational Data Breakdown 88

Table 5.1 Typology of Understanding 144

Table 5.2 Matrix of Appraising Understanding 146

Table 6.1 The Integrative Review Process (Whittemore and Knafl 2005) 155

List of Figures

Figure 4.1 Sociogram for Ben and Rose 75

Figure 4.2 Sociogram for David 77

Figure 5.1 Theory of Reconciling Communication Repertoires 118

Figure 5.2 Reconciling Repertoires 121

Figure 5.3 Effort Efficiency – Balancing Demands and Outcomes 123

Figure 5.4 Establishing a Connection 127

Figure 5.5 Opportunity Seeking: Ben and Jane 129

Figure 5.6 Connection Maintenance 131

Figure 5.7 The Connection Continuum 132

Figure 5.8 Parallel participating in Shared Activities 135

Figure 5.9 Collaborative Participating: Linda and David 136

Figure 5.10 Impact of Routine on Understanding 136

Figure 5.11 Routine Activities: Rose 137

Figure 5.12 Subtle Hinting: David 139

Figure 5.13 Multi-messaging 140

Figure 5.14 Message Recognition 143

Figure 5.15 Revising: David 147

Figure 5.16 Acquiescing: Jane and Ben 149

List of Appendices

Appendix I Ethical Approval from UCC Social Research Ethics Committee 272

Appendix II Ethical Approval from Service Provider 1 273

Appendix III Ethical Approval from Service Provider 2 274

Appendix IV Proxy Information Sheet and Consent Form 275

Appendix V Information Sheet and Consent Form for those Self-consenting ... 278

Appendix VI Observational Data Bank 281

Appendix VII Blank Video Transcript 282

Appendix VIII Sample Memos 283

Appendix IX Blank Interview Transcript 284

Appendix X Photographs of Sorting 285

Appendix XI CINAHL Search 286

Appendix XII Social Science Premium and Education Collection Search 287

Appendix XIII Linguistics Collection Search 288

Appendix XIV Scopus Search 289

Appendix XV Detailed Dissemination Plan 290

Appendix XVI Acceptance of Oral Paper for IASSIDD World Congress 295

Appendix XVII Awarding of Carla Vlaskamp Award 296

Appendix XVIII Awarding of College of Medicine and Health Bursary 297

Appendix XIX Masterclass: Communicating with Persons with Severe/Profound Intellectual Disability 298

Glossary of Abbreviations

AAIDD	American Association on Intellectual and Developmental Disabilities
ABA	An Bord Altranais
ADMA	The Assisted Decision-Making Act (2015)
APA	American Psychiatric Association
CINAHL	Cumulative Index to Nursing and Allied Health Literature
COMH	College of Medicine and Health
EPSEN	The Education for Persons with Special Education Needs Act 2004
ERIC	Education Resource Information Centre
EU	European Union
HIQA	Health Information and Quality Authority
HSE	Health Service Executive
IASSIDD	International Association for the Scientific Study of Intellectual and Developmental Disabilities
ICD -10/-11	International Statistical Classification of Diseases and Related Health Problems -10th revision/-11th revision
IDS-TILDA	Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing
IHREC	Irish Human Rights and Equality Commission

IQ	Intelligence Quotient
NDA	National Disability Authority
NIDD	National Intellectual Disability Database
NMBI	Nursing and Midwifery Board of Ireland
PIMD-SIRG	Profound Intellectual and Multiple Disabilities Special Interest Research Group
PRP	Progress Review Panel
UCC SREC	University College Cork Social Research Ethics Committee
UN	United Nations
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
UNDIS	United Nations Disability Inclusion Strategy
VFM-PRDS	Value for Money and Policy Review of Disability Services

Authors Declaration

This is to certify that the work I am submitting is my own and has not been submitted for another degree, either at University College Cork or elsewhere. All external references and sources are clearly acknowledged and identified within the contents. I have read and understood the regulations of University College Cork concerning plagiarism.

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Acknowledgements

I wish to acknowledge the following people who, without their support and encouragement, this study would not have been possible.

My supervisors, Dr. Tom Andrews, Prof. Juliet Goldbart and Dr. Margaret Landers whose advice, guidance and support has been indispensable in this process. Dr. Tom Andrews whose patient and considered approach and incredible knowledge of Grounded Theory was instrumental in guiding me through this study as a novice to the methodology. Thank you for pointing me in the direction rather than telling me the way and patiently nurturing and developing my critical and conceptual thinking. Prof. Juliet Goldbart whose deep and extensive knowledge and expertise in this area has been invaluable. Thank you for stimulating discussions, challenging me, reassuring me and introducing me to the international community of people striving to improve the lives of individuals with severe/profound intellectual disability. Dr. Margaret Landers for so willingly and readily joining the supervision team. Your theoretical and methodological knowledge as well as reassuring and supportive approach through PRPs and over these last few months is much appreciated. Thank you for supportive questioning, thought-provoking discussion and constructive feedback. Sincere thanks to you all for guiding me along this journey. I am grateful that I was supervised in a way that enabled me to take ownership of this study. I have grown personally and professionally through this process as a result of our interactions and work together.

Prof. Eileen Savage who assisted me in starting on this journey as Head of School. Your advice, guidance and support were instrumental in setting me on this path. Thank you for sharing your experience and expertise, being open and approachable, listening and readily advising over the last number of years.

Prof. Josephine Hegarty who was Director of Graduate Studies when I started this journey and is Head of School as it comes to an end. Your belief in me has given

me confidence to develop and advance as both a PhD student and member of staff. Thank you for nurturing me as an academic and supporting me to reach my potential.

Dr. Patricia Leahy Warren, Director of Graduate Studies, the Graduate Studies Office and Library services for willingly sharing information and resources that ensured this work was possible. The resources, education and training opportunities and supports you offer and organise are priceless to students undertaking research.

My colleagues throughout the School of Nursing and Midwifery who travelled with me on this journey. I want to particularly thank the intellectual disability nursing lecturing team who have listened, understood, encouraged, supported and listened some more as I progressed on this journey. I know I am fortunate to be a member of this team.

To my parents who recognised the value of education and were unwavering in their support when I wanted to undertake yet another course. I am grateful for your hard work and sacrifice to ensure I could follow my path.

My husband, Chris and children, Ódhran and Róise. Thank you for your tolerance, patience and bearing with me. You sustained me through this process. Thank you for everything.

Finally, thank you to the service providers, gatekeepers and especially the participants of this study. It would not have been possible without you. Thank you for welcoming me into your lives, sharing your experiences and contributing to this study. I am eternally grateful.

Abstract

Title Reconciling Communication Repertoires: A Classic Grounded Theory of Navigating Interactions Involving Persons with Severe/Profound Intellectual Disability.

Aim The aim of this study is to generate a theory that explains how people communicate with and understand each other in interactions involving persons with severe/profound intellectual disability.

Background Nationally and internationally, policies and strategies informed by a rights-based approach and advocating person-centredness, inclusion, empowerment and self-determination are shaping service provision to persons with intellectual disability. The goal is to improve the quality of life of individuals and their families. Listening to their perspectives is fundamental to meeting these goals. However, communication with people with severe/profound intellectual disability is challenging and difficult. Therefore, this study explores these interactions to contribute to knowledge, evidence and inform practice in this area.

Method Classic Grounded Theory methodology guided this study towards meeting its aim. As per this method, concurrent theoretical sampling, data collection and analysis were undertaken. Data collection involved video recordings, individual and group interviews. Data was analysed using Classic Grounded Theory methods of coding, constant comparison and memoing.

Findings The Theory of Reconciling Communication Repertoires was generated. Nurturing a sense of belonging emerged as individuals' main concern that is resolved by reconciling communication repertoires. Interactions are navigated through five stages; motivation to interact, connection establishment, reciprocally engaging, navigating understanding and confusion resolution.

Conclusion The Theory of Reconciling Communication Repertoires explains how interactions involving people with severe/profound intellectual disability are navigated. It unifies discrete areas of research in the larger substantive area. It contributes to the knowledge and evidence base and has the potential to inform practice, policy, management, education and research.

Chapter 1 Introduction

1.1 Introduction

One cannot not communicate

This quote from Watzlawick et al. (1967 p.30) needs to be the first sentence of this thesis because it is what this study is about. People with severe/profound intellectual disability experience significant challenges and difficulties when communicating but they cannot not communicate. This study examines what they and their communication partners do when communicating.

The purpose of this chapter is to introduce this thesis and orientate the reader to the study. It introduces the background and catalysts for undertaking this research as a preamble to Chapter 2. This chapter will discuss the above issue as one such catalyst. Secondly, unresolved communication difficulties as a barrier to person-centredness for people with severe/profound intellectual disability are discussed. An exploration of the relationship between person-centredness and communication in this context is provided. Lastly, this study was also undertaken to explore the findings of a previous study (Martin et al. 2012a, b) in more depth. Details of this study are presented before the chapter concludes with an outline of the sequential structure of this thesis.

1.2 One Cannot Not Communicate

Watzlawick et al. (1967) argue that the most basic property of behaviour is that it has no opposite. There is no such thing as non-behaviour and so one cannot not

behave (Watzlawick et al. 1967). To extend this, if all behaviour is communicative (Blakar and Nafstad 2005) and one cannot not behave, one cannot not communicate (Watzlawick et al. 1967). Furthermore, Watzlawick et al. (1967) contend that communication occurs even when it is unintentional, unconscious or unsuccessful relating to understanding. Again, this is because one cannot not behave and thus cannot not communicate.

This view of communication is important when considering interactions with people with severe/profound intellectual disability. It is important to highlight that these individuals behave intentionally and unintentionally, consciously and unconsciously, successfully and unsuccessfully (Greathead et al. 2016; Bruce and Vargas 2009; American Speech-Language-Hearing Association 1992) and so communicate. Admittedly, these communicative behaviours tend to be idiosyncratic and unconventional (Parry Hughes et al. 2011; Petry and Maes 2006) and therein lies one of the factors contributing to the complexity of interactions. These behaviours are difficult for interaction partners to interpret and understand. This barrier to being understood limits the power of communication for people with severe/profound intellectual disability; that is the power of communication to enable interactions with others, influence over one's environment and participation in society (Beukelman and Mirenda 2013). These are some of the principles underpinning the person-centred movement in the field of intellectual disabilities.

1.3 Person Centredness

Person centredness is a term used to describe a standard of care where the service user is at the centre of support and care delivery (McCance et al. 2011). McCance et al. (2011) assert that the current emphasis on person-centredness shows a drive to rectify imbalances in care and a movement away from a medically dominated or disease orientation of care towards a relationship focussed, collaborative and holistic approach. Person-centredness, and variants of the term, permeate through all aspects of care, support, service-design and policy as it is considered a key component of high-quality care (Coyle and Williams 2001). However, Thurman et al. (2005) caution the risk of misguided tokenism when the communication needs and supports of service-users are not carefully considered. Communication is essential for person centred care because it provides the means to attain the individual's choices, preferences and goals (Calculator 2009; Lund and Light 2007). Mansell (2010) identified communication barriers as one of a number of obstacles to person-centred services for people with profound intellectual and multiple disabilities. Therefore, it is pertinent that we increase knowledge and understanding of these interactions to inform practice and provide person centred care and supports to individuals with severe/profound intellectual disability.

1.4 Previous Research

These issues of supporting communication and providing person centred care were explored in a previous MSc study (Martin et al. 2012a, b). This study explored registered intellectual disability nurses' experiences of non-verbal communication

with people with intellectual disability. One issue relating to interpretation of behaviours emerged a number of times. Some participants discussed how if the person with intellectual disability does not co-operate with a request, this was deemed to be an expression of choosing not to participate. Participants seemed to not consider the possibility that the individual did not understand the request. This issue merited more in-depth exploration due to the potential consequences for individuals with intellectual disability.

This group are dependent on their communication partners to interpret their experiences and read their expressive behaviours (Roemer et al. 2017). Yet, the specific issues associated with interactions involving people with severe/profound intellectual disability increases the risk of misunderstanding or misinterpretation occurring (Adams and Oliver 2011; Petry and Maes 2006; Hogg et al. 2001; Porter et al. 2001; Grove et al. 1999; Clark et al. 1991).

Each of these factors prompted this research. People with severe/profound intellectual disability can communicate. However, interactions are difficult for both the individual and their communication partner. Communication issues also pose difficulties for policy makers and service-providers who strive to provide and design person centred services and care. Therefore, this study explores these interactions with the aim of generating a theory that will explain the methods and processes people use to communicate with and understand each other. The remainder of this thesis sets out the methods, findings and implications of this study; a sequential overview of which is now provided.

1.5 Sequential Overview of Thesis

This thesis is presented over seven chapters commencing with this introductory chapter. The subsequent chapters offer the background, methodology and method followed by a presentation of the theory generated, a discussion of the theory in relation to existing literature and consideration of the implications of this study.

Chapter two provides a contextual background to this study. An overview of interpersonal communication, intellectual disability and particularly severe/profound intellectual disability is provided. The influence of international and national human rights and policy agendas on their quality of life and the provision of care and services is discussed. This chapter demonstrates the importance of this study to informing fulfilment of individuals' rights, implementation of policies and strategies and supporting individuals to have an optimal quality of life.

Chapter three debates different ontological and epistemological positions that underlie research. It discusses the position adopted and justifies selection of Classic Grounded Theory as the most appropriate methodology to guide this study towards meeting its aim. Different grounded theory methods are considered but selection of Classic Grounded Theory is explained and justified.

Chapter four details implementation of Classic Grounded Theory methods in the present study. An in-depth and detailed description and transparent discussion of

each stage of the study demonstrates the strict adherence to the philosophies and processes of this method. Measures taken to ensure all ethical responsibilities were met are discussed and described in detail. It is evident that every effort was taken to ensure meaningful and respectful inclusion of participants with severe/profound intellectual disability. Measures taken to ensure the quality of this study are described and the role of the researcher is clarified.

Chapter five presents The Theory of Reconciling Communication Repertoires that was generated. The core concept of reconciling communication repertoires and its centrality to the theory is explained. The sub-core categories of motivation to interact, establishing a connection, reciprocal engaging, navigating understanding and resolving confusion are set out along with the conditions and contexts that vary the concepts.

Chapter six considers and contextualises the Theory of Reconciling Communication Repertoires in the existing body of knowledge and evidence. The integrative review process suggested by Whittemore and Knafl (2005) guided the review. The theory is compared and contrasted with extant literature from the substantive area. The contribution of this study to the body of knowledge is demonstrated as the findings support and/or extend existing knowledge and offer new perspectives.

Chapter seven is the final chapter and offers the implications and potential contribution of the study and its findings to practice, policy, management,

education and research. The strengths and limitations of the study are identified and discussed. A dissemination strategy and plan for going forward are outlined that will maximise the potential of this study to inform each area listed above.

1.6 Summary

This chapter has presented the catalysts and motivations for this study as a preface to the more detailed background and context that will be provided in the next chapter. An argument has been made that as person centredness is considered key in the pursuit to providing high quality care, more knowledge is required to inform how interactions with people with severe/profound intellectual disability are navigated. The methods and processes of understanding and being understood need to be uncovered in order to attain individuals' experiences, choices, preferences, wishes and goals that inform person centred care. A sequential overview of this thesis which set out to examine this issue is presented. Chapter 2 follows, which provides a detailed background and context for this study.

Chapter 2 Background

2.1 Introduction

This chapter provides an overview of intellectual disability, and more specifically severe/profound intellectual disability, and interpersonal communication, the substantive area under study. It offers context for this study of interactions involving people with severe/profound intellectual disability and their communication partners in the current disability landscape that is concerned with human rights and social inclusion. Core to the rights agenda is improvement of the quality of life of people with intellectual disability. The intersection of communication, quality of life and the issues faced by those with a severe/profound disability particularly is outlined. The policy and legislative frameworks, from an Irish, European and International perspective, that are shaping service provision and delivery are presented indicating the relevance and currency of this study to informing implementation of these agendas. The chapter concludes with a discussion of how the implementation of these strategies has progressed. Firstly, however, an overview of interpersonal communication is provided.

2.2 Interpersonal Communication

Griffiths and Smith (2016 p.25) suggest that communication is essentially a process where two or more individuals co-operate to create mutual meaning. It is a means of making connections through which flow ideas, beliefs, opinions and information

(Burton and Dimbleby 1998). Among the multiple reasons we communicate, is the need to satisfy personal needs, express ourselves, form relationships, be involved with others, and make sense of the world and our experience of it (Burton and Dimbleby 1998). Interpersonal communication involves at least two people who establish a communicative relationship and can affect each other through their behaviour as individuals and partners in a relationship (Lane 2016). Interactions exist along a continuum from impersonal to interpersonal and where the interaction falls depends on relational history and uniqueness of both parties (West and Turner 2011). It is significantly affected by culture, relationships, gender, roles, needs, background and history (Lane 2016). Finnegan (2002 p.5) writes about interpersonal communicating as an entity that extends beyond linguistic or cognitive messages to include experience, emotion and the unspoken; a creative human process that encompasses multiple means of interacting through smells, sounds, touch, sights, movements, embodied engagements and material objects.

The power of interpersonal communication to positively impact a person's life is well documented (Sandstrom and Dunn 2014; Knapp and Daly 2002). It is considered a critical component of mental and physical wellbeing (Kok and Fredrickson 2013). Mukherjee (2017) discusses how the positive emotions a person experiences following a positive interaction brings about a pleasant state of body and mind. Effective interpersonal communication can help establish long-term and fulfilling relationships (West and Turner 2011). Locher et al. (2005) found

social isolation and low levels of social support were associated with poorer physical well-being including poor diet. Similarly, Tomaka et al. (2006) found that the presence of support that fostered belongingness related most consistently to better health outcomes. This study examined the relations between social isolation, loneliness and social support to health outcomes (Tomaka et al. 2006).

Interpersonal communication has received substantial attention among health and allied professions as a critical component of high-quality care. Nursing has embraced the concept. The Nursing and Midwifery Board of Ireland (2016) identifies communication and interpersonal competences as one of the necessary requirements to register as a nurse. Theories of interpersonal communication and therapeutic relationships in nursing have been developed (Watson 1985; Peplau 1952). An extensive body of knowledge (Arnold and Undermann-Boggs 2020; Grant and Goodman 2018; Balzer-Riley 2017; Kagan and Evans 2013), relating to interpersonal communication in nursing specifically, continues to grow. Good communication between nurses and those they care for is considered an essential component of successful, individualised care (Kourkouta and Papathanasiou 2014). Rogers (2015 p. v) states that at the heart of nursing is a capacity '*to make connections: to communicate clearly, deeply and meaningfully'*.

The ability to communicate and interact interpersonally is often taken for granted (West and Turner 2011). People with disability may have fewer opportunities to interact (Tough et al. 2017) as they can experience social isolation and have small social networks mostly comprising family members and professionals (Clifford-

Simplican et al. 2015). Gilmore and Cuskelly (2014) argue that three domains influence the vulnerability of people with intellectual disability to loneliness. These are social attitudes and expectations, opportunities and experiences, and skill deficits associated with intellectual disability (Gilmore and Cuskelly 2014). Social attitudes and expectations, opportunities and experiences are a societal level issue and efforts to address these will be discussed later in this chapter in relation to rights, policy and law. To elaborate further on Gilmore and Cuskelly's (2014) third identified influential domain, skill deficits associated with intellectual disability, a brief background and explanation of intellectual disability is now presented. This will be followed by a more detailed discussion of communication in relation to severe/profound intellectual disability.

2.3 Intellectual Disability

The World Health Organisation (WHO 2019) defines intellectual disability in terms of cognitive processes and adaptive behaviour stating it is '*a significantly reduced ability to understand new or complex information and to learn and apply new skills…a reduced ability to cope independently…that…begins before adulthood, with a lasting effect on development*'. The American Psychiatric Association (2013) also offer these three criteria; deficits in intellectual functioning, deficits in adaptive functioning and onset in childhood. However, the WHO (2019) recognises the impact of the environment on a person's disability highlighting the extent to which it facilitates or hinders their participation in society. The American Association on Intellectual and Developmental Disabilities (AAIDD) offer a similar

definition with further detail. They define intellectual disability as '*characterized by significant limitations in both intellectual functioning and in adaptive behaviour, which covers many everyday social and practical skills…and…originates before the age of 18*' (Schalock et al. 2010). The AAIDD (2019) explains that intellectual functioning refers to general mental capacity and limitations are indicated by an IQ score of 70-75 or less. Adaptive behaviour is considered the conceptual, social and practical skills people learn and use daily such as language and literacy, interpersonal skills, social problem solving, activities of daily living and occupational skills to name but a few (AAIDD 2019). Importantly, the AAIDD (2019) emphasise caution at the use of standardised tests in the assessment of intellectual disability stressing that additional factors need to be considered including environment, culture and recognition that strengths often co-exist with difficulties.

In a meta-analysis of population-based studies published between 1980 and 2009, Maulik et al. (2011) estimate the global prevalence of intellectual disability to be 1%. This figure is also offered by the American Psychiatric Association (APA 2019). In Ireland, there were 28,388 people registered on the National Intellectual Disability Database at the end of December 2017 (Hourigan et al. 2018). This database is a service planning tool that captures service usage and informs current and future service needs among people with intellectual disability (HIQA 2019a). Therefore, the database provides a profile of those availing of HSE (Health Service Executive), non-statutory and educational services. People with intellectual

disability not availing of these services may not be included in this database. There were 3897 people with severe intellectual disability and 949 with profound (Hourigan et al. 2018). While intellectual disability is generally classified in terms of mild, moderate, severe and profound (ICD-11 2018; ICD-10 2016), this study is concerned with those with a severe and profound intellectual disability specifically.

2.4 Severe/Profound Intellectual Disability

According to the ICD-10 (WHO 2016) a severe intellectual disability is characterised by an approximate IQ range of 20-34 and the person is likely to need continuous support. A profound intellectual disability is indicated by an IQ under 20 and the individual has severe limitations in self-care, continence, communication and mobility (WHO 2016). Although these classifications are frequently used it is recognised that standardised tests of intelligence have significant limitations particularly when used to assess people in the lower ability ranges (Hessl et al. 2009). The influence of environments and supports are not captured in these characterisations. In the 9th edition of the *AAIDD Definition, Classification and Systems of Supports*, Luckasson et al. (1992) replaced the IQ classification system of intellectual disability with an intensity of support system: intermittent, limited, extensive and pervasive. This signalled a major shift in how intellectual disability was conceptualised towards recognition that disability can result from the interactions of persons with their environment (Parmenter 2011). In providing feedback on the latest revision to the ICD (WHO 2018), Tassé et al.

(2013) on behalf of the AAIDD, proposed revision of the definition and classification of intellectual disability in accordance with their above cited definition (See Schalock et al. 2010). Tassé et al. (2013) also suggested that classification of severe and profound intellectual disability should be combined to a single category termed 'pervasive'. The implications of this would be considerable as there is a wide spectrum of ability across individuals with severe or profound intellectual disability. Schalock and Luckasson (2015) also recognise the diversity among this group, stating they anticipate a classification system not based on cut-off scores or absolutes but recognises the complexity of human functioning.

International consensus and clarity regarding terminology is required (Nakken and Vlaskamp 2007). Various combinations of 'severe', 'profound', 'pervasive', 'complex', 'significant' and 'multiple' are used alongside further combinations of 'learning disability', 'intellectual disability' or 'developmental disability'. However, in the absence of such consensus, researchers (e.g. Hetzroni and Shalev 2017; Vos et al. 2013; Hostyn et al. 2011) tend to offer description and portrayal of severe and profound intellectual disability as is relevant to their study. The present study is concerned with the nature of interpersonal interactions in the context of significant communication and intellectual disabilities in everyday, naturally occurring encounters. It relates to interactions involving people who require extensive or pervasive support for daily activities (as per the AAIDD 2010 Manual) and function at the earlier stages of communication development (Bunning et al.

2013; Coupe O'Kane and Goldbart 1998). It should be noted that this broad characterisation of severe/profound intellectual disability is adopted in this study to be inclusive of individuals described using the terms listed above. Therefore, literature that uses these terms are referenced throughout this document. For the purposes of accuracy, the terminology used by referenced authors is maintained. Otherwise, severe/profound intellectual disability is used.

People with severe/profound intellectual disability require extensive or pervasive support to participate in daily life (WHO 2001), to engage meaningfully (Hughes et al. 2011) and to partake in activities others take for granted across the lifespan. Support is generally required for activities of living such as mobility, communication and self-care (Alquraini and Gut 2012) as well as more complex and specific needs stemming from co-morbid conditions (Bunning et al. 2013). In an analysis of patterns of multimorbidity in older persons with intellectual disability using data generated from wave one of the IDS-TILDA, McCarron et al. (2013) found only 4.37% of people with severe/profound intellectual disability had no co-morbid conditions. It was found that among those with severe/profound intellectual disability, 22.82% had co-morbid hypertension, 24.76% had eye disease, 24.27% had heart disease and 14.56% had endocrine disease (McCarron et al. 2013). A study by van Timmeren et al. (2017) of patterns of multimorbidity in people with severe or profound intellectual and motor disabilities found that more than 50% had an eight-combination co-morbidity. In a prevalence, aetiology and comorbidity study of intellectual disability in one Finnish district, Arvio and

Sillanpää (2003) found that among persons with severe/profound intellectual disability, 92% had between one and six associated impairments of which speech difficulties, epilepsy and motor impairments were most common. These statistics demonstrate the complexity and scale of the support needs of this group.

Considering the multiplicity and complexity of disability and difficulties experienced by people with severe/profound intellectual disability, it is to be expected that interpersonal interactions would be challenging and significantly different from those involving people with no disability (Forster and Iacono 2014). Furthermore, they typically rely on others for support in communicating and interacting with others (Ogletree et al. 2012). These two issues are now discussed.

2.5 Severe/Profound Intellectual Disability and Communication

Communication difficulties are common among those with intellectual disability (Bonnike et al. 2018) but especially so for those with severe/profound intellectual disability who have limited ability to use a formal symbolic code and have inconsistent and ambiguous ways of communicating (Grove et al. 1999). Skills and abilities, usually taken for granted in everyday communication, are not available (Forster and Iacono 2008) and therefore, communication is far from straightforward (Bunning et al. 2013). Petry and Maes (2006) discuss how level of intellectual disability, extent of motor limitations and severity of sensory impairments interfere with cognitive and communicative ability. It is challenging to develop high quality interactions due to the complexity of their disabilities (Neerinckx and Maes 2016).

Those with severe/profound intellectual disability tend to function at the earlier stages of communication development (Coupe O'Kane and Goldbart 1998). A fundamental problem is the extent to which they can engage within a symbolic linguistic system for either comprehension or expression (Hogg et al., 2001). There is agreement that communication ability is usually at pre-symbolic or proto-symbolic levels (Chadwick et al. 2019; Bellamy et al. 2010; Maes et al. 2007). Individuals have a limited catalogue of skills to draw from (Munde et al. 2012). Communication is characterised by bodily and idiosyncratic expressions (Petry and Maes 2006), subtle signals and utterances (Neerinckx et al. 2014), facial expressions (Munde and Vlaskamp 2015) and muscle tension all of which can be context bound and individual (Hostyn and Maes 2013; Porter et al. 2001). Sometimes, behaviour that challenges may be used as a means of expression (Hogg et al. 2004). Those with a severe intellectual disability may be able to use some symbolic communication (Johnson et al. 2011) but this is unlikely among their peers with profound intellectual disability (Griffiths and Smith 2016). Furthermore, indications of alertness and attentiveness can be subtle and go unnoticed (Munde et al. 2012).

It is also important to acknowledge the extra-personal factors that influence interactions. Kamstra et al. (2019) highlight the contextual factors that impact interactions. According to Hostyn and Maes (2009), the context is the setting and circumstances in which an interaction takes place. Kamstra et al. (2019) explain that setting refers to persons' physical environment not directly related to them

while circumstances refer to contextual factors directly relating to persons such as their positioning or proximity to others. This impacts on the person's ability to reach or touch another person, make contact and engage with them. This is particularly pertinent for those who are unable to move independently. Nijs et al. (2016), found a relationship between peer-directed behaviour and positioning in a study that examined how the positioning of children and young adults affected the possibility for peer to peer interaction. More peer-directed behaviours were observed when the child/young person could see or touch their peers (Nijs et al. 2016). These unconventional, ambiguous and idiosyncratic forms of communication pose an ongoing challenge and difficulty for communication partners to understand and interpret meaning adequately and accurately (Vlaskamp 2005; Halle et al. 2004; Grove et al. 1999).

2.6 Communication Partners Perspectives

There is consensus in the literature that communication partners find interactions challenging. Communicative attempts can be so idiosyncratic and subtle that they can go unnoticed by communication partners (Munde and Vlaskamp 2015; Wilder and Granlund 2003). Furthermore, a communication signal can hold different meanings across individuals, or it can hold different meanings across different situations for the same person (Munde and Vlaskamp 2015; Petry and Maes 2006; Hogg et al. 2001). Familiar communication partners often construct meaning through close observation, inference, best guess or examination of the antecedent and consequential effects of the communication attempt (Petry and Maes 2006;

Olsson 2004). Atkin and Perlman Lorch (2016) suggest this may be intuitive among communication partners with whom long-term relationships are established.

Communication partners often hold interpreter roles, facilitating communication for the person (Blain-Moraes and Chau 2012; Hogg et al. 2001; Grove et al. 1999). Consequently, the strategies communication partners use can determine the extent to which individuals with severe/profound intellectual disability can participate in their communities (Koski and Launonen 2012). This role can place considerable responsibility and demands on communication partners.

In order to interact successfully, communication partners need to adjust their communication style or strategy (Purcell et al. 2000). Partners in a study by Forster and Iacono (2008) reported that communicating in the preferred style of the person with profound intellectual disability is important in interactions. However, they also reported this can conflict with organisational policy and preferred practice (Forster and Iacono 2008). Additionally, it has been found that communication partners have difficulty adjusting their communication strategy to meet the needs of individuals (McConkey et al. 1999).

Although there is considerable agreement in the literature regarding the nature and characteristics of communication and interaction among people with severe/profound intellectual disability and their communication partners, it is important to recognise the heterogeneity of this group (Griffiths and Smith 2016). There is considerable intragroup variability (Hostyn and Maes 2013; Olsson, 2005;

Nakken and Vlaskamp 2002) that reflects the individuality of each person. Recognition of this individuality is a key value shaping service provision and supports for persons with intellectual disability. In Ireland, the HSE has expressed its commitment to enabling cultures of person-centredness in order to provide person centred care and services that support people to live lives of their choosing (Gadd and Cronin 2018). According to The Health Information and Quality Authority (HIQA) (2019b), human rights are at the core of person-centred care and planning and use the FREDA principle, (fairness, respect, equality, dignity and autonomy) in their guidance to care and support in health and social care settings. Indeed, it is this recognition of individuals' human rights that is influencing international and national policy and legislation and shaping service delivery. These issues will now be discussed.

2.7 Communication as a Right

Communication is fundamental to humanity (McLeod 2017), an important and essential human need and a basic human right (Sen 2015). It is essential to our expression, self-determination, sense of belonging, inclusion and in acknowledging the value of ourselves and others (McEwin and Santow 2018). Communication is critical to human interaction and participation, enables expression of needs and wants and facilitates inclusion in communities and society (McLeod 2017). Communication skills underpin positive social relationships and successful community inclusion including education, employment and civic participation (Mulcair et al. 2018).

Communication as a fundamental right was first stated at international level in Article 19 of the Universal Declaration of Human Rights (1948):

> *Everyone has the right to freedom of opinion and expression; this right includes freedom to hold opinions without interference and to seek, receive and impart information and ideas through any media and regardless of frontiers. (United Nations 1948).*

Article 19 is a powerful statement in that it clearly states that all people, everyone, '*without distinction of any kind'* (United Nations 1948 Article 2) has the right to communicate. The right to freedom of opinion and expression is repeated in Articles 5 and 15 of the *International Convention on the Elimination of All Forms of Racial Discrimination* (United Nations 1965), Articles 19 and 25 of the *International Covenant on Civil and Political Rights* (United Nations 1966), Articles 12 and 13 of the *Convention on the Rights of the Child* (United Nations 1989) and Article 21 of *Convention on the Rights of Persons with Disabilities* (United Nations 2006).

The ability of people with severe/profound intellectual disability to exercise their right to communicate can be restricted by their communication difficulties and any associated social or environmental barriers (Mulcair et al. 2018). The *Convention on the Rights of Persons with Disabilities (UNCRPD)* (United Nations 2006) came about in recognition of this and to effect change in attitude and approaches towards this group. The UNCRPD reaffirms that people with disability must enjoy all human rights and fundamental freedoms that promotes respect for their inherent dignity (United Nations 2006). It is built on principles of inclusion,

equality, respect and non-discrimination. Article 2 of the UNCRPD offers five definitions of key issues relating to fulfilment of these rights including communication, language, discrimination on the basis of disability, reasonable accommodation and universal design. These five issues are seen to be critical to upholding the rights of persons with disabilities. Furthermore, Article 21 (United Nations 2006) specifically focuses on communication rights of people with disabilities.

> *Freedom of expression and opinion, and access to information.*
>
> *States Parties shall take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice, as defined in article 2 of the present Convention…*
> *(United Nations 2006)*

Five measures to ensure people with disabilities can exercise this right are listed in this Article. Ireland signed the Convention in 2007. It was ratified in March 2018 and came into force in April of that year. In an effort to meet obligations set out in the UNCRPD, a suite of national legislation and policies have been put in place including, most significantly with respect to intellectual disability, the *Disability (Miscellaneous Provisions) Bill 2016* and the *Transforming Lives* programme to name but a few. The Irish Human Rights and Equality Commission in collaboration with the National Disability Authority have responsibility to review the adequacy and effectiveness of these measures in the State and is the independent monitoring mechanism for the UNCRPD in Ireland.

At European level, there is a strong mandate for the EU and its member states to improve the lives of persons with disabilities. The *European Convention on Human Rights (1950)* was informed by the *Universal Declaration of Human Rights (1948)* and again states the rights of all persons to freedom of expression under Article 10. Furthermore, the EU Charter of Fundamental Rights sets out a person's rights as recognised by the EU under Dignity, Freedoms, Equality, Solidarity, Citizen's Rights and Justice with Article 1 stating that '*Human Dignity is inviolable. It must be respected and protected*'. Articles 21 and 26 specifically highlight the rights of persons with disabilities to non-discrimination and community integration respectively. The EU's responsibilities in relation to these issues are clearly delineated in the Treaty on the Functioning of Europe. Specifically, Article 19 states the EU are required to '*combat discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation*'.

From an intellectual disability and health perspective, The European Declaration on the Health of Children and Young People with Intellectual Disabilities and their Families: Better Health, Better Lives (WHO Regional Office for Europe 2010) sets out ten priorities for action in an effort to uphold the rights of this group. Priority no. 7 is particularly pertinent in the context of this study. It states…

> *Empower children and young people with intellectual disabilities to contribute to decision-making about their lives.*
>
> *Children and young people with intellectual disabilities can and will make their needs and wishes known and contribute to their community, given appropriate support and a receptive*

environment. Family members and advocates also need encouragement and support to make themselves heard.

It is unanimous, clear and unquestionable from global, European and Irish perspectives that people with intellectual disability have an established right to communication and social inclusion. The ability to communicate is crucial to support a person's inclusion and engagement in their communities (Detheridge 1997). However, communication difficulties associated with severe/profound intellectual disability are one of a number of barriers this group encounter that impede realisation of this right. The right to understand what is communicated, express one's own thoughts, desires and needs and relation to others is undisputed (Tabacaru 2016). Fulfilment of this right for people with severe/profound intellectual disabilities requires skilled communication partners who recognise and discriminate communication attempts and respond appropriately and consistently (Koski et al 2010). The present study contributes to the body of knowledge and evidence striving towards making interactions of this nature the norm.

2.8 Severe/Profound Intellectual Disability, Communication and Quality of Life

The fundamental aim of each Declaration and Charter of Rights discussed thus far is to ensure an acceptable and optimal standard of quality of life for individuals. The lively debate regarding definition of quality of life has ensued for decades (Carbajal 2019; Theofilou 2013; Schalock 2000; Rapley and Ridgway 1998; Felce

and Perry 1995) and an examination of same is beyond the remit of this chapter. However, Schalock et al. (2002) present a dual-faceted conceptualisation of quality of life. They argue it is a sensitising concept for policy development, service evaluation and development of innovative programmes that remains rooted in individual perceptions and values relating to general feelings of well-being, positive social involvement and opportunities to fulfil potential (Schalock et al 2002).

Petry et al. (2005) suggest quality of life may differ for people with profound and multiple disabilities due to their reliance on others to meet their needs. The extent of their intellectual disability potentially coupled with motor or sensory difficulties results in a dependence on others to attain an optimal quality of life (Neerinckx and Maes 2016; Nakken and Vlaskamp 2002). Dammeyer and Køppe (2013) argue that supporting social interaction and communication can reduce dependency and improve social connectedness, independence, and quality of life.

Much research has been undertaken relating to the determinants of quality of life for people with intellectual disability (Rand and Malley 2017; Lombardi et al. 2016; Millar and Chan 2008). For people with profound intellectual and multiple disabilities, many factors including health status, involvement in activities and social networks and critically, their experiences of high-quality interactions (Forster and Iacono 2014; Petry et al. 2007; Petry et al. 2005) affect their quality of life. Hostyn et al. (2011b) and Nind (2009) agree that reciprocal relationships are an important factor impacting on quality of life for persons with

severe/profound intellectual disability. Schalock et al (2002) and Kamstra et al. (2015) also recognise interpersonal relations as a core element of quality of life. However, Beadle-Brown et al. (2015) argue that the quality of life of persons with intellectual disability can be enhanced or diminished by the ability of communication partners to use appropriate forms of communication. With this in mind, it is clear that the development of appropriate communication methods and high-quality interpersonal interactions are crucial for the quality of life of persons with severe/profound intellectual disability. This current study contributes to the knowledge base in this regard and makes recommendations to support this in Chapter 7. It is also important that international and national policy drive the rights agenda so it becomes a reality for people with intellectual disability.

2.9 International and National Policy Driving the Rights Agenda

Commitment to recognising, meeting and upholding the rights of persons with disabilities is evident in world, European and national policies, strategies and agendas. These policies and strategies aim to improve mental and physical health and well-being, community participation and address discrimination and barriers that negatively impact on the lives of this group. Principles and values of respect, inclusion, person centredness, individuality, choice and quality of life guide the development of these strategies and underpin the actions therein.

At a global level, the World Health Organisation *Global Disability Action Plan 2014-2021* calls for the removal of barriers and improvement of access to health, education and community inclusion to improve the quality of life of people with

disability. In a similar vein, the United Nations *Disability Inclusion Strategy* (UNDIS) (2019) requires that organisations in the UN system state their intention and commitment to pursue goals of inclusion and empowerment of those with disabilities and their human rights, well-being and perspectives. This is to ensure they are valued and respected in terms of dignity, rights and equality (UNDIS 2019).

The *European Disability Strategy 2010-2020* clearly states its aim is to empower people with disability to enjoy their rights and benefit from social participation and community inclusion under eight action areas including Accessibility, Participation, Equality, Employment, Education and Training, Social Protection, Health and External Action. Throughout the strategy principles of inclusion, respect, empowerment and individuality are evident.

These action plans and strategies can be seen to permeate national strategies and agendas. The *National Disability Inclusion Strategy 2017-2021* (Department of Justice and Equality 2017) is a whole Government of Ireland approach to improving the lives of persons with disability. The *Transforming Lives* agenda is driving and shaping disability service delivery, particularly intellectual disability supports. The *Value for Money and Policy Review of Disability Services (VFM-PRDS)* (Department of Health 2012) was the impetus for this agenda. This review makes several recommendations but recommendations 7.6 and 7.7, under '*Vision and Goals*' and recommendation 7.8, under '*Future Direction*' are particularly pertinent from a service-user perspective.

> ***Recommendation 7.6****: The following vision statement should be adopted as an expression of a revitalised and re-orientated Disability Services Programme: To contribute to the realisation of a society where people with disabilities are supported, as far as possible, to participate to their full potential in economic and social life and have access to a range of quality personal social supports and services to enhance their quality of life and well-being.*
>
> ***Recommendation 7.7:*** *The vision should be underpinned by the following goals:*
> *1. Full inclusion and self-determination through access to the individualised personal social supports and services needed to live a fully included life in the community.*
> *2. The creation of a cost-effective, responsive and accountable system which will support the full inclusion and self-determination of people with disabilities.*
>
> ***Recommendation 7.8:*** *The person-centred model described in this Review should form the basis of the future direction of disability policy.*

This review specifically states that choice, control, independence and community inclusion are the keys to a person-centred service (VFM-PRDS 2012). These principles have come to underpin disability strategies and policies in Ireland since.

Although commenced before publication of VFM-PRDS, *Time to Move on from Congregated Settings* (HSE 2011b) set out a national strategy to relocate persons living in congregated settings to dispersed community-based housing. This report claims to be guided by person-centred principles of self-determination, inclusion, supporting people to live a fulfilled life and individuality.

New Directions (2012-2016) and the *Interim Standard for New Directions Services and Supports for Adults with Disabilities (2015)* set out the future provision of day service, activation and training services for people with disability to support their inclusion in their communities. The New Directions agenda repeatedly advocates supporting people in communities, so they have the widest possible choice and options about how they wish to live their lives and spend their time. Provisions of the *UNCRPD* of particular importance to *New Directions* are Articles 5, 19, 21, 26 and 30 which relate to equality, non-discrimination, community living, freedom of expression and opinion, attainment and maintenance of maximum independence and opportunities to contribute to society. This programme frequently acknowledges that people with severe/profound intellectual disability have specific needs that must be met. Furthering the education and training aspect of support, the Department of Education and Skills (2019 p.6) *Statement of Strategy 2019-2021* states the '*delivery of a quality learning experience that challenges each person to realise their potential, to raise their aspirations and to achieve their personal ambitions'* is key to meeting their vision.

Similarly, the HSE (2011a) programme *Progressing Disability Services for Children and Young People* aims to develop a single national approach to delivering disability health systems for children and their families in a child and family centred way regardless of where they live, what school they go to or the nature of disability. It is guided by values and principles of respect and dignity, equity, empowerment and excellence.

Person-centredness, choice, individualised supports, self-determination, inclusion and quality of life are the key principles underpinning each of these strategies and programmes. Indeed, '*Equality and Choice*' and '*Person-Centred Disability Services*' are two of the eight themes of the *National Disability Inclusion Strategy 2017-2021* (Department of Justice and Equality 2017). Communication is fundamental to fulfilling these principles. Communication enables identification of a person's preferences, needs, wishes, goals. As discussed, this is a significant challenge for people with a severe/profound intellectual disability. Therefore, if the aims of these policies and programmes are to be fulfilled for people with severe/profound intellectual disability, we need to learn more about the ways they understand and express their choices and preferences. This study explains how this is achieved in interactions between persons with severe/profound intellectual disability and their communication partners.

2.10 The Irish Legislative Landscape

There are a number of legislative Acts that enshrine the rights of people with intellectual disability in Irish Law. The *Education for Persons with Special Education Needs Act (EPSEN) (2004), The Disability Act (2005)*, and *The Assisted Decision-Making Act (2015)* are of particular relevance in the area of inclusion and communication. An in-depth examination of these laws is beyond the scope of this paper. However, it is important to recognise their importance in legislating for and protecting the rights of people with intellectual disability.

A central tenet of the *EPSEN Act (2004)* is that children with special educational needs should be educated in an inclusive environment unless an assessment carried out under the Act finds this would not be in the best interests of the child and/or other children with whom they would be educated (National Council for Special Education 2014). Inclusion is a core value in this Act and it explicitly states that school provision should be informed by rights and equality principles (Griffin and Shevlin 2011).

The Disability Act (2005) requires Government departments and public bodies to strive for improvements in the quality of life of people with disability. This Act was designed to support the participation of people with disability in society by providing disability specific services and improving access to mainstream services (Department of Justice, Equality and Law Reform 2006). Section 28(3) relates specifically to people with intellectual disability stating:

> *The head of a public body shall ensure, as far as practicable, that information published by the body, which contains information relevant to persons with intellectual disabilities, is in clear language that is easily understood by those persons (Disability Act 2005).*

Lastly, *The Assisted Decision-Making (Capacity) Act 2015* provides a statutory framework for people to be assisted and supported to make decisions about their welfare, property and affairs particularly when the person lacks or may lack capacity to make the decision unaided (The Alzheimer's Society of Ireland 2018). This Act ensures the person's right of autonomy and self-determination is

respected and places a legal requirement on service providers to comprehensively facilitate a person when decision making by providing appropriate supports and information to their individual circumstance (HSE 2018). Inclusion Ireland (2016) described this Act as signalling a '*seismic cultural shift*' away from paternalism and 'best interests' toward a right-based approach of choice, control and consent.

These Acts preserve the rights of people with intellectual disability to inclusion, non-discrimination, choice, control and self-determination. Communicating with individuals with intellectual disability in an accessible and individualised way is required to meet the legal obligations set out in these laws. Individualised communication supports require understanding the nature of these interactions. The findings of this study should provide such knowledge and identifies factors that support the achievement of understanding.

2.11 Implementation and Progression of Policies and Strategies

Meeting obligations and implementing policies and strategies for people with severe/profound intellectual disability is challenging services and systems. The present *National Disability Inclusion Strategy 2017-2021* is currently being reviewed and so the progress report is not available. However, in July 2018, Inclusion Ireland examined the progression of this strategy. While this review did not identify the impact on people with severe/profound intellectual disability specifically, it expressed frustration at the slow pace of progress in relation to implementation of the *UNCRPD* and development of supports around the *Assisted Decision-Making (Capacity) Act*. Positively, progress was noted in relation to

implementation of *New Directions* for those who require '*high level support*' (Inclusion Ireland 2018, online).

In 2013, Inclusion Ireland published a position paper on the implementation of the *National Disability Strategy 2004*, the predecessor to the *National Disability Inclusion Strategy 2017-2021*. Resourcing of the Health Services Executive Disability Unit and disability services was criticised for jeopardising the human rights of (all) people with intellectual disability although the impact of austerity measures at that time are acknowledged (Inclusion Ireland 2013). Concerns regarding the continued practice of accommodating people with severe or profound intellectual disability in congregated setting were expressed. The *Time to Move on Strategy* (2011) recommended that all individuals with intellectual disability living in congregated-type settings (approx. 4000 in 2008) would be supported to move to homes in the community by the end of 2019. The 2018 Annual Progress Report on the Time to Move on Strategy (HSE 2019) states that the number of people with severe/profound intellectual disability living in congregated setting has fallen by 986 from 2009-2018. However, 55% of people who continue to reside in congregated settings have a severe (40.2%) or profound (15%) intellectual disability. During Dáil questions (May 15th, 2019), Minister of State with responsibility for Disability Issues, Finian McGrath, answered that by the end of 2019, 2100 people with disability will continue to live in congregated settings. Minister McGrath stated that the objective now is to reduce this number further by 2021 with a view to eventually eliminating all congregated settings.

Pertinent to this study, *the National Quality Improvement Operational Plan for Disability Services in Ireland (the Operational Plan)* (HSE 2018) which builds on the *Transforming Lives* programme found that communication is proving to be a barrier to achieving high quality services. The *Operational Plan* specifically states that difficulties are experienced in ascertaining the views of people with severe/profound intellectual disability. This plan is a culmination of several of the Irish programmes, policies and strategies discussed in this chapter. The identification of communication as a barrier for this group indicates its significance across these drivers. Additionally, it augments the argument for this study. The implementation of these strategies for people with severe/profound intellectual disability requires more knowledge about how they communicate and interact if the goals of improving their quality of life are to be met.

2.12 Conclusion

This chapter has provided an overview of the nature of intellectual disability and specifically severe/profound intellectual disability. With this background, a discussion of the nature and means of communication with people with severe/profound intellectual disability is offered. It is clear that communication and interpersonal interactions are essential to humanity. The impact of positive interpersonal interactions has been shown across mental and physical wellbeing research as well as professional practice and service delivery research. Experiencing interactions has been linked with better health outcomes while isolation and loneliness has been related to more unfavourable outcomes. People

with intellectual disability are vulnerable to isolation and loneliness due to societal barriers and consequent to the nature of their disability. There is general agreement in the literature that positive interpersonal interactions can enhance and contribute to the quality of life of people with intellectual disability at an individual level. However, it is reliant on the ability of their interaction partner to communicate in an appropriate and suitable way. Fulfilment of the right to communicate, express oneself and be understood, identifying a person's preferences, needs and goals and interacting in a meaningful and person-centred way requires skilled communication partners who can recognise and discriminate communication attempts and act and respond appropriately and consistently.

An in-depth examination of Charters and structures that support the rights of individuals to communicate is presented. These have a considerable influence on the development of policy and legislation at international, European and Irish levels. These are outlined cognisant of the rights agenda and impact on and for individuals with intellectual disability. The currency and relevance of this study to informing implementation of these policies and agendas, contributing to the evidence base informing practice and enhancing the quality of life of those with intellectual disability is clearly identified and justified.

This study contributes to the body of knowledge and evidence striving towards making high quality, responsive and meaningful interactions the norm for people with severe/profound intellectual disability. This study seeks to explain the means and strategies people use to navigate interactions involving people with

severe/profound intellectual disability in order to engage reciprocally and meaningfully. The ontological, epistemological and methodological position taken will be presented in the next chapter, with the methods and findings presented thereafter.

Chapter 3 Research Methodology

3.1 Introduction

The background, context and rationale for this study have been provided in the previous chapter. The purpose of this chapter is to set out the methodological position of this study. A high-quality research study requires a rigorous and systematic approach that comes about through congruous integration of the aims, paradigm and methodology guiding the study (Houghton et al. 2012). Detailing the philosophical assumptions that underlie and guide a study enables those using it to better comprehend, question and apply the findings as well as engage in academic debate (Scotland 2012).

Several philosophical, ontological and epistemological positions exist that will be examined in this chapter including realist and relativist ontologies and positivist, post-positivist, constructionist and interpretivist epistemologies. A discussion of the position adopted in this study and its guiding influence is included. An examination of Classic Grounded Theory, the methodology used to undertake this study is provided, including its key principles and tenets and justification for its use.

Firstly, however, Weaver and Olson (2006) highlight the importance of ensuring that the paradigm fits with the research question/aim rather than the aim/question fitting the paradigm. Saunders et al. (2009) support this claim stating that the ontological and epistemological stance should enhance understanding of

the issue under study and enable the researcher to meet the study aim/question. Therefore, selection of a philosophical stance should not be determined by judging which position is better than another, but by asking the question '*which is the right stance for this research aim/question?*' (Nicholls 2009a). To this end, the aim and key factors that influence the philosophical stance of this study are now briefly presented.

3.2 Study Aim

The aim of this study is to explain the patterns of behaviour associated with communicating in interactions involving people with a severe/profound intellectual disability. Meeting this aim requires examination of interactions between people with a severe/profound intellectual disability and their communication partners. Interpersonal interactions are subjective experiences to the persons participating. They tend to be unique, inconsistent and inimitable reducing the extent to which they can be measured or predicted. Interpersonal interactions are co-constructed by their participants, who each bring their own subjective interpretations but seek to reach a mutual understanding/interpretation during the interaction.

Meeting this aim requires judicious consideration and identification of an appropriate ontology, epistemology and methodology. As previously mentioned, this not only ensures the study aim is met but contributes to the quality of the study. Therefore, an examination of research paradigms follows.

3.3 Paradigms for Research

Paradigms in research are belief systems about the nature of reality (ontology) and knowledge construction (epistemology) (Hinshaw 1996; Jacob 1989) used by researchers to generate knowledge (Levers 2013). Fossey et al. (2002) describe paradigms as sets of assumptions, research strategies and rigour criteria shared and taken for granted by those who hold the stance. Denzin and Lincoln (2017) offer a definition that captures each of these perspectives stating that a paradigm is a net that holds ontological, epistemological and methodological beliefs acknowledging the taken for granted or assumed components of paradigms. Scotland (2012) asserts that each paradigm is underpinned by its own ontological and epistemological assumptions and as such, these cannot be empirically proven or disproven but are reflected in their methodology and methods.

Although there is agreement that the paradigm underpinning a study is philosophical and intellectual, it has practical influences in terms of informing decision making and offering guidance during the research process. This is indicated by the verbs used to highlight their influence such as regulating, structuring, bridging (Weaver and Olson 2006), shaping (Ravitch and Riggan 2012), cohering (Leshem and Trafford 2007), contextualising, guiding, ballasting and contributing to methodological precision (Durham et al. 2015). They provide lenses, frames and processes through which the study aim is met (Weaver and Olson 2006). Paradigms have traditionally been defined in terms of a dichotomy

between two ontological positions and epistemological stances therein (Durham et al. 2015).

3.4 Ontology and Epistemology

Crotty's (1998 p. 10) definition of ontology as '*the study of being'* is frequently cited. It concisely captures the main concern of this branch of philosophy. However, to elaborate further, Denzin and Lincoln (2017) state that ontology raises questions about the nature of reality and human existence in the world. Essentially, does reality exist independent of or within human consciousness and experience? (Campbell 2015; Levers 2013). Mills et al. (2006) argue that choosing an ontological position strengthens the research design and illuminates the epistemological and methodological avenues available. This would indicate that ontological beliefs dictate epistemological beliefs.

To cite Crotty (1998 p.3) again, epistemology is the study of knowledge and '*a way of understanding and explaining how we know what we know*'. It focuses on how to create meaningful sense of the world (Levers 2013). It is concerned with how knowledge is created, acquired and communicated (Scotland 2012) indicating its importance to research as a way of creating knowledge. Denzin and Lincoln (2017) and Guba and Lincoln (1994) agree that epistemological inquiry looks at the relationship between the knower and the known and asks how knowledge comes to be known.

Two polarised epistemological stances, objectivism and subjectivism, align with the ontological positions of realism and relativism respectively. Objectivism assumes that all humans gain the same understanding and meaning is achieved external to humans as it is determined by the structure of the real world (Jonassen 1991) i.e. ontological realism. Subjectivism refers to beliefs that social phenomena are created from the perceptions and interactions of humans (Saunders et al. 2007) i.e. ontological relativism. Therefore, realism and relativism are recognised as opposing ontological positions. An outline of these positions is offered along with a delineation of their epistemological viewpoints.

3.4.1 Realism

The realist ontological perspective contends that reality exists independent of the human mind regardless of comprehension or direct experience (Levers 2013). In other words, a realist ontology does not require epistemological awareness. A reality exists independent of the knower (Cohen et al. 2007). Consequently, a discoverable reality exists independent of the researcher (Pring, 2000). According to Weaver and Olson (2006), positivist and post-positivist epistemologies are based on realist ontology.

3.4.1.1 Positivism

The positivist epistemology is objectivist, assuming reality is not understood by individual perception (Scotland 2012). Positivists seek to discover knowledge of an objective reality that is absolute and value free (Scotland 2012). Impartiality is

possible because it is believed that the researcher and researched are independent entities (Scotland 2012).

Positivism deductively develops abstract laws describing and predicting patterns in the physical world (Suppe and Jacox 1985) explaining relationships (Scotland 2012) and identifying causes and outcomes (Creswell 2009). This is achieved through experimentation in stringently and rigorously controlled conditions (Peat et al. 2002). Positivism underpins quantitative methods such as clinical trials, experimental and quasi-experimental designs, epidemiological surveys and tests of validity and reliability (Nicholls 2009a).

Attempts to control variables can be difficult particularly if variables are hidden from the researcher until their effects become evident (Scotland 2012). Furthermore, positivism's claims of discovering value free, universal truth are questionable (Weaver and Olson 2006). Recognition of these limitations led to the emergence of post positivism during the 20th century.

3.4.1.2 Post Positivism

Post-positivism emerged with questioning of the assumption of absolute truths in positivism and recognition that its measures are limited to human comprehension (Weaver and Olson 2006). Although some positivist assumptions carried through to post positivism, there are distinctions between the two positions. The positivist emphasis on well-defined concepts and variables, control, precision and empirical testing of theories and hypotheses (Guba and Lincoln 1994) as well as cause and

effect are maintained in post-positivism (Durham et al. 2015). However, post-positivists acknowledge the existence of unobservables and their explanatory capabilities (Kuhn 1962; Popper 1959; Bronowski 1956).

Post-positivism questions the notions of absolute truth and total objectivity, accepting the shortcomings of measurements (Levers 2013) and seeking to be as objective/neutral as possible. Therefore, '*warranted assertability*' is sought (Lather 1990; Phillips 1990). Consequently, the use of multiple measures, observation, triangulation (Houghton et al. 2012) and replication (Weaver and Olson 2006) is advocated to enrich and explain the data and reduce bias.

A second distinction centres on the principle of falsification which states that scientific theories can never be proven true (Scotland 2012). They can only be tentatively accepted when all attempts to refute them fail (Scotland 2012). Due to this tentative nature of knowledge, hypotheses are not proven rather than rejected (Creswell 2009).

Lastly, as a result of acknowledging the influence of unobservables, post-positivists require more than empirical data (Scotland 2012). Therefore, participants' perspectives are often sought.

3.4.1.3 Suitability of Realist Ontology

A realist ontology and its associated epistemological positions were unsuitable to guide this study towards meeting its aim for several reasons. Firstly, key tenets such as control, value-neutrality, objectivity, rationalism and logical reasoning

conflict with the characteristics of the phenomenon under study. Controlling the environment or influential variables and testing was not a requirement in this study. It was important to study naturally occurring interactions across environments.

Secondly, and building on this issue, the methods associated with this paradigm have profound limitations in relation to their capacity to capture people's experiences, interpersonal connections and the social and cultural systems within which they live (Nicholls 2009a). Intentionality and agency of participants are undetected (Scotland 2012) which is foundational in research of human interactions. Positivist denial of unobservable values ignores a fundamental dimension of interpersonal interactions. Although it could be argued that post-positivism acknowledges and seeks participant perspectives, its reduction of the experience to scores and percentages can be dehumanizing (Weaver and Olson 2006).

Essentially, a realist ontology is untenable with the present study. Therefore, attention is now turned to relativism as a potential ontological position.

3.4.2 Relativism

As a polar opposite to realism, relativism challenges the belief in a single objective reality. Relativism believes in multiple realities depending on meanings attached to truth and evolves according to experience (López-Alvarado 2017). In other words, social reality is a finite subjective experience (Denzin and Lincoln 2005), a

human experience and human experience is reality (Levers 2013). Therefore, reality emerges when human consciousness engages with objects that are ascribed meaning (Crotty 1998). This notion of subjective realities contradicts the notion of universal truths advocated by realists. This is the foundational belief that polarises both positions. Guba and Lincoln (1994), Allen et al. (1986) and Guba (1990) state that constructionism and interpretivism are ontologically relativist.

3.4.2.1 Constructionism

According to Guba and Lincoln (1994 p.111) constructionism is epistemologically subjectivist, elaborating that the researcher and participants are assumed to interact to *create* findings as the study proceeds. Constructionists construct and co-create knowledge with participants reaching understanding in a participative and conversational way (Charreire Petit and Huault 2008). Positivists and post-positivists view this approach as undermining the study findings (Lincoln 1998). Schwandt (2000 p. 197) discusses how this co-creation occurs against a '*backdrop of shared understandings, practices and language'* and other influential aspects of a social experience. Lee (2012) highlights ontological issues of co-constructing and distinguishing between reality and appearance. Lee (2012) concludes that constructionism risks mistaking appearance for reality. This is significant in the context of the present study, particularly regarding participants with intellectual disability. The communication issues this group encounter raise this risk of reporting appearances rather than their reality. The risk is such that to adopt this epistemological position would undermine the findings.

3.4.2.2 Interpretivism

Interpretivism also has a relativist ontology and subjectivist epistemology. Interpretivism believes more than one truth exists in a reality that is socially and experientially based (Guba 1990). Emphasis is placed on recognising, understanding and narrating the meaning people draw from the actions and reactions of others (Weaver and Olson 2006; Fossey et al. 2002). This highlights one distinction between this relativist position and those aligned with realism. While positivism holds that truth and reality are value free, interpretivists consider it to be value relative or value mediated (Lincoln and Guba 1985).

This focus on the subjective experience requires seeking to understand a phenomenon from the perspective of a person who has experienced it (Nicholls 2009a). However, research is guided by the researcher's ontological and epistemological beliefs about the nature of knowledge and how it can be understood (Denzin and Lincoln 2005). Consequently, researchers must remain mindful of their impact on the study (Houghton et al. 2012). This is necessary for several reasons. Firstly, inter-subjectivity between the researcher and participants is fostered (Yarwood 2014). Shared awareness and understanding are achieved through the research relationship (Weaver and Olson 2006) and so researchers must remain aware of their contribution to this shared understanding. Secondly, interpretivists reach an understanding by gathering data from participants and interpreting them (Nicholls 2009a). It is argued that interpretation is necessary to move beyond the data (Rapport 2005; Graneheim and Lundman 2004;

Nandhakumar and Jones 1997). However, it again highlights the influence of the researcher on the research and its findings. To address this issue, interpretivists engage in reflexivity as a means of acknowledging their beliefs and values that may impact the study (Lathlean 2010; Baker 2006; Carolan 2003; Abramson 1992).

The capacity of relativism and interpretivism to capture subjective experiences has led to its widespread use in nursing research (Harvey and Land 2017). Its subjective philosophy fits with individualised, holistic care espoused in nursing (Drew and Dahlberg 1995). It was therefore important to consider its suitability for this study.

3.4.2.3 Suitability of Relativism

The philosophical alignment of relativism and nursing makes it worthy of consideration, but further examination of the position raised questions as to its suitability for this study. Although it is sensitive to individual experiences and perspectives, it has shortcomings. One key argument relates to the usefulness of the findings (Hammersley 1992; Bury 1986). Individual experiences and perspectives can be unique and therefore, each can claim legitimacy rather than precedence (Andrews 2012). Knowledge produced by this paradigm therefore, may seem fragmented rather than unified and coherent (Scotland 2012).

Further to the issue of multiple truths, is the limited ability of this paradigm to identify patterns, commonalities and consensus in the data (Houghton et al. 2012). Consensus is important in meeting the aim of this study. Gaining the perspectives of participants with severe/profound intellectual disability required searching for

patterns and commonalities in their behaviours that could indicate their experiences. The expressive communication challenges they encounter are such that discovery of their experiences requires attending to their behavioural patterns; particularly those that are communicative and have pattern consistency.

From a methodological perspective, without consensus or commonality, there is limited generalisability. The contextualised nature of the knowledge implies it cannot be generalised but only transferred to similar contexts (López-Alvarado 2017). Additionally, consequent to the discovery of these multiple truths, relativist research seeks to achieve legitimacy and trustworthiness of the findings rather than explaining or claiming certainty (Scotland 2012).

Given the limitations of relativism to guide this study towards meeting its aims, relativism was also an untenable option. Consequently, another approach to selecting a framework to guide the processes of this study was required. Of concern was the ability of the chosen guiding framework to discover the experiences or perspectives of the participants; particularly those who have difficulty expressing themselves. A research methodology provides insight into the researcher's worldview and is a demonstration of the philosophical assumptions underlying the study (Cordeiro et al. 2017). Therefore, it is reasonable to examine how methodologies contribute to the creation of knowledge (Nicholls 2009b).

3.5 Methodology

A methodology is the theoretical framework of the research (Cordeiro et al. 2017). It is the strategy that guides decision-making and selection of methods (Crotty 1998). While ontology raises questions about the nature of reality (Denzin and Lincoln 2017) and epistemology about knowledge (Crotty 1998), methodology asks how we can know what can be known (Guba and Lincoln 1994). Therefore, it is concerned with why, what, how, where and when data is collected and analysed (Scotland 2012).

Different methodologies were examined to identify one that would ensure the study aim was met including Discourse Analysis, Ethnography and Interpretive Phenomenological Analysis. The interpretive approach to data analysis was the main reason these were not selected (Eriksson and Kovalainen 2015; Smith and Osborn 2009; Antaki 2008). It was believed that the quality of the study would be undermined by the risk of misinterpreting data collected from participants with intellectual disability particularly. This study required a methodology that acknowledges individuality and the influence of different contexts but also recognises and captures patterns and commonalities in the experiences of participants. The most significant issue with these methodologies was the extent to which they could accommodate and include persons with severe/profound intellectual disability and significant communication difficulties as participants. The chosen methodology needed to rigorously guide the study towards meeting its aim. It needed to be flexible enough to allow for multiple data collection

methods that can gather the experiences and perspectives of participants while ensuring rigour and high quality. It was for these reasons that Grounded Theory was the chosen methodology for this study. It is at the quantitative/qualitative methodological interface (Taylor 2013) or as Glaser and Strauss (1967) assert, it is a general methodology.

3.6 Grounded Theory

Grounded Theory is frequently used in nursing research (Schreiber and Stern 2001). It is unique in that it is neither quantitative nor qualitative (Nicholls 2009b) but a general approach to research. Grounded Theory aims to generate robust, reasoned theory using a range of quantitative and qualitative principles (Nicholls 2009b). It offers a qualitative approach rooted in epistemological objectivity (Annells 1996).

3.6.1 Development of Grounded Theory

Grounded Theory originated from a study undertaken by Glaser and Strauss titled *Awareness of Dying* (1965) which related to interactions between medical staff and terminally ill patients in hospices (Kenny and Fourie 2014). *The Discovery of Grounded Theory* (1967) was published two years after *Awareness of Dying* as a presentation of the methodology they designed and used during the study. It defined and demarcated a rigorous methodology and has become a handbook and guide for those adopting this approach (Kenny and Fourie 2014).

Positivism was dominant when the *Awareness of Dying* study was being undertaken and qualitative approaches were criticised for being unscientific and lacking rigour (McCann and Clark 2003). Glaser and Strauss sought to challenge these criticisms out of frustration with the emphasis on verifying theories to the detriment of generating theory. They argued that the two-fold process of firstly generating and then verifying theory should receive equal treatment (Kenny and Fourie 2014). They further highlighted the need to generate theory which arises from social research that would be more successful than theories '*logically deduced from a priori assumptions*' (Glaser and Strauss 1967 p. 6). This new methodology was entitled *Grounded Theory* to stress the overarching objective of grounding theory in empirical research. According to Glaser and Strauss (1967), this systematic, ordered and structured methodology, informed by quantitative principles, addresses the criticisms of qualitative research while acknowledging its valuable contribution to knowledge.

3.6.1.1 Classic Grounded Theory

Classic Grounded Theory is considered ontologically and epistemologically neutral (Breckenridge et al. 2012; Glaser 2005). This position has been criticised for being non-committal (Bryant 2009) and not meeting the expectation that researchers explicate their philosophical position (Grix 2002). Holton (2007) has defended this stance by explaining that Classic Grounded Theory should not be confined to any one perspective but considered amenable to the epistemological perspective appropriate to the data and the researcher's ontological position. The Classic

Grounded Theorist remains open and sensitive to the emergence of theoretical codes from multiple theoretical perspectives rather than assuming a theoretical position in advance of the study (Glaser 2005).

As Grounded Theory became an increasingly used methodology and generated much debate and discourse such as that outlined, the traditional or Classic Grounded Theory methodology became one of a number. Most significantly, Glaser and Strauss went separate ways, proposing different ways that Grounded Theory ought to be practiced (Willig 2013).

3.6.1.2 Straussian Grounded Theory

In their efforts to advance Grounded Theory, Glaser and Strauss' perspectives became increasingly divergent to the extent that they published separately rather than collaboratively during the 1970s and 80s (Kenny and Fourie 2014). Publication of *Basics of Qualitative Research: Grounded Theory Procedures and Techniques* by Strauss and Corbin in 1990 was a particularly significant turning point. In this publication, Strauss and Corbin (1990) lay out a revision of Grounded Theory as originated, challenging the principles of emergence and open-mindedness. They offered a coding framework designed to systematically deduct rather than induct theory from data. They argued the difference between an open mind and an empty mind (Jones and Alony 2011) disputing the practice of abstaining from literature prior to undertaking the study.

In the 2008 edition of the book, and following Strauss' death in 2006, Corbin declared approaching Grounded Theory from a relativist ontological perspective. Epistemologically, she indicates subjectivity by stating it is not possible to *"separate who I am as a person from the research and analysis that I do"* (p. 11). Based on this position, Levers (2013) asserts that a theory developed using Straussian Grounded Theory '*is unquestionably the researcher's unfettered interpretation of the data'.* This fundamentally differs from Classic Grounded Theory which claims to be a general approach that strives for emergence. This aspect of Straussian Grounded Theory was problematic for this study where the findings needed to credibly represent participants' experiences. Risks associated with interpreting perspectives needed to be managed.

Glaser criticised Strauss and Corbin's (1990) book, including this issue relating to analysis, and published *Basics of Grounded Theory Analysis: Emergence vs. Forcing* in 1992. He structured this book using the same chapter sequence as Strauss and Corbin (1990) enabling the reader to discern correlation and divergence between both approaches (Kenny and Fourie 2014). Clarity and distinction between both approaches continued to be made as both factions published further articles and books explaining, arguing and defending their stance. However, the Grounded Theory dispute did not remain two sided as Kathy Charmaz proposed a third approach to the method which came to be known as Constructionist Grounded Theory.

3.6.1.3 Constructionist Grounded Theory

Charmaz studied Grounded Theory under both Glaser and Strauss. Responding to the call to adopt Grounded Theory flexibly (Glaser and Strauss 1967), Charmaz (2006) attempted to interpret it within a constructionist paradigm. Charmaz (2000) articulates a relativist stance but references an empirical world. Breckenridge et al. (2012) conclude that Constructionist Grounded Theory is distinctly different to Classic Grounded Theory. Although the key principle of induction remains, the predetermined philosophical lens fundamentally conflicts with the general inductive nature of the classic method. Furthermore, there is a shift away from emergence and the researcher has a recognised role in constructing the theory (Levers 2013). This compromises openness. Classic Grounded Theory asserts that the theory emerges from the data whereas the researcher generates data and theory in Constructionist Grounded Theory (Timonen et al. 2018). Charmaz (2014 p. 339) encourages construction of an '*interpretive rendering'* rather than an external reporting of the world being studied. Therefore, the influence of how the researcher interprets the data must be acknowledged. This aspect of Constructionist Grounded Theory was problematic for this study as it would weaken findings relating to participants with severe/profound intellectual disability. With this approach, the theory is co-constructed from the data. It does not emerge as per Classic Grounded Theory. This was a particularly important distinction to consider when selecting the most appropriate Grounded Theory approach for this study.

3.6.2 Adopting a Grounded Theory Methodology

Examination and appraisal of these distinct methodologies led to the decision to adopt Classic Grounded Theory to guide this study. The philosophical debate will continue, but a preoccupation with the ontological and philosophical issues can distract from the original purpose of the methodology; to generate a theory that fits, works and is relevant (Breckenridge et al., 2012). It brings about knowledge that resides in the data (Willig 2013) not what is interpreted or deduced. It recognises that knowledge can be captured rather than interpreted. This was one of the reasons this methodology was selected. It enables experiences to be captured rather than interpreted which strengthens findings, particularly in relation to participants with severe/profound intellectual disability.

Furthermore, the methods enshrined in Classic Grounded Theory to ensure openness rather than subjectivism, induction rather than deduction, discovery rather than construction and conceptualisation rather than description will ensure that this study results in the emergence of a robust grounded theory that explains the patterns of behaviour associated with communicating with people with a severe/profound intellectual disability. Grounded Theory methods and processes that ensure these criteria and principles are met include memoing, theoretical sampling, theoretical saturation, constant comparison, theoretical coding and theoretical sensitivity. Memoing and constant comparison address the influence of the researcher on the data and ensure the findings are reflective of participant experiences rather than the researcher's interpretation or construction of the

phenomenon. Adoption of these processes in this study is detailed in the following chapter.

3.7 Philosophical Assumptions of this Study

At this point, it is timely to point to the philosophical stance of this study. As Cordeiro et al. (2017) pointed out, selection of methodology can indicate the researcher's philosophical stance. It is clear from the earlier discussion that the opposing absolute positions of realism and relativism are unsuitable. However, a subtle realism stance is more fitting and taken in this study. Hammersley (1992) views subtle realism as a middle ground between realism and relativism. Andrews (2012) and Madill (2008) assert that this perspective acknowledges the existence of an independent reality while recognising there is no access to that reality. This study recognises that research involves subjective perceptions and observations and different methods will produce different portrayals of participant experiences which is in keeping with subtle realism (Duncan and Nicol 2004). However, such a stance regarding subjective perceptions and observations does not preclude the existence of independent phenomena and the possibility of studying relationships and experiences (Hammersley 1992; Kirk and Miller 1986). Importantly, the subtle realist does not claim to have absolute certainty but *'reasonable confidence'* regarding the research findings (Murphy et al. 1998 p.69) which is in keeping with Classic Grounded Theory.

3.8 Conclusion

The need to declare an ontological and epistemological stance is advocated in the literature. The nature of this study required taking a methodological approach to indicate the philosophical stance. A realist ontology and associated epistemological positions are inappropriate due to key tenets of control and value neutrality as well as its limitations in capturing subjective experiences. Although relativism can capture subjective experience, the usefulness of the findings can be questionable. Furthermore, its ability to identify patterns and consensus in the data is limited. It is recognised that the research methodology can provide insight to the researcher's worldview and demonstrate philosophical assumptions. A subtle realist perspective is adopted in this study which is in keeping with Classic Grounded Theory methodology. This methodology guided this study towards meeting its aim of explaining the methods and processes people use to communicate with and understand each other in interactions involving people with a severe/profound intellectual disability. It was designed to explain contextualised social processes; in this study, the social process of interpersonal interactions in the context of severe/profound intellectual disability. Therefore, its original purpose fits with the nature of this study. A detailed justification for choosing this methodology has been offered. The following chapter will clearly detail how Classic Grounded Theory methods were applied to produce a robust grounded theory that explains the social processes underlying interactions with people with severe/profound intellectual disability.

Chapter 4 Method

4.1 Introduction

Chapter three discussed and debated the philosophical and methodological issues and justified a subtle realist position in this study. Classic Grounded Theory guided this study towards meeting its aim. The selection of this methodology has been presented and justified in the previous chapter. Therefore, this chapter sets out how Classic Grounded Theory was implemented in the present study. The chapter is structured chronologically starting with the study aim and process of obtaining ethical approval. The methods of gaining access to participants and liaising with gatekeepers is outlined. Following this, the sampling procedures are detailed. In keeping with Classic Grounded Theory, theoretical sampling was used. Decisions made relating to this procedure are transparently presented. As theoretical sampling is informed by data collection and analysis, these are presented together. Each stage of the study was informed by, and is therefore presented alongside, the corresponding guidance from the Classic Grounded Theory literature. This chapter concludes with a discussion of the measures taken to ensure quality and the role of the researcher in the study. Firstly, a brief reminder of why Classic Grounded Theory is the chosen method for this study.

4.2 Why Classic Grounded Theory?

A wealth of research surrounding communication with people with intellectual disability of varying levels (McCausland et al. 2017; Lancioni et al. 2017; Brady et

al. 2016), in varying settings (Wilder et al. 2015; Boardman et al. 2014; Ziviani et al. 2004) and with varying communication partners (O'Toole et al. 2018; Lewis et al. 2017) exists. Research to date adopts quantitative, qualitative and mixed method approaches that often accurately describe the nature or aspects of the interaction. Sometimes these studies concentrate on one contributor to the communication partnership while others examine both perspectives as discussed in the background chapter. However, there is a significant lack of theory that explains the interaction. There is a notable paucity of a theory that fits, works and is relevant to the complex and challenging activity that is communicating with people with a severe/profound intellectual disability. Much is known from an empirical, experiential and descriptive base but indicators discovered in these studies have yet to be conceptualised. A Classic Grounded Theory methodology provides a means of generating theory about the psychosocial processes that present within human interactions (Streubart-Speziale and Carpenter 2011).

4.3 Aim and Objectives

The aim of this study is to generate a theory that will explain the methods and processes people use to communicate with and understand each other in interactions in the substantive area of communication with persons with severe/profound intellectual disability. Glaser (1978) asserts that a grounded theory should develop from the participants' main concern. Therefore, a broad aim, such as this, allows the main concern of participants to emerge. To meet this aim, the following objectives were set:

1. To identify people's main concern when interacting
2. To discover the reasons for this concern
3. To determine how this concern is addressed
4. To generate a grounded theory that explains how people with severe/profound intellectual disability and their partners communicate with and understand each other

An important factor to consider in this study was the means of identifying the main concern of participants with severe/profound intellectual disability. Proxy reports raise questions around credibility, trustworthiness (Scott and Havercamp 2018) and bias. Therefore, it was important to gather these participants' perspectives in a way that facilitated their means of communicating. As this group tend to communicate using non-verbal, behavioural means, observations were deemed the most suitable and appropriate data collection method. Furthermore, Classic Grounded Theory seeks to explain patterns of behaviour people use to address a concern (Vander Linden 2017). This study sought to explain the communication behaviours people use to communicate with and understand each other in interactions. Therefore, the following questions were asked of the data:

1. What is each person in the interaction doing verbally?
2. What is each person doing non-verbally?
3. What caused each person to act in this way?
4. What is the result of the person acting in this way? What do they achieve or not achieve?

5. How does the communication partner react or respond?
6. How does anyone else in the environment react?

Before undertaking the study to meet this aim and achieve these objectives, ethical approval had to be obtained. The methods of upholding ethical obligations and process of gaining ethical approval will now be presented.

4.4 Ethical Considerations

Ethical approval is a prerequisite of any study and an intrinsic part of the access process (Høyland et al. 2015) as it can contribute to the development of trust among gatekeepers and participants. Robust and stringent monitoring and governance contributes to participants' confidence that harmful research is not undertaken (Cowan 2009).

The need for such protection from harm came about as a result of infamous and notorious studies that were undertaken without due regard for the human rights and safety of participants; the Nazi medical experiments, the Tuskegee Syphilis Study and the Jewish Chronic Disease Hospital Study to name but a few. Unethical studies involving participants with intellectual disability specifically include the Willowbrook Study, The Fernald and Wrentham Radiation Experiments and the Vipeholm Dental Caries Study. Ethical codes and regulations were developed as a result of such studies including the Nuremberg Code (1949), Declaration of Helsinki (1964) and the Belmont Report (1976). These codes advocate the principles of beneficence and non-maleficence, autonomy and justice and the

ethical requirements for informed consent, privacy, anonymity and confidentiality. These principles along with the Code of Professional Conduct for each Nurse and Midwife (An Bord Altranais 2000), the Code of Professional Conduct and Ethics for Registered Nurses and Registered Midwives (Nursing and Midwifery Board of Ireland 2014), the HSE National Consent Policy (2013) and Ethical Guidance for Research with People with Disabilities (National Disability Authority 2009) informed and guided ethical and procedural decision making for this study.

4.4.1 Beneficence and Non-Maleficence

The principles of beneficence and non-maleficence pertain to the ethical requirement of not only respecting a person's decisions and protecting them from harm, but also taking steps to ensure their well-being. It essentially obligates the researcher to do no harm, maximise benefits and minimise possible harms (Office for Human Research Protections 2016). Careful consideration had to be given to the potential benefits and risks to participants in this study. No physical risk or harm to participants was anticipated. However, it was recognised that some potential participants may find video recordings intrusive. Potential participants were informed from the outset that the study would involve observations and video-recording and perhaps an interview. The purpose and necessity for video recording and the method of data analysis was explained to participants without an intellectual disability and those providing proxy consent. On receipt of this information, some people chose to participate, and others decided not to.

Therefore, transparency regarding the data collection and analysis methods offered protection from the potential intrusiveness and discomfort of being video-recorded.

Additionally, the interviews could possibly be distressing as the interpersonal nature of the topic may be emotive. Participants were informed that the interviews were optional, and they were entitled to withdraw at any point should they wish. Participants without a severe/profound intellectual disability willingly engaged in interviews. One participant, a mother, became upset during an interview. Although the option to end the interview or withdraw was reiterated, she asked to continue as she found the discussion beneficial and appreciated having her story listened to. Available supports were offered to her although she chose not to avail of them. She voiced her gratitude for listening to her again in a follow-up telephone call the following day and a visit a week later. No one else became distressed or required supports following their participation in the study. While immediate benefits to participants appeared limited at the outset of the study, several appreciated attention being afforded to such a significant problem in their lives. Such benefits have been reported previously (Rossetto 2014; Lee Murray 2003).

A further key ethical issue requiring deliberation is the extent to which people with an intellectual disability need protecting and who is best placed to do this (Nind 2008). Tuffrey-Wijne et al. (2008) and Witham et al. (2013) argue that it is unethical to exclude people with severe intellectual disabilities from research that

could gain insight into their experiences and shape care into the future. The potential harm to participants with an intellectual disability was envisaged to be limited to the perceived intrusiveness of video recording their interactions. Although consent to participate was provided by proxy, it was agreed that any indication by the person that they did not wish to be recorded or observed would be considered exercising their right to withdraw and would supersede the proxy consent. During data collection, two participants with intellectual disability were intrigued by and inspected the camcorder. When they saw a video of themselves played back, one smiled and the other clapped. This was considered an indication that they, at least, did not mind being recorded.

It could be argued that by participating in research, individuals are taking a risk by disclosing personal and private experiences, thoughts and emotions. This disclosure occurs in the context of trust. The researcher has an obligation to respect and uphold this trust by taking actions to ensure that the privacy, confidentiality and anonymity of participants is protected and maintained, thus, minimising any physical, psychological or emotional harm caused by exposure of the data.

4.4.1.1 Privacy, Confidentiality and Anonymity

Ensuring participants' privacy and confidentiality and protecting their anonymity is fundamental to research. This means ensuring that participants cannot be identified or information that could identify them is not revealed (Padgett 2017). Privacy refers to a persons' right to determine the time, extent and general

circumstances under which their private information will be shared with or withheld from others (Fouka and Mantzorou 2011 p.6). Participants' privacy is respected by taking actions to preserve their anonymity and confidentiality. Anonymity is upheld when identity cannot be linked with responses (Lichtman 2014). Confidentiality is ensured by safe management of collected data to ensure it is kept private from others (Grove et al. 2015). Anonymity and confidentiality in this study were ensured by using pseudonyms and carefully reporting the findings. As can be seen in Chapter 5, data is anonymised by using outline sketches of video stills. The level of abstraction from time, place and people (Glaser 2002) associated with Classic Grounded Theory further supports the anonymity of participants.

Privacy, confidentiality and anonymity required particular attention with regard to the use of video recording in the present study. Gathering and storing visually recognisable images runs a higher risk of identity exposure (Padgett 2017) requiring careful data management. Initially, data was stored in keeping with the UCC Code of Research Conduct (2010). However, this code was reviewed, and the data is now stored according the UCC Code of Research Conduct v2.2 (2018) as the study was not completed by this date. This code requires that data be stored securely with back up records for a minimum of ten years after completion of the study. Therefore, the data is currently being stored on the UCC OneDrive with a backup copy on an external hard drive, both with password protection. The transcripts of the observations and interviews are anonymised with pseudonyms. These are stored on the UCC OneDrive with back up hard copies stored in a locked

cabinet in UCC. These will be kept for ten years in accordance with this code after which the files will be deleted and hard copies shredded.

The privacy of non-participants further necessitated deliberation when video recording. Every effort was made to position the camcorder so that those not participating were not recorded. If a non-participant was about to enter the recording frame, the camera was repositioned or the zoom function was used to keep them outside the frame. If the person entered the recording frame, recording stopped or the camera was pointed towards the floor until they exited the recording frame minimising the length of time they were recorded. In shared or public locations recording could not be avoided and so the behaviour of non-participants was not analysed.

4.4.2 Autonomy

The principle of autonomy, also known as respect for persons, recognises the right of individuals to be regarded as autonomous agents and the entitlement of protection for those with diminished autonomy (Office for Human Research Protections 2016). Central to this principle is the requirement for voluntary informed consent to participate and recognition of the right to withdraw from the study.

4.4.2.1 Informed Consent

The need for informed consent is core to all ethical research studies. It protects participants' autonomy and recognises their right to receive adequate and

appropriate information in order to make an autonomous decision to partake in a study (Halkoaho et al. 2015).

Historically, people with intellectual disabilities have been considered unable to independently make decisions (Nind 2008). However, more recently there has been a shift towards supporting them to make decisions under an ethos of dignity, autonomy and equality (NDA 2009). It is recognised that there is much tension in the debate surrounding the capacity of people with an intellectual disability to give informed consent. Informed consent requires ensuring the potential participant has sufficient information to and is capable of making the decision autonomously and voluntarily (Iacono and Murray 2003). Capacity to give informed consent can be impaired by cognitive difficulties such as memory or problem solving or by difficulties expressing views.

Capacity and incapacity to provide informed consent needs to be considered within the context of peoples' right to engage in the research process should they wish. It has been found that capacity can be increased by taking positive action. Wong et al (2000), for example, found that capacity to consent increased as the decision-making task was broken down into separate elements presented at different times. Similarly, Dunn et al. (2006) simplified the information into key elements and delivered the information in a video form. Yet these proactive approaches are ineffective methods of providing information to those with a severe/profound intellectual disability identified to participate in this study. Therefore, an alternative approach had to be adopted.

Brookes and Davies (2008 p.130) state that information may need to be absorbed over time with understanding reached by partaking in '*the doing*' of the research. Therefore, proxy consent was sought from and provided by parents/siblings of participants with an intellectual disability (Appendix IV). Proxy consent is not ideal but sometimes may be a necessary compromise (Nind 2008). According to Black et al. (2010) and De Vries et al. (2013), proxy consent requires assent or at least the absence of dissent from the person proxy consent is provided for. Those providing proxy consent were informed that should the person with intellectual disability indicate in any way that they did not wish to participate during a data collection period, data collection would be suspended. If this occurred on three occasions this would be considered an expression of choosing to withdraw from the study. Exercising a choice to withdraw would supersede the proxy consent provided. No participant indicated a choice to withdraw. This is in keeping with the HSE National Consent Policy: Part 3-Research (2013).

Potential participants without an intellectual disability were provided with information regarding the study in a face to face meeting and were given an information sheet and consent form (Appendix V) with a return SAE. All potential participants took a few days to deliberate and the majority consented to participate. Those who chose not to participate did so without judgement or consequence. All except two participants without intellectual disability were interviewed either individually or part of a group. The two participants who chose

not to be interviewed did so due to time pressures. Again, this was respected without judgement or consequence.

4.4.3 Justice

The principle of justice states that participants should be treated fairly in terms of the risks and benefits of the research and without prejudice (Rich 2016). As such, it requires that the burden placed on participants is proportionate to the probability of benefitting from the study (Owonikoko 2013). There is minimal immediate benefit of this research to the participants, but it will advance knowledge. However, in this context, every effort was made to avoid inconveniencing participants. Therefore, data collection only took place at times and locations convenient to them. The length of time spent recording was negotiated with participants being mindful of other commitments and demands. Participants with severe/profound intellectual disability were observed for indications they would like the recordings to stop. These behaviours included walking away, going to another room to watch TV or closing their eyes. Some recording sessions ended before any indications were observed.

Some potential participants without an intellectual disability expressed apprehension regarding analysis of their interactive behaviours. It was made clear that the study and data analysis were not about making judgements but to analyse and name their interactive behaviours. In order to reassure participants further, the method of data analysis was explained to them in more detail. With this knowledge, most people agreed to participate. Being transparent about the study

nature and methods was key to gaining the trust and acceptance of potential participants during the sampling stage.

4.4.4 Ethical approval

In the current study, the process of gaining ethical approval commenced with seeking ethical approval from the University Social Research Ethics Committee. The application outlined the research methods and included the actions and processes to be employed to ensure ethical obligations and responsibilities are met. On obtaining ethical approval (Appendix I), the Director of the Research and Development Department in a service providing supports to people with an intellectual disability was contacted. This service required local ethical approval and so another application for ethical approval was submitted. Ethical approval was granted (Appendix II) and the name of a gatekeeper was provided to facilitate accessing participants. This process was repeated with a second service provider who also required local ethical approval. On receipt of ethical approval (Appendix III), a gatekeeper in that organisation facilitated recruitment of more participants.

4.5 Access and Gate-Keeping

Obtaining permission to access participants and/or a study site is a necessary step in the majority of research studies and involves approval of an ethics committee, service providers local Research and Development departments and negotiation with gatekeepers. Access should not be considered as a once off task. Rather it is an ongoing process of procedural negotiation and building interpersonal rapport with gatekeepers and participants that requires patience and diplomacy (Gerrish

and Lathlean 2015; Høyland et al. 2015; Robson 2011). Both research sites in this study provided the name of a gatekeeper when providing ethical approval.

In research, gatekeepers are typically described as those who act as intermediaries between researchers and participants (De Laine 2000). As such they hold important and powerful positions in the research process as they can provide a '*physical*' and '*social bridge*' to research participants (Clark 2010 p.487). Although there is some debate regarding the power and, sometimes, control associated with this position (Høyland et al. 2015), gatekeepers in the present study were facilitative, knowledgeable and supportive. It is well recognised that gaining access to people with an intellectual disability for research purposes is complex and often multi-tiered in terms of gaining ethical approval and negotiating with gatekeepers, service-providers, parents/guardians/carers (Boggis 2011). As this study involved participants with a severe/profound intellectual disability, a degree of gatekeeping and access negotiation was anticipated. However, interactions with gatekeepers were beneficial in this study, refining and honing the design (Walker and Read 2011) to ensure the wellbeing of and minimise disturbance to participants. The gatekeepers had an appreciation for the value and importance of research and were eager to seize the opportunity to explore the experiences of people with a severe/profound intellectual disability. This was key to their ongoing support of the study.

Initial contact with both gatekeepers was by phone. This involved general introductions, discussion about the PhD programme structure and purpose of the

study. There was also some discussion about both professional backgrounds. For both sites, this was followed by a face-to-face meeting in the service to discuss a plan and strategy for recruiting participants. The research proposal was discussed and the measures to meet ethical obligations, as agreed with the Ethics Committees, were reiterated. The sampling strategy was explained and both gatekeepers agreed to assist with identifying potential participants.

4.6 Sampling, Data Collection and Data Analysis

In keeping with Classic Grounded Theory methods, theoretical sampling, data collection and analysis were undertaken simultaneously. This is an essential feature as it provides the researcher with an opportunity to collect data that meet the specific requirements of the emerging theory (Elliott and Lazenbatt 2005). This is critical to ensuring the quality of the eventual theory. Although presented linearly here, theoretical sampling, data collection and analysis occurred concurrently as each informed the other.

4.7 Sampling

Sampling is an important and necessary step of the research process as it is not usually possible to include an entire population (Hunt and Lathlean 2015). The selection of participants for inclusion in research requires judicious consideration in order to meet the aims of the study. However, a grounded theory has specific needs that only emerge in the course of data analysis. It is during the process of

analysing the data that the sampling needs of the emergent theory are identified. Therefore, theoretical sampling was used to select study participants.

4.7.1 Theoretical Sampling

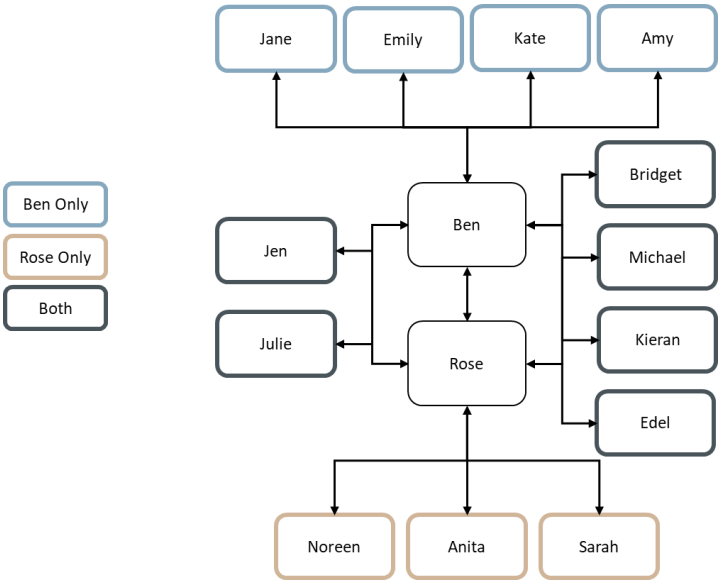
According to Glaser (1978; 1967) theoretical sampling involves concurrently selecting participants, collecting, coding and analysing data and then deciding where to collect data next based on the emerging theory. Participant recruitment, data collection and analysis continue until data saturation is achieved. It is a method of checking the emerging concepts and theory rather than verifying preconceived hypotheses (Glaser 1978).

Theoretical sampling begins with selection of participants who have commonly experienced the process under study (Creswell 2007). The study required observations of interactions involving a person with severe/profound intellectual disability. Therefore, it was decided to start by sampling for a person with severe/profound intellectual disability and then recruit communication partners from their network. The first participant in the present study was a man, Ben (pseudonym), who has a severe intellectual disability. Ben avails of five day residential and day activation services from the first research site. He was initially identified by the gatekeeper. Following a discussion with the researcher to ensure Ben would be a suitable participant, the gatekeeper rang his mother, Bridget (pseudonym), and asked for permission to share her contact details with the researcher. With her agreement, I met Bridget and provided details of my professional background, the research project and what participation would

involve. She requested a few days to think about participation. I gave her the information sheet and consent forms (Appendix IV; Appendix V) which contained my phone number and email address should she have any questions or issues she would like to discuss further. Three days later, Bridget rang to confirm she would provide proxy consent for Ben and that she, her husband, Michael, another son, Kieran, and his wife, Edel, would like to participate as communication partners (all pseudonyms). The gatekeeper introduced me to support staff in Ben's residence and activation areas. A further eleven people who interact with him at least five times per week over the previous two years were identified. Of these eleven, six agreed to participate in the study; five support staff and one friend with a mild intellectual disability.

Ben's sister (not included in the above sample) Rose (pseudonym) has a profound intellectual disability and was also included in the study. Bridget again provided proxy consent for Rose. Eleven people in Rose's network were identified as potential participants and nine consented to participate in the study. Four family and two staff members were common in both networks and consequently, Rose's network expanded the sample by three (Figure 4.1).

Figure 4.1 Sociogram for Ben and Rose

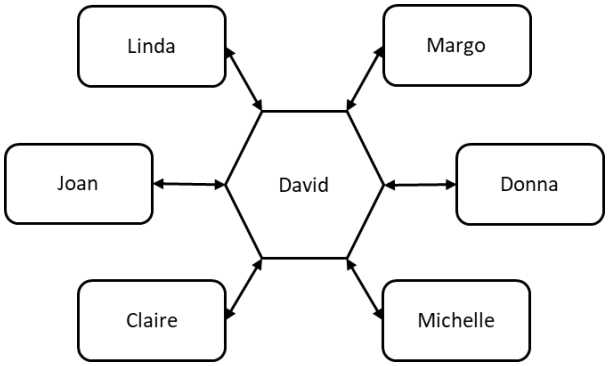


Including Rose provided opportunity to analyse the influence of severity of intellectual disability on interactions as the sample included two people with different levels of intellectual disability while remaining cognisant of interpersonal factors. Furthermore, the interaction practices of partners when communicating with people of different intellectual ability could also be explored as common partners could be observed interacting with both. The gatekeeper clarified both levels of intellectual disability from that recorded in their files. Bridget provided confirmation. The researcher did not access any participant files as it was unnecessary and would be a breach of confidentiality.

As data collection and analysis continued, the need to theoretically sample for a participant with a severe/profound intellectual disability and physical disability became apparent. Ben and Rose used physical prompts, gestures or could move towards an object when making a request. Many people with severe/profound

intellectual disability also have physical disabilities and therefore, it was necessary to analyse interactions in this context. The gatekeeper from the second research site identified a man, David (pseudonym), who has a profound intellectual disability and quadriplegic cerebral palsy. David lives at home with his parents and younger siblings and avails of day services only. The gatekeeper approached David's father to request permission to share his contact details. After speaking with me, he provided proxy consent for David to participate. He explained that this would allow David the opportunity to experience the research. However, he reiterated that if David expressed discontentment with the video recordings or showed any signs of distress, he would support David's choice to withdraw from the study. It was agreed that he would be given advance notice of data collection also. As David's siblings were children at the time, he chose not to allow data collection in the home. Therefore, due to work and school commitments David's family did not participate in the study. However, six people from David's activity network agreed to participate (Figure 4.2). As David avails of services from a different provider, there were no participants in common with Ben and Rose's network.

Figure 4.2 Sociogram for David



The final sample totalled twenty-two participants - three people with severe/profound intellectual disability, Ben, Rose and David, and nineteen people with whom they interact. One hundred and fifty-seven interactions were identified. Data saturation was reached after analysing forty-five of these.

4.7.2 Gaining Trust and Acceptance

The recruitment of participants required continuation of the negotiations involved in the access and gatekeeping process. At this stage, however, negotiations were with participants and those providing proxy consent. Key to this process was gaining trust and acceptance. Approaching potential participants to request involvement in the study was our first-time meeting. There were no existing relationships and therefore, apprehension and curiosity commonly featured. Consequently, it was necessary to engage with the potential participants in a genuine and transparent way to foster trust and acceptance. Meeting a lecturer/researcher was foremost in the minds of potential participants. This contributed to the apprehension and curiosity present and created a distance in the interactions initially. Høyland et al. (2015) discuss how assuming different

identities enables the building of trust and establishment of a research relationship. In other words, engaging with the potential participant so they identify with the researcher in another way. Knowledge around the role of a researcher can include many unknowns to those outside the field. Therefore, Høyland et al. (2015) recommend finding a way to enable potential participants to identify with the researcher. In this study, identifying with common experiences of being a nurse supporting adults and children with severe and profound intellectual disability worked to bridge this issue and create a common ground with support staff in both services. A similar approach worked effectively with family members. We shared similar family backgrounds such as living in a rural area and we discussed the benefits and challenges of this. This created a point of relatability (Carnevale et al. 2008) on which trust was built. '*Small talk*' was also effective (Høyland et al. 2015) as participants engaged in conversations for longer or offered new or unexpected insights of their own volition. These discussions were recorded as field notes. They recorded very useful data as they tended to follow a video recording or interview. The participant would take the opportunity to add something after they had time to think and reflect. It provided further insight to their experiences, perspectives and main concern.

Some potential participants were curious as to how they were identified to participate. Transparency regarding the process satisfied this curiosity. Knowledge that the research had been approved by ethics committees and was endorsed by a gatekeeper further assisted in the development of trust and agreement to

participation. Additionally, providing detailed, explicit and user-friendly information creates a perception of competence, instils confidence and enables an informed decision (Savage and McCarron 2009). This transparency was also in keeping with ethical responsibilities.

Trust, rapport and credibility are important influential variables in the recruitment of participants and in facilitating research relationships (Clark 2010). Their influence can be pronounced in studies using theoretical sampling methods as recruitment can appear targeted. Theoretical sampling requires that sampling, recruitment and data collection and analysis be undertaken concurrently as each informs the other. It is only by analysing the data that the sampling needs of the emergent theory become evident. Therefore, the next stage of this iterative process is data collection.

4.8 Data Collection

An important strategic decision is how to collect data. Different methods offer different insights. Observations offer an opportunity to identify what is happening while interviews give insight into why something happens (Robson and McCartan 2016). Therefore, selection of method(s) is based on the type of information sought. A key determinant of data collection methods in this study was the ability of the method to facilitate insight into the experiences of people who communicate non-verbally. Typically, such information is gathered through interviews. However, in this circumstance, when communication tends to occur through behaviours, it was necessary to include observational methods to gather

data. In order to go beyond the question of *what is happening*, interviews were included to offer insights into the *why* dimension of interactions. These were undertaken with the interaction partners of those with intellectual disability. Field notes offered context when analysing the data. Data was collected across multiple settings including participants' homes, service-based residences and activation areas.

4.8.1 Observations

As interactions involve interpersonal actions and behaviours, the most appropriate way to ascertain how people interact is to observe them. Participant observation was the primary data collection method used in this study. It is a method that can inform theory development by offering insight into participants' behaviours and contexts that influence their behaviours (Dahlke et al. 2015).

Much preparation is required for observations and there are several methodological issues to be considered including determining the researcher's role in and method of recording the observation. Gold (1958) identified four observational roles a researcher may adopt including complete participant, participant as observer, observer as participant and complete observer. Carefully considering the researcher's role is important to maximise the representativeness of the data collected to the phenomenon. In this study, the role of observer as participant was adopted. This sees the researcher briefly participate with participants, but the role is made explicit and observations are overt (Gold 1958). Participants intermittently included me in their interactions. My perspective on a

conversation topic might be sought or sometimes, Ben and Rose approached me and lead me by the hand towards an activity. It was important that I adopted this role as I became part of activities. This created a more relaxed atmosphere for participants. Otherwise, my observer role might have become more pronounced and may have caused hesitancy among participants.

To ensure efficiency and maximise each observation opportunity, the observation recording methods were carefully deliberated on. Observations yield data that reveal the richness and complexity of interpersonal interactions and can foster a deeper and fuller understanding (Leedy and Ormrod 2010). Observations were recorded using a camcorder and field notes. Video recordings enabled detailed transcribing of the wide variety of ways in which people act and interact (Appendix VII). They are the most effective way of capturing interactive behaviours that may be less obvious, momentary or fleeting in real-time but can be detected on play back and repeated viewings.

All interactions were openly video-recorded. In one setting, a service-based residence, participants kept the camcorder and a tripod for two weeks and recorded segments of time themselves. This enabled more variation in the times of the day when interactions could be recorded. I was present at two sets of recordings in this setting and at all other settings.

To supplement the video recordings, field notes were used. These are a record of researcher observations in the field. It is recommended that field notes are

recorded at the earliest point after recording an event to ensure accuracy (Padgett 2017). Field notes were taken immediately on completion of a data collection episode as it is difficult to record field notes as an observer participant while video recording. Being removed from the scenario was conducive to thinking about the data without distraction (Booth 2015). Once the video was transcribed, the field notes were appended to the associated transcript.

Although observations provided rich, detailed data that captured the complexity of interactions involving people with severe/profound intellectual disability and their communication partners, there were several advantages and disadvantages to this method that merit acknowledgment.

4.8.1.1 Methodological Considerations of Observations

Field notes and video recording are complementary data recording methods. Key arguments against the use of field notes in observational studies are that they cannot be replayed, can be inherently biased by the note-taker and are reliant on memory to prevent the loss of information (Tessier 2012). Video recording and the constant comparison process during data analysis remediate these shortcomings. Codes generated from field notes were repeatedly compared to other codes thus establishing their fit in the theory or otherwise. Safe storage of video recordings ensures they can be viewed repeatedly. Further considering the issue of bias in data collection, it has been argued that video recording overcomes biases associated with the effect of participant's memory or provision of socially acceptable answers that may occur during interviews (Booth 2015). This was

found to be an issue in other studies in this area (Healy and Noonan-Walsh, 2007). The directedness of observations enables the researcher to gather data about what people do and how they behave, removing the sense of '*artificiality*' that can be associated with other techniques (Robson and McCartan 2016 p. 320).

Although video recording minimised the limitations of field notes, the opposite was also true. Field notes minimise the limitation of video recordings. A video camera will only capture happenings within the range of its lens during the period of recording. Field notes are an effective method of recording relevant data that is beyond the scope of the lens and/or outside the recording times. This facilitates analysis (Muswazi and Nhamo 2013) by providing contextual information that may not be captured in the range of the lens. Participants were eager to discuss interactions once the camera was turned off. This information was recorded using field notes and supplemented the video recordings. Such discussions with participants enriched the data but indicates one of the strongest criticisms of observations; observer effect which was evident in the early stages of recording.

4.8.1.2 Observer Effect

A key argument against observations is that the presence of an observer, either a person or camera, can impact upon the behaviours of participants. Consequently, the trustworthiness and validity of the data can be brought into question (Booth 2015). It is noted to be particularly problematic when observation is overt as is the case in this study (Pan et al. 2013). The impact of being observed on participants was evident in the early stages of recording. Participants with an intellectual

disability looked at the camcorder with curiosity and intrigue. They held it, looked around it, repositioned it. It distracted them from their activity or interaction. Therefore, I recorded the person or the environment and played it back on the camcorder screen. They laughed or smiled seeming amused to see themselves on the screen. They returned to their activity once their curiosity was satisfied and otherwise seemed unperturbed by the camcorder or my presence.

Similarly, the impact of being observed was evident among those without an intellectual disability. This correction process was very interesting. Changes in partners' interaction style or communication methods confused participants with an intellectual disability. They seemed perplexed about what was happening. Therefore, participants without an intellectual disability had to revert to their usual communication and interaction methods to dispel any confusion and maintain the interaction. Additionally, having open discussions with participants without an intellectual disability dispelled fears of being assessed or judged. This enabled them to feel more comfortable while being recorded. As the research relationship and trust developed, participants without an intellectual disability became increasingly enthusiastic about the study requesting and advising of extra opportunities for data collecting, suggesting their growing comfort with being recorded. Schnelle et al. (2005) have discussed how prolonged exposure to observation can reduce observer effect.

It must be acknowledged that observations are limited to capturing what people do (Robson and McCartan 2016). They are less effective at capturing why people

behave or act in a certain way. It is for this reason that although observations were the primary method of data collection in this study, interviews were also used to address this shortcoming.

4.8.2 Interviews

Addressing the question of why people interact as they do require the use of semi- and unstructured interviews. Despite distinct approaches to interviewing, Mason (2002) highlights core common features of this type of data collection method. Firstly, it is an interactional dialogue involving two or more people. Secondly, there is a central theme or topic that the researcher wishes to address in a fluid and flexible way. Lastly, a situational or contextual perspective is held where meanings and understandings of the central theme are constructed or reconstructed during the interview. Interviews, particularly semi- and unstructured, are a commonly used data collection method, especially when seeking data of a qualitative nature. In this study, interviews were used to supplement the observations. Semi-structured and unstructured interviews were carried out with eleven participants without an intellectual disability; two parents, a brother, a sister-in-law, two activation staff, a music therapist and four residential support staff. While an interview schedule was not drawn up for the semi-structured interviews, I was aware of the codes and concepts that were emerging during analysis of the observational data. Therefore, interviews commenced with a broad question such as '*tell me about how you interact with Ben/Rose/David*' or '*what would you like to tell me about communicating with Ben/Rose/David?*' The participant(s) were

encouraged to speak freely by intermittently nodding in acknowledgment or asking for further elaboration. Probing questions were asked if codes or concepts arose to uncover data that would contribute to concept development.

Most interviews occurred before or after a recording period, but some were arranged at alternative times convenient to participants. They were in keeping with Mason's (2002) characterisation. Interviews were carried out on one to one basis or alternatively with 3-4 family members together. They were informal and fluid, responsive to the issues discussed by participants. There was also some variation depending upon participants' and interview context such as personal/professional relationship with the person with severe/profound intellectual disability. Interviews with those with a personal relationship, such as parents and family members, tended to be more emotive. Interviews involving participants with a professional relationship inclined towards discussing supports and meeting needs.

The interviews provided information that could not be captured in video-recordings such as motivations, perspectives etc. (Rubin and Rubin 2012). As previously mentioned, observations provided data regarding what people do and how people behave. The interviews provided an effective and efficient means of gathering more detailed data on why people behave in a certain way (Lamont and Swidler 2014). Additionally, although a level of emotional experience was suggested in participants' behaviours in the observations, the interviews uncovered an emotional experience that was not captured in the observations

(Pugh 2013). This is important in the context of interpersonal interactions which, by their nature, have an emotional dimension. For example, it was clear in the observations that participants were trying very hard to communicate and involve the person with severe/profound intellectual disability. The interviews uncovered why they tried so hard. They explained their views and discussed their thoughts which are not always outwardly observable.

Using multiple data collection methods yielded a considerable amount of data. Concurrent analysis indicated when theoretical sampling and data collection could cease. Once codes were saturated and elaborated on, data collection ended (Glaser 1978).

4.8.3 Saturation

There is much debate in the literature regarding the definition and process of reaching saturation (Nelson 2016; O'Reilly and Parker 2012). Glaser and Strauss (1967) assert that saturation is reached when additional data is not contributing to the development of a category's properties. As similar instances recur, there is an '*empirical confidence*' that a category is saturated (Glaser and Strauss 1967 p.61). O'Reilly and Parker (2012) assert that the debate around saturation only exists because the concept has been applied to other methodologies. When considered in the context of its origins, in Classic Grounded Theory, there is less debate and confusion. Glaser and Strauss (1967 p.62) set out the criteria for determining saturation as '*a combination of the empirical limits of the data, the integration and density of the theory and the analyst's theoretical sensitivity*'.

Therefore, judgement of saturation in this study was informed by these three criteria. Saturation was reached after analysis of forty-two observations and nine interviews. Three more recordings were analysed after this to confirm saturation. As nothing new emerged, saturation was deemed reached.

4.8.4 Data Management

A considerable amount of raw data was gathered using different methods and therefore proper management was essential particularly for ease of retrieval (Padgett 2016). Twenty-seven episodes of recording, totalling eight hours, forty-two minutes and three seconds were taken. However, interactions only took place for seventeen minutes and eleven seconds of this time. One hundred and twenty-one interactions took place that varied in length from three seconds to eleven minutes, forty-five seconds. Forty-two observed interactions were analysed before reaching saturation.

Table 4.1 Observational Data Breakdown

Total Number of Recordings	27
Total Recorded Time	08:42:03
Total Interaction Time	00:17:11 (3.29%)
Shortest Interaction	00:00:03
Longest Interaction	00:11:45
Total Number of Interactions	121
Number of Interactions Analysed	45 (37%)

Each individual recorded episode was titled according to location and numbered. It was watched to obtain a macro view of the events recorded. It was watched again, and individual interactions were identified and extracted from the recording. Each interaction was logged in an Excel data bank that noted the primary recording it was sourced from, clip title, participants (by pseudonym) in that clip, timing in the larger recording and clip length (Appendix VI). I transcribed each interaction verbatim in 3-5 second intervals accounting for verbal and non-verbal content of each person in the interaction. The clip title, pseudonyms and timing of the interaction were recorded on the transcript as well as a space to record codes (Appendix VII).

I also transcribed recorded interviews verbatim. Field notes of observations, conversations or discussions were taken at the time or as soon as possible after the event. Both transcripts and field notes were labelled according to date, location and participant (by pseudonym).

4.9 Data Analysis

Data analysis requires discipline to remain consistent with the philosophical methods of the study (Sandelowski 1995). The goal of analysis in Classic Grounded Theory is to generate categories with properties and indicators that fit, work and are relevant to develop an integrated theory (Glaser 1978). The methods of analysis ensure this goal. Coding progresses from substantive coding to theoretical coding. Initially substantive coding is undertaken in order to label the behaviours that participants engage in. Substantive codes conceptualise the behavioural

components and patterns of the research area (Glaser 1978). Theoretical codes then conceptually connect substantive codes resulting in an integrated theory that explains the phenomenon being studied (Glaser, 1978). However, a critical component of data analysis across all stages of Classic Grounded Theory is the practice of memoing.

4.9.1 Memoing

Glaser and Strauss (1967 p.108) state that memos are '*an immediate illustration for an idea*'. Gibson and Hartman (2014) identify memoing as one of the key operations of doing Classic Grounded Theory. Such is the importance of memos that Glaser (1978 p.83) describes them as the '*bedrock*' for generating theory. This is because memos move the theory from raw data to abstraction and support the development of ideas around and relationships between codes. Glaser (2013 p.3) describes memos as '*vital*' for recording ideas and tracking the generation and analysis of concepts emerging during all stages of coding.

I quickly realised the value of memos when undertaking this research. Discussion of their value in the literature did not go unnoticed but my experiential learning underscored the arguments for their use. However, their significance as asserted in the literature can cause undue and unnecessary anxiety around writing a memo for the novice Grounded Theory researcher. As I read about Classic Grounded Theory, I perceived the considerable emphasis on memoing as meaning they must be written properly and certainly not incorrectly. Glaser (2013) recognises this issue arguing that it stems from an academic tendency towards guidance. I

attended Grounded Theory workshops and seminars. I discussed my concerns with my supervisors, students at workshops and other troubleshootees at seminars. In time, I overcame my need for guidance and structure, and I found memoing to be liberating and empowering. Memoing gathers thoughts and ideas regarding the data and substantive area in a safe way because constant comparison negates any potential bias. It helped me achieve a sense of ownership in the process of developing the theory.

Glaser (2013) argues that private, free style memoing stimulates preconscious processing of the data through the practices of constant comparison and pattern seeking. Constantly comparing and revisiting incidents feeds into a preconscious knowing that can be captured and brought to consciousness through memoing. This focus on incidents when memoing rather than on data type addresses challenges to analysing data from different sources such as observations, interviews and field notes. Capturing thoughts regarding incidents facilitates analysis and supports the conceptual move from raw data, regardless of source, to explanatory abstraction (Birks et al. 2008).

Referring to memoing as a lifestyle (Glaser 2013) accurately depicts the extent to which memoing becomes part of daily life. There is no way of knowing the time of day or night that a thought or idea will occur. Memoing captures these thoughts and therefore it is necessary to stop and write (Appendix VIII). Although interrupting coding to memo is continually advocated in Classic Grounded Theory literature (Gibson and Hartman 2014; Glaser 2013; Glaser and Holton 2004), I

found it is necessary to carry a memo note book with me every day. I needed to be able to write a memo at any time. Thoughts and ideas regarding the data would surface when my mind was relaxed, open and clear. I found this to be particularly true when I was away from the computer or desk. Thoughts would come to me while I was gardening or out for a walk. Indeed, at times when I was frustrated or experiencing a mental block around analysis, I would go to the garden or for a walk. This allowed me the time to relax my mind to think clearly. Therefore, it is necessary to always be ready to memo. Glaser (2013) recommends stopping and jotting a note to memo at a later stage if it is particularly inconvenient to memo in the moment. This indicates not only the importance of memos to Grounded Theory but how they become a lifestyle habit. It is necessary to start memoing at the earliest point in the study and certainly by the commencement of substantive coding.

4.9.2 Substantive Coding

Substantive coding involves conceptualising the empirical substance of the research area (Holton and Walsh 2017). Substantive codes build the conceptual theory but are distinct from theoretical codes (Glaser 1998). Substantive codes identify concepts and their indicators or properties; they are a direct conceptualisation of incidents in the research area. Theoretical codes relate substantive codes to each other to create an integrated theory. The substantive coding stage comprises open coding and identification of the core category through to selective coding with ongoing memoing.

4.9.2.1 Open Coding

Open coding is the initial stage of data analysis in Grounded Theory. Gibson and Hartman (2014) assert that open coding is about drawing boundaries around incidents of data; in other words, labelling incidents of participants' behaviour. The need for concurrent engagement in data collection and analysis is particularly highlighted during open coding as it provides direction for theoretical sampling (Glaser 1978).

Analysis was carried out after each data collection period with on-going, concurrent memoing. Beginning with open coding, approximately forty labels or codes were initially generated. By *'fracturing*' the data and coding behavioural patterns, the process of moving beyond description to explanation of the processes (Glaser 1978 p. 55) was begun. I developed a document for transcribing the videos that enabled me to code behaviours, moments or incidents (Appendix VII). I entered the code for each behaviour in a 'notes' column to the right of the transcript. Similarly, there was a coding or notes column on the interview transcripts (Appendix IX).

Glaser (1978 p. 57) identified six rules that guide the process of open-coding to ensure its proper use and success, all of which were adhered to. He asserted that questions should be asked of the data. This is to enable identification of the main concern of participants, the indicators of behavioural patterns and processes being engaged in. The questions listed earlier (para 4.3) were asked of the data.

These questions were:

1. What is each person in the interaction doing verbally?
2. What is each person doing non-verbally?
3. What caused each person to act in this way?
4. What is the result of the person acting in this way? What do they achieve or not achieve?
5. How does the communication partner react or respond?
6. How does anyone else in the environment react?

Development of these questions was informed by Glaser's (1978) recommendations regarding questions to be asked of the data. These questions identified the communication behaviours, the causes, outcomes and variables influencing interactions. In the early stages of analysis, I adhered to Glaser's (1978) direction to analyse line by line quite literally. Glaser argued this ensures categories are verified and saturated, no category is overlooked, and a robust theory is produced. This emphasised the importance of line by line coding to me and therefore I meticulously coded literally line by line. This was initially a laborious task as some behaviours were subtle or several behaviours occurred together. Secondly, participants were contributing to the interaction concurrently. With further reading, supervisory guidance and increasing analytical experience I came to realise that Glaser did not intend literal line by line coding but behaviour pattern coding. Glasper and Rees (2017) explain that the researcher codes patterns of behaviour that participants engage in regularly even if they are

unaware of this. With time, codes saturated, and I became increasingly familiar with patterns, so the analysis became less laborious.

Glaser (1978) advises coding for a core category and subsequently for the categories that relate to it. Identifying the core category is critical as the grounded theory is generated around it. Its key function is to integrate the theory. Identifying a core category that fulfils these functions leads to *theoretical completeness* and delimits the theory (Glaser 1978 p. 93). In its absence, the emergent theory will be questionable in terms of relevance and work (Glaser 1978). Once the core category emerges, selective coding begins.

4.9.2.2 Selective Coding

Selective coding involves exploring and augmenting the core category and concentrating on how it organises and integrates the theory (Gibson and Hartman 2014). Memos became more focussed and gaps were identified that informed theoretical sampling. Codes generated during open coding were gradually refined and honed into concepts through memoing, selective coding and constant comparison. Consequently, participants' main concern became more apparent. Additionally, searching for the answer to the question '*what is the participants' main concern or problem?*' helped identify the core category.

Early in analysis, I thought 'being connected' was the core category. However, on-going analysis identified issues around fit. Constant comparison highlighted gaps; issues that were incomplete or insufficiently addressed. Therefore, *being*

connected was only part of how the main problem was processed or resolved. It was not the problem. Data collection and analysis was delimited to informing development of the core category and its related concepts. The emergence of acquiescence was a turning point in data analysis. Acquiescence intrigued me because understanding was not reached and misunderstanding was not addressed. Interactions continued in the absence of understanding. I compared incidents to explore why understanding did not matter. *Being with* explained this behavioural pattern. This later became *nurturing a sense of belonging*. This was participants' main concern that is resolved by reconciling communication repertoires, the core category of the theory. This was identified as the core category as it explains variability in behavioural patterns and connects all other categories and their properties. It integrates the theory.

Theoretical sampling also became more focussed. For instance, it was clear that Ben and Rose used body language and gestures in their interactions. However, it was necessary to theoretically sample to include someone who would not be in such a position. Consequently, David was included in the study. This led to development and refinement of the core category because more data was gathered around the issue of repertoire breadth. I continued memoing, asking myself questions, asking questions of the concepts and their indicators. I read and re-read memos. I compared concepts, indicators and concepts to indicators examining differences and similarities, variables and how each influenced each other.

Substantive coding involved methods and techniques that were new to me including memoing, constant comparison and conceptualising. Memoing has been discussed previously (para. 4.9.1). Constant comparison was key to the elaboration and integration of the core category. Conceptualising proved more difficult as I was challenged to move beyond description. Learning about, understanding and practicing constant comparison and conceptualising will now be discussed.

4.9.2.3 Constant Comparison

Gibson and Hartman (2014) refer to the constant comparative method as a building process that seeks to establish the nature of concepts to generalise the theory and establish its boundaries. The constant comparison method is the basis for the development of the concept indicator model which involves ongoing comparison of indicator to indicator, indicator to concept and concept to concept (Glaser 1978). Glaser and Strauss (1967) argued the distinction between the constant comparative method of Grounded Theory and other general approaches to qualitative data analysis concerned with verification.

The purpose of the constant comparison method in Grounded Theory is not to test hypothesis but to creatively generate and discover theory. I found this distinction important when analysing. This ensured I asked, 'what is happening here?' rather than 'is this what's happening here?' I was seeking to discover rather than verify. This enabled me to be open and flexible (Gibson and Hartman 2014) to emerging similarities, differences and degrees of consistency when generating hypotheses

regarding the data. It was intriguing and absorbing to analyse the ways people managed interactions and situations. It was fascinating to see interactions slowed down for analysis seconds at a time and see the impact of micro and fleeting behaviours. Following comparison, thoughts and ideas were generated that became the building blocks for this theory. This is where constant comparison and memoing intertwined because my thoughts and ideas were captured in memos.

The constant comparative method brings about conceptual abstraction of the empirical data (Holton and Walsh 2017). This is fundamental to meeting the goal of conceptually explaining the latent patterns of social behaviour. Conceptualising was found to be a more difficult and challenging endeavour.

4.9.2.4 Conceptualising

Glaser (2002 p. 2) synopsises Classic Grounded Theory as the '*generation of emergent conceptualizations into integrated patterns, which are denoted by categories and their properties'*. Glaser and Strauss (1967) characterise a concept as analytic and sufficiently generalised to accurately label its indicators and properties. Secondly, it should be perceptible in that the concept vividly captures the experience of those who have been through the phenomenon under study.

To meet this characterisation, concepts and their properties must be carefully constructed (Glaser 1998). The processes of Classic Grounded Theory, pacing, simultaneity and sequencing make conceptualisation rigorous and responsible (Glaser 1998). Through pacing, concepts are not forced but allowed time to come

to consciousness and emerge (Glaser and Holton 2004). Simultaneity and sequencing ensure data needed to develop the theory's concepts is identified, gathered and analysed in a considered, patient and openminded way.

Through conceptualization, grounded theory transcends description (Glaser 2002 p. 24). Moving from description to conceptualisation was found to be particularly challenging. A tendency towards description rather than conceptualisation led to frequent slipping down the conceptual slope towards description particularly during the write up. Supervision meetings were crucial to addressing this problem. Initially, my supervisors highlighted the issue and pointed to descriptive passages in my writing. In time, I came to recognise these as descriptive myself. This indicated to me that I was developing and moving from description to conceptualisation. Holton and Walsh (2017) recognise this difficulty of transcending description for conceptualisation for the Classic Grounded Theory novice and those trained in evidence-based professional disciplines. They recommend consciously shifting thinking towards explaining rather than describing when writing. Glaser (2002) provided some clarity regarding the properties of conceptualisation that assisted me with overcoming this challenge.

Firstly, concepts should be abstract of time, place and people. This notion of writing independent of time, place and particularly, people was new and unknown. It signalled a departure from writing in a style guided by person centeredness and advocacy. It required a conscious letting go of this style that

came about through memoing and exploration of preconceptions, values and principles.

The second property of enduring grab was less problematic but required careful contemplation to ensure preconceived concepts from existing professional knowledge did not force their way. Identifying new concepts was liberating and empowering. However, it was important to be cognisant of language when presenting the concept. I wanted to be sure I was labelling according to what was in the data rather than a preconceived concept. When I coded or labelled, I asked myself 'why have I chosen this word or label?' Taking this time to think about labels and concepts ensured preconceived concepts did not force their way. I also found writing to concept specification rather than definition challenging. I addressed this by returning to my memos, reading and re-reading them to enhance my clarity around indicators.

I continued to selectively collect data and code until saturation was reached by sufficient elaboration and integration of the core category, its properties and its connection to other categories and concepts (Holton 2010). This led to the last step of analysis, theoretical coding.

4.9.3 Theoretical Coding

Following the fracturing and slicing of data at the substantive coding stage, theoretical coding serves to weave the categories together in an interrelated, multivariate set of hypotheses that explain how the main concern is resolved or

processed (Glaser 1998). This enables transferability of the theory to other substantive areas where the category and/or its properties may be relevant. I found theoretical coding very challenging with limited literary guidance available on how to undertake it (Wuest 2012). I became frustrated but persisted with an equally potent stubbornness to continue until the theoretical code emerged. I read available literature, particularly Glaser (2005; 1998; 1978), Hernandez (2009) and Artinian et al. (2009). These authors repeatedly and consistently advocated patience and tolerating confusion. I relied on these works and supervision meetings particularly to guide and encourage me through theoretical coding. I attended a Grounded Theory Workshop as a troubleshootee. The discussion that ensued was helpful in terms of clarity around theoretical coding and renewed my energy to continue. Artinian et al. (2009) further argues that the theoretical code emerges with on-going sorting and memoing.

4.9.3.1 Sorting

Sorting requires the analyst to order and integrate ideas with the goal of finding emergent and parsimonious fit for all relevant concepts in the emerging theory (Holton and Walsh 2017). Glaser (1978) offers analytical rules for this stage. Sorting requires space, time and pacing. I initially tried sorting with a pen and paper, but this was too restrictive (Appendix X). I changed to using large post-it notes on a noticeboard to sort as it provided space where concepts could be moved, promoted and demoted. I photographed the noticeboard regularly to track my changes. It was also lower risk in terms of interference between sorting

periods that would be associated with floors or tables. As the structure became more refined, I moved to a flow chart programme, Gliffy. This enabled tracking of moves and reorganisation. Starting with the core category and sorting concepts according to their relationship to the core offered structure. I continued memoing as a means of sorting my thoughts and bringing the relationships between concepts to consciousness. Abiding by these rules provided guidance in the absence of a predefined structure for the theory. As the concepts became ordered in terms of their connections and fit with each other, I looked at different coding families outlined by Glaser (2005; 1998; 1978) to identify which theoretical code linked this Theory of Reconciling Communication Repertoires.

4.9.3.2 Theoretical Codes

Kelle (2007) states that theoretical codes describe the relationships between substantive codes. They are not preconceived or forced but emerge in the later stages of analysis to organise the theory (Glaser 2005). Theoretical codes pattern out thus providing an integrated grounded theory (Glaser 1998).

Although Glaser (2005) states that theoretical codes are not necessary, he asserts that a grounded theory is more plausible, relevant and enhanced when they are used. The theory will not be integrated. Rather it will be presented as discrete categories that require descriptive incidents to support understanding. Furthermore, defaulting to a forced theoretical code will force relationships and compromise and undermine the grounded theory (Glaser 1998).

Glaser (2005; 1998; 1978) discusses theoretical coding at length presenting several 'coding families' in each publication. However, in the process, I came to realise that like much of the Classic Grounded Theory methodology, theoretical coding is an intellectual exercise that comes about as a result of theoretical sensitivity to the emergent theoretical code. The theoretical code will emerge with awareness of the different coding families and ongoing memoing. Glaser's listing of the theoretical coding families, although limited in detail, provided welcome guidance as a novice researcher. Wuest (2012 p. 240) recommends reflecting on '*the big picture*' to identify the relationships between and influences on categories. She suggests diagramming as helpful for visual thinkers, an approach that was particularly useful in this study (Appendix X). I initially thought the theoretical code was a basic social process. It seemed an obvious code given the study is about interactional processes. However, it did not account for all the concepts. I looked at the 6Cs family. This seemed more accurate, but again, there were aspects of the study that did not fit. Eventually, strategizing emerged as the overarching theoretical code for this grounded theory. Going through this process demonstrated Glaser's assertions around fit, pacing, not forcing and emergence. I saw in a real and practical way how the steps of Classic Grounded Theory and staying true to them results in a parsimonious theory.

4.9.3.3 Strategizing

Glaser identifies strategizing as one theoretical coding family in *Theoretical Sensitivity.* Artinian et al. (2009) identify this code as a process used to manage or

deal with a situation in order to accomplish a goal. Jarzabkowski et al. (2007) contend that it is the actions, interactions and negotiations taken in order to achieve an activity or realise a goal. Glaser (1978 p. 76) uses words like '*tactics, manoeuvrings and techniques'* as alternatives to explain the strategy coding family but cautions of potential confusion with the consequential coding family. This aspect of accomplishing a goal was the reason the basic social processes or consequential theoretical codes did not fit.

Key to avoiding this mistake is to recognise whether the use of tactics or manoeuvrings is a conscious act. A conscious manoeuvring indicates the strategizing family. Strategizing emerged as the overarching theoretical code for this grounded theory as participants actively and consciously choose and adjust their communication methods at each stage of the process according to the likelihood of meeting their interaction goal. Efforts are made to maintain a connection and nurture a sense of belonging at each stage. I recognised strategizing as the theoretical code because it met all four criteria for a quality Classic Grounded Theory; fit, work, relevance and modifiability.

4.10 Ensuring Quality

An evaluation of research quality is necessary for the findings to be utilised in practice (Noble and Smith 2015). This evaluation involves a judgement of methodological appropriateness, application and rigour and insightfulness of interpretations (Padgett 2017). Elliott and Lazenbatt (2005) highlight that questions regarding the quality of Classic Grounded Theory research have been

raised in nursing research but argue that it should be considered a package of rigorous methods that uphold the quality standards of this method. The quality of the theory should be assessed based on methodological thoroughness, significance of the research question and incisiveness of the analyst (Holton 2008). According to Glaser and Strauss (1967), Classic Grounded Theory provides for systematic generation of theory from data acquired by a rigorous method. They espouse *fit, work, relevance* and *modifiability* as criteria for assessing the quality of a Classic Grounded Theory.

4.10.1 Fit, Work, Relevance, Modifiability

Glaser sees fulfilment of these four criteria as indicative of a quality grounded theory. Fit relates to categories being readily applicable to and indicated by the data (Glaser and Strauss 1967). In other words, the categories generated must fit the data (Glaser 1978). Data should not be forced to fit into preconceived categories.

The second criterion, work, relates to the explanatory power of the grounded theory. The theory must be capable of explaining how the concerns of those in the area are resolved (Gibson and Hartman 2014). Glaser (1978) elaborates on this criterion discussing how the theory should be able to explain what happened, predict what will happen and interpret what is happening in the substantive area.

According to Holton and Walsh (2017) relevance makes the research important as the main concern of participants is studied. The emergence of core problems and

processes enables a grounded theory to achieve relevance (Glaser 1978). Relevance is discovered in the data.

The last of Glaser and Strauss' (1967) criteria is modifiability. This refers to the openness of the theory to extension and further development to accommodate new and future insights (Weed 2009). Glaser (1978) argues that generation is an ever-modifying process and therefore, modifiability is important in Classic Grounded Theory. Modifiability safeguards continued relevance of the theory to the substantive area (Holton 2008).

Each of these criteria were met in this study by adhering to the in-built quality assurance procedures of Classic Grounded Theory including concurrent theoretical sampling, data collection and analysis, constant comparison and memoing.

4.10.2 Methodological Quality Assurance

When assessing the quality of a Classic Grounded Theory study, these methodologically critical procedures should not be considered in isolation but as a cyclical, mutually informative process. Simultaneous data collection and analysis enables the researcher to check that categories remain constant across new data and ensures findings that accurately represent the phenomenon under study are generated (Elliott and Lazenbatt 2005).

Theoretical sampling serves to ensure completeness of the theory by responding to the specific data needs of the emerging theory (Glaser and Holton 2004). Gaps in the data or unanswered questions can be addressed by theoretically sampling.

Furthermore, theoretical sampling establishes emergent fit and supports the study to achieving relevance (Glaser 1978).

Lastly, memos hold multiple quality assurance functions. They are a record of conceptual ideas and a record of thoughts for theoretical sampling. They provide a track record of the analysis and become the building blocks of the theory (Elliott and Lazenbatt 2005). Furthermore, memos deal with the issues of subjectivity, preconceived ideas or researcher bias because the researcher is forced to focus on the data (Glaser 1998).

Evidently, as a methodology, Classic Grounded Theory is unique in that it has in-built quality control measures that are typically associated with quantitative methods but can account for the complexity and diversity of the human experience typically associated with qualitative methods. Therefore, rigorous adherence to these methods as evidenced in the detailed discussion provided, points to the quality of this grounded theory. The implementation and application of each of these methods and processes has been transparently and thoroughly presented in this chapter.

4.10.3 Responding to Threats to Quality

Threats to quality of research typically relate to issues of reactivity and biases (Padgett 2017). In a Classic Grounded Theory study these are typically addressed by constant comparison and memoing. However, two issues that merit attention in this study are reactivity associated with the observational methods adopted and

trustworthiness of interpretations of the behaviours of those with a severe/profound intellectual disability. The issue of reactivity has been dealt with in the data collection section (para. 4.8.1.2). However, clarification regarding any questions of interpretation trustworthiness will now be provided.

Data regarding participants with severe/profound intellectual disability was gathered using observational methods. Some participants without an intellectual disability participated in interviews and this provided more insight into their behaviours and experiences. Data pertaining to those with a severe/profound intellectual disability did not have this added dimension. However, constant comparison demonstrated that patterns of behaviour were consistent across those with and without intellectual disability. There was variation in terms of extent and degree, but behavioural patterns were consistent across participants. Therefore, the constant comparative method addressed potential issues relating to the trustworthiness of these interpretations.

4.11 Role of the Researcher

The role of the researcher in Classic Grounded Theory is given considerable attention across Glaser's writing. His writing details not only practical aspects of the method but also intellectual and cognitive aspects that he considers fundamental to developing the frame of mind necessary for doing Grounded Theory (Holton and Walsh 2017). He cites an ability to tolerate confusion, tolerate confusion's attendant regression and conceptualise data as necessary characteristics of a Grounded Theory researcher (Glaser 2010). These

characteristics have been conceptualised in the Classic Grounded Theory literature as staying open, theoretical pacing and being theoretically sensitive.

4.11.1 Staying Open

Glaser repeatedly emphasises the importance of staying open to emergence and not forcing preconceptions. This frame of mind is essential to enable true emergence of concepts from the data. Glaser (1978) states that the analyst cannot start a Grounded Theory with preconceived notions of what will be found in the study. Glaser and Strauss (1967) stress the importance of being open and flexible in developing the theory. With a clinical, teaching and research background in the substantive area of this study and experience of interacting with people with severe/profound intellectual disability, preconceived knowledge and ideas were inevitable; an issue acknowledged in Grounded Theory literature (Gibson and Hartman 2014). However, to adhere to the principles and methods of Classic Grounded Theory and maintain the quality of the eventual theory, steps were taken to deal with these preconceptions. The most effective method was memoing. Memoing was an effective way of examining and delving into preconceived ideas bringing their potential influence to a conscious level. This instils awareness of these preconceived ideas on the emerging theory.

Another method of dealing with preconceptions, linked with memoing, was ongoing questioning of the emerging categories. Questions such as '*did that label, code, category emerge from the data or is it preconceived?*' or '*why did I choose that label?*' maintained a conscious awareness of the potential influence of

preconceived ideas. Insofar as possible given teaching responsibilities, literature pertaining to the area was avoided until an appropriate stage. When it was necessary to engage with the literature, its influence was managed by memoing.

Staying open also involved staying open through the research process itself. The researcher cannot submit to preconceived ideas regarding where sampling will occur and how data will be collected. Theoretical sampling implies that sampling cannot be predetermined. It is responsive to the emergent needs of the theory. Similarly, open-mindedness should be maintained regarding data collection. The mantra '*all is data*' should be to the mind's forefront. Preconceived notions about data collection methods will limit data to that which is captured by the method used. Details of theoretical sampling in this study clearly show it was responsive to the emerging theory. Additionally, the use of multiple data collection methods indicates an openness to the different ways that experiences can be expressed and captured to provide rich data for analysis.

4.11.2 Theoretical Pacing

Glaser (1978) describes Classic Grounded Theory as a delayed action phenomenon. Data collection, analysis and coding needs to be paced to allow time to intellectually process the data. According to Holton (2008), significant theoretical realisations occur with the allowance of time for preconscious processing to emerge in the consciousness. This necessitates patience and tolerance so as not to rush or force codes, categories or concepts.

In this regard, Classic Grounded Theory as a method is not only an intellectual exercise but contributes to personal development, a critical facet of the PhD process. I experienced frustration at different points of this study but equally, I am stubborn and persistent. Patience, self-awareness, tolerance and persistence are personal characteristics that were tested but subsequently developed through this process.

4.11.3 Being Theoretically Sensitive

Such is the importance of being theoretically sensitive, that Glaser (1978) published a book to foster its development in analysts. In its first page, Glaser states some of its purposes are the '*development of the necessary theoretical sensitivity in analysts*' and to provide a '*fund*' of ideas for analysts. Gibson and Hartman (2014) define theoretical sensitivity as an ability to describe what theory is, to know how it is constructed and appreciate how it varies. Suddaby (2006) describes it as a tension between the mechanical application of a technique and the importance of interpretive insight. It can be impeded by preconceived ideas and notions (Hernandez 2010).

Theoretical sensitivity is a skill that needs to be developed on an on-going basis. Some methods to support its development are line-by-line coding, constant comparison, memoing and engaging with the methodological texts. The use of line-by-line coding and constant comparison sensitises the researcher to the words or phrases that indicate concepts (Gibson and Hartman 2014). Memoing sensitised me to the preconscious knowledge gained from engaging with the data

systematically and in depth. Engaging with methodological texts, particularly *Theoretical Sensitivity*, offered guidance and clarification about the concept and its development.

4.12 Conclusion

This chapter has presented the implementation and application of Classical Grounded Theory methodology and procedures to explain the methods and processes people use to communicate with and understand each other in interactions involving persons with severe/profound intellectual disability. Each stage of the study was transparently discussed and thoroughly detailed. The aims and objectives were clearly presented. The procedure of gaining ethical approval was carefully explained. It is clear that great care was taken to ensure ethical obligations were met. Earning the trust and acceptance of gatekeepers, participants and those providing proxy consent was critical to successfully gaining access and liaising with gatekeepers. Concurrent theoretical sampling, data collection and analysis was undertaken in keeping with Classic Grounded Theory methodology. It is evident that the procedures advocated by Glaser were steadfastly adhered to through engagement with literature, supervisory guidance and memoing. Strategies to meet challenges experienced through these stages were honestly and candidly discussed and explained. The chapter concludes with a discussion of quality assurance and the role of the researcher in this study. This further highlights the extent to which Classic Grounded Theory methods were consistently adhered to in order to develop a quality, substantive theory.

This theory, The Theory of Reconciling Communication Repertoires will be presented in the next chapter. The appropriateness of decision making, and depth of analysis discussed in this chapter is evident in the explanatory power of the theory.

Chapter 5 Theory of Reconciling Communication Repertoires

5.1 Introduction

Thus far, the backdrop to this study has been provided with consideration of micro and macro factors. The ontological and epistemological stance has been argued. The methodology and methods used to undertake the research have been transparently presented, justified and discussed. At this stage, it is timely that the grounded theory developed through this study, the Theory of Reconciling Communication Repertoires, is presented. The core strategy of reconciling communication repertoires (para. 5.3) is central to the entire theory. Therefore, this is presented following a brief overview of this theory. Although presented in a linear way, it will become clear that this is an evolving and iterative process of strategic navigation shaped by the outcomes of five distinct stages or sub core categories; motivation to interact (para. 5.5), connection establishment (para. 5.6), reciprocal engaging (para. 5.8), navigating understanding (para. 5.9) and resolving confusion (para. 5.10). Each of these sub core categories are varied by an individual's attempt to economise effort. Therefore, the concept of economising effort (para. 5.4) is presented before these five sub core categories. Furthermore, an interaction can only occur if a connection is established. Once established, the connection must be maintained by defusing interference. Connection maintenance hinges on connection establishment. The remaining

three sub core categories are contingent on successfully maintaining this connection. Therefore, the concept of connection maintenance (para. 5.7) is presented between stages two and three, connection establishment and reciprocally engaging.

5.2 Overview of the Theory of Reconciling Communication Repertoires

Effective communication can be a deceptively complex process that involves an interplay of physical and cognitive skills to express and receive messages. Complexity is amplified with increasing diversity of communication repertoires of the interaction partners. The Theory of Reconciling Communication Repertoires (Figure 5.1) sets out the strategies people use to navigate interactions involving persons with severe/profound intellectual disability over five stages; motivation to interact, connection establishment, reciprocally engaging, navigating understanding and confusion resolution.

When these interactions are of a social nature, the motivation to interact stems from a desire to nurture a sense of belonging. Given the diversity of communication repertoires, the parties must reconcile their respective repertoires to a space that maximises potential for each to engage and understand. Successful interactions rely on concurrently and effectively reconciling communication repertoires, establishing and maintaining a connection and reciprocally engaging. This process can be taxing. Therefore, effort is economised by considering the level of effort required alongside motivation

strength and value of the likely outcome. Increased effort diminishes the likelihood of attempting to interact.

Establishing a connection involves seeking an opportunity and acting to grab the attention of the interaction partner. A connection is established when the parties are attending to each other. Once established, the connection is maintained by defusing interference while reciprocally engaging. Interference causes fluctuations in the strength of the connection from fully connected through connection jeopardy to disconnected.

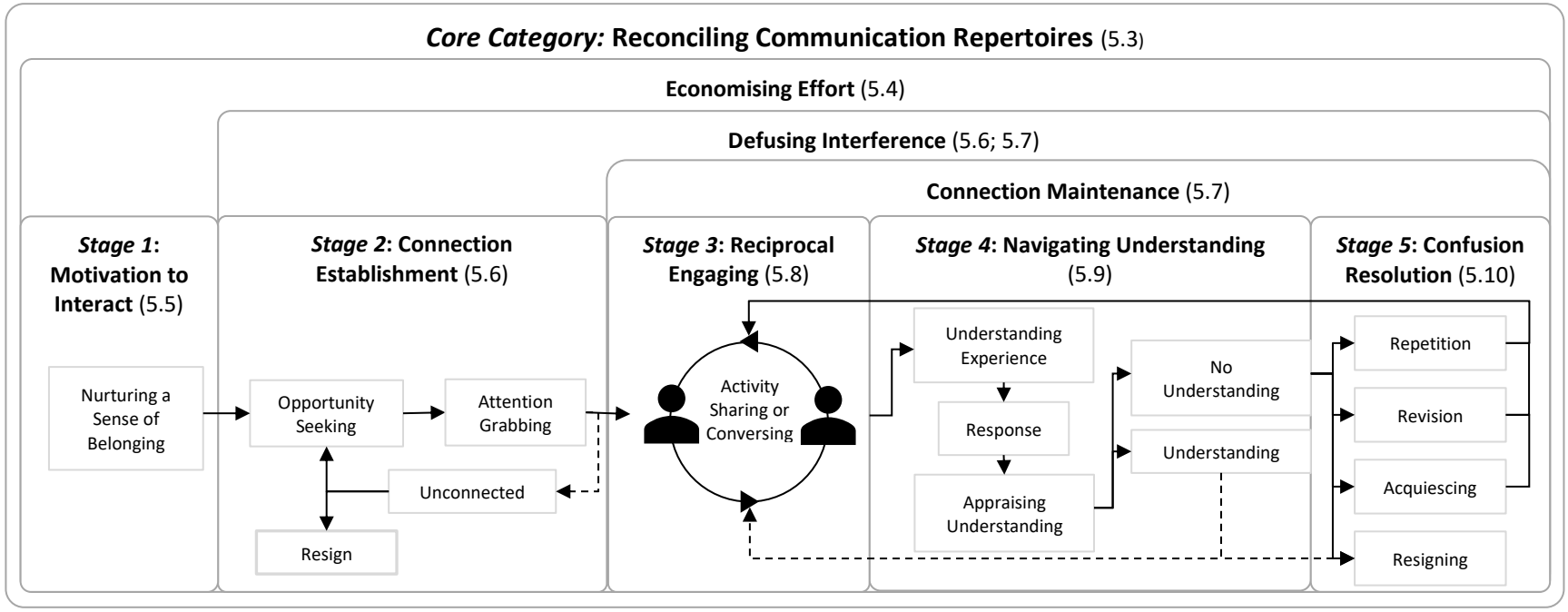
Reciprocal engagement commences on establishment of the interaction. The parties attend to one another and contribute to the interaction in a bi-directional way. To reiterate, this is most effective when communication repertoires are reconciled. The complexity and challenge of this process is evidenced by their short, infrequent nature and seldom achievement of understanding.

The Theory of Reconciling Communication Repertoires recognises two understanding perspectives; that of the receiver who experiences understanding and the sender who appraises understanding. These are conceptualised in stage four: navigating understanding. Furthermore, it identifies strategies people use to resolve confusion when understanding is not reached. Four strategies of resolving confusion are explained: revising, repeating, acquiescing and resigning.

It is noteworthy that those with a severe/profound intellectual disability use the same strategies to navigate the interaction as their partner, despite having a

narrower communication repertoire. The range of the persons' repertoire influences the extent to which they can reconcile. A wider repertoire indicates greater availability of communication skills to draw from. The Theory of Reconciling Communication Repertoires sets out the strategies, both people with severe/profound intellectual disability and their partners use to interact.

Figure 5.1 Theory of Reconciling Communication Repertoires



**Paragraph cross-referencing in brackets*

5.3 Reconciling Communication Repertoires

Reconciling communication repertoires is the core strategy used to resolve the difficulties people with a severe/profound intellectual disability and their partners encounter through each stage of the interaction. Each person's communication repertoire is unique and individual. A communication repertoire is a cache of communication skills and aptitudes the person can draw from in order to interact with others. This indicates how this theory highlights abilities rather than disabilities.

Individuals reconcile their communication repertoires by adopting strategies that complement their communication partner's repertoire. A successful outcome from each stage of the interaction, requires adopting an approach or strategy that maximises and complements the skills available in the communication partner's repertoire. For example, when opportunity seeking the person will wait for the most opportune time to attention grab by observing their partner. The person will strategically wait and observe to identify a time when their partner is ready to connect, and their attention can be drawn. Similarly, the methods of reciprocal engagement are selected based on their likelihood of fitting with both repertoires. Reciprocal engagement through activity sharing is used in interactions where verbal communication skills may be limited or not present in an individual's repertoire. The activity removes the reliance on verbal skills required in a conversation. This approach recognises interaction skills such as observation,

sharing, turn-taking that may exist in both communication repertoires; thus, reconciling communication repertoires.

The disparity between repertoires requires an attempt to at least narrow or at best close the gap thus finding a mutual communication space in which to interact. This is difficult but experiential knowledge gained through previous interactions informs the reconciliation strategy. Greater reconciliation responsibility tends to be placed on those with a wider repertoire due to a greater availability of skills and strategies to draw from. This is not to suggest that those with a narrower repertoire are unable to reconcile. Rather, the extent of the repertoire determines the range of skills and strategies available.

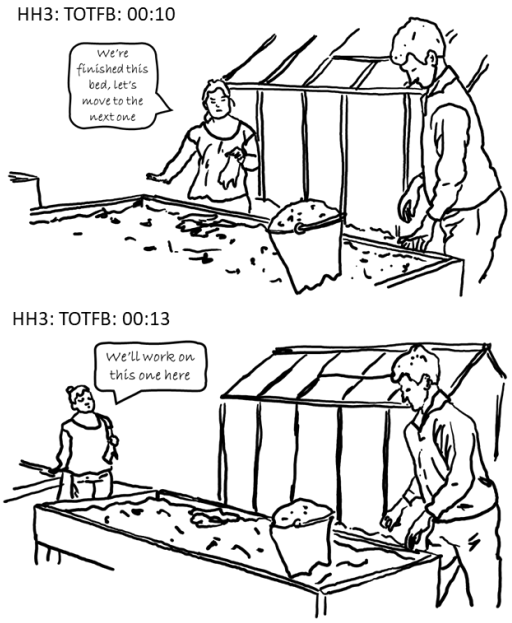
Additionally, the availability of reconciliation skills and strategies fluctuates in the course of the interaction as roles interchange. There are different requirements at different stages of the interaction. For example, a wider repertoire of expressive strategies enables greater scope to reconcile a disparity with the receptive repertoire of the partner. A wider repertoire of receptive strategies implies greater scope to reconcile with their expressive repertoire.

In order to establish a connection, any disparity between the person's attention-grabbing repertoire and their chosen partners attention capacity must be reconciled. A different repertoire of skills is required to simultaneously maintain the connection, defuse interference and reciprocally engage. Reciprocal engagement presents a new situation brought about by the rotation of roles

between expressor and receiver. Each rotation brings a simultaneous rotation between expressive and receptive repertoires. If understanding is not achieved, confusion resolution demands another skill set. This can be particularly difficult for those with a narrower repertoire as an alternate method to express themselves may not be available. This demonstrates that reconciling repertoires is an on-going process throughout the interaction.

Understanding is more probable when repertoires are successfully reconciled. The partners have found a mutual communication space in which to interact and therefore can reciprocally engage in a context of understanding. Failure to achieve understanding indicates repertoires have not been reconciled.

Figure 5.2 Reconciling Repertoires



Jane recognised that Ben was confused by her first instruction so revised her position, gesture and verbal methods reconciling their communication repertoires. Ben moved towards the flower bed when he understood her instruction.

At this point, the demand of reconciling repertoires is evident. As previously mentioned, interactions between people with severe/profound intellectual disability tend to be short and infrequent because of the effort demand. This demand exists in an already challenging context of significant intellectual disability and potentially high support needs and/or intensive care provision. Therefore, prior to initiating an interaction, persons will economise their effort.

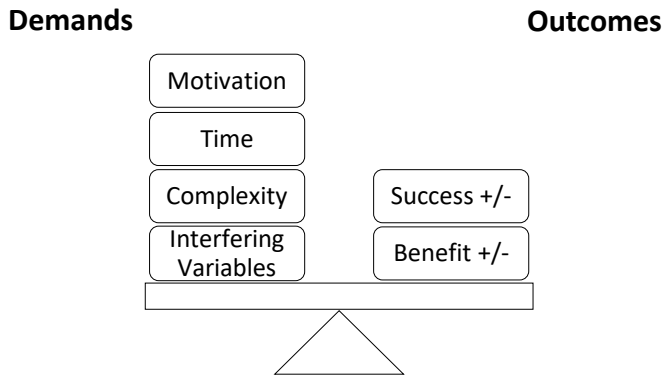
5.4 Economising Effort

In the Theory of Reconciling Communication Repertoires, economising effort is a condition that influences a person's actions. The effort demanded to interact successfully is a consideration for both persons with severe/profound intellectual disability and their partner. Effort is required to reconcile repertoires, establish and maintain a connection, reciprocally engage, defuse interference and potentially resolve confusion. Effort demand increases in parallel to a widening disparity between communication repertoires, increasing appeal of interfering variables and/or increasing complexity of the reciprocal engagement activity. The effort demand can have a counter effect on the duration and/or frequency of interactions. A narrower communication repertoire is aligned with experiencing shorter and/or less frequent interactions. An attempt is made to be energy efficient by considering the effort demand against the motivation strength and most probable outcome (Figure 5.3). A higher strength of motivation and/or likelihood of success is aligned with a higher likelihood of expending effort and vice versa. Consideration is given to the appeal of potential or actual interfering

variables, complexity of the proposed reciprocal engagement activity and time demands.

> *And people will walk away from them too because they feel that they… that they are not getting through to them. Or that they feel that they are not going to understand anyway so why bother.*
>
> *(Bridget)*

Figure 5.3 Effort Efficiency – Balancing Demands and Outcomes



5.4.1 Interference Appeal vs. Probable Outcome

In order to be successful, the attention-grabbing act and reciprocal engagement method must appeal to the interaction partner individually. The strength of appeal is subjective as it is reflective of personal preference. The method must be more appealing than any present or potential interference. If the appeal of an actual or potential interference is estimated to be lower than the attention-grabbing act or reciprocal engagement activity, effort will be expended. The presence of a more appealing interference raises the effort demand. Consequently, the likelihood of expending effort is lower.

5.4.2 Complexity of Interaction vs. Probable Outcome

Complexity of the interaction is a significant factor that affects the likelihood of success when gauging the effort demand. Increasing complexity widens the repertoire disparity, increases the reconciliation demand thus increasing the effort demand. Additionally, increasing complexity adds to the time demands. Greater effort is required to find a mutual communication space. Again, increasing effort demands are associated with decreasing likelihood of initiating or sustaining an interaction.

Bridget: *And the thing is that what they will understand is limited too. You know…*
Michael: *Yes…*
Bridget: *It's not reached in the majority. It's in the minority of times.*

(excerpt from family interview. Bridget and Michael are Ben and Rose's mother and father.)

5.4.3 Time Demands vs. Probable Outcome

Time is an issue in its own right. Time is required to establish a connection, reconcile repertoires, reciprocally engage and potentially resolve confusion. Finding a mutual communication space can take time, particularly as the repertoire disparity widens. If time demands extend and/or the probability of a positive outcome are low, the chances of investing effort to initiate and/or sustain an interaction are correspondingly low. Furthermore, the presence of demands external to the interaction can tip the balance e. g. other tasks, meeting the needs of others etc. Competing demands are prioritised in accordance with the motivation to interact and the probability of a positive outcome.

And it's very tiring. Because it takes an awful lot out of you to spend that five minutes…a lot of the time because you haven't the energy and you haven't the support either. Because it's a full-time job.

(Bridget)

In summary, an attempt is made to economise effort by weighing the demands of and motivation driving the interaction against the likely outcome(s). Competing appeal of the engagement and interfering variables, complexity of the interaction, time and effort demands are weighed against the probability and/or benefit of a positive outcome. Increasing demands are correlated with a decreasing probability of expending effort. However, a strong motivation to interact is associated with a likely attempt to invest the effort required.

5.5 Stage 1: Motivation to Interact

The first sub core category is motivation to interact. This is the impetus for the interaction. Concerns regarding isolation and loneliness due to short, infrequent interactions stir a desire to nurture a sense of belonging which is recognised as a basic human need. This is the main concern that is resolved by reconciling communication repertoires. Interaction partners do not know if the person with intellectual disability feels isolated or lonely. However, they conclude that short, infrequent interactions coupled with a narrow communication repertoire is a recipe for isolation and loneliness. Attempts by those with severe/profound intellectual disability to engage tend to follow an extended period without an interaction. This suggests the person is motivated to nurture a sense of belonging.

However, having a narrow communication repertoire increases the effort demand and decreases the likelihood of a successful outcome. Consequently, the likelihood of attempting to establish a connection is lower.

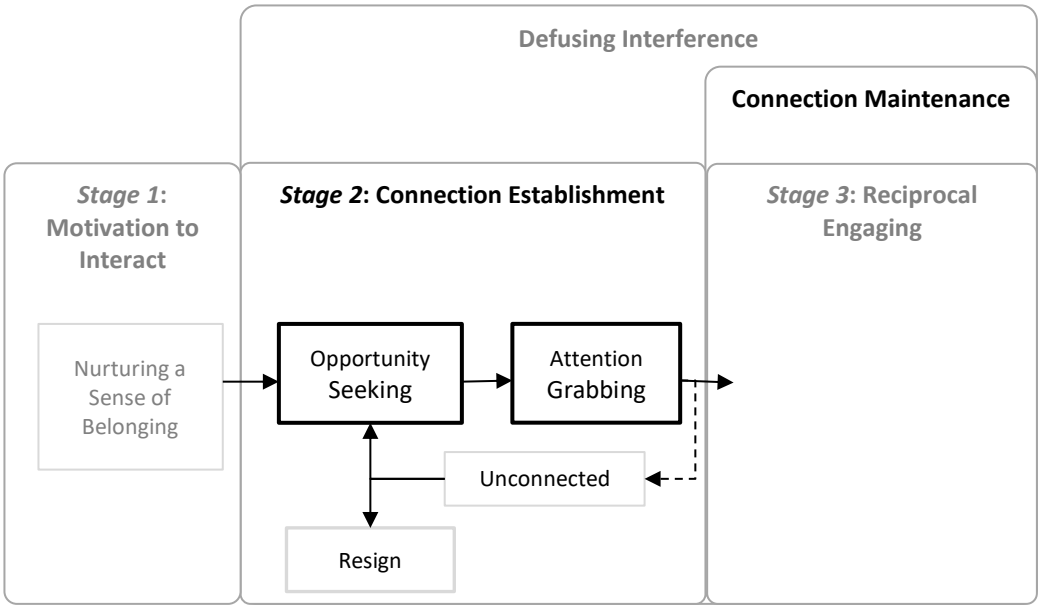
> *And that's important for everybody. I mean that's all anybody wants in life is to be accepted and be included. I'm saying that to everybody …You know not just Ben and Rose… Every one of us needs that…ya that's a very normal thing to want… to be accepted and to be included. You know?? It's part of humanity really…*
>
> *(Bridget)*

In order to alleviate this concern, a conscious effort is made to establish a connection and engage. It is hoped that the interaction will have a positive impact, reducing feelings of isolation or loneliness for the duration of the interaction as a minimum. A sense of belonging is experienced through the experience of being connected and so connection maintenance is prioritised. Understanding is desirable but unnecessary because the main concern is addressed in the process of interacting rather than the activity itself. The reciprocal engagement activity serves as a strategy to establish and maintain the connection rather than being the purpose of interacting. This reduces the likelihood of attempting to resolve confusion as the raised effort demand jeopardises the connection. In a context of misunderstanding, the person chooses to acquiesce to the misunderstanding rather than risk breaking the connection. This demonstrates the priority attributed to the connection and nurturing a sense of belonging.

5.6 Stage 2: Connection Establishment

Connection establishment is a pre-condition to the interaction. Establishing a connection is critical as without it, there is no interaction. Successfully nurturing a connection is contingent upon its establishment and maintenance. Connection establishment comprises two distinct strategic actions: opportunity seeking and attention grabbing (Figure 5.4).

Figure 5.4 Establishing a Connection



5.6.1 Opportunity Seeking

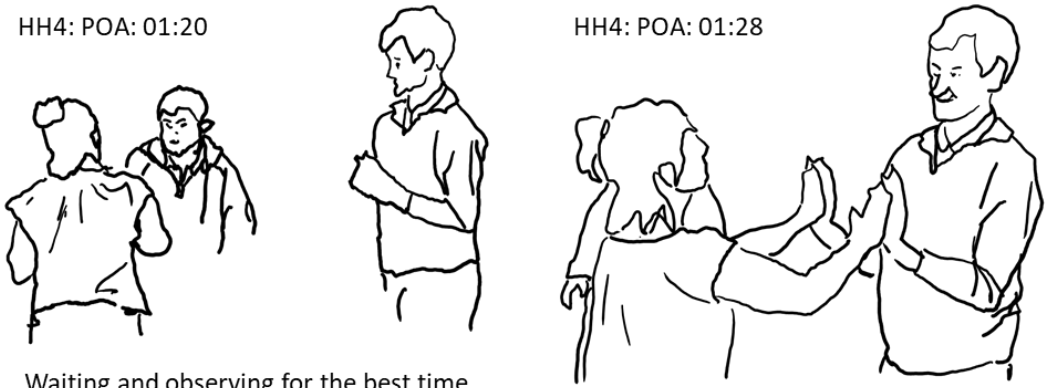
Opportunity seeking involves waiting and observing for a prudent moment to attention grab. In doing so, the person is economising effort. The length of time spent opportunity seeking depends on the presence of an interference. Interfering variables are assessed in relation to likelihood of attention grabbing successfully. If interference appeal is too strong, the person will choose to wait as this is effort efficient. The person continues to opportunity seek until the interference passes

or its appeal weakens (Figure 5.5). Attention grabbing will then be attempted. The person may also choose to resign and not attempt to establish a connection. Alternatively, the person may select to interrupt the interference by using a more appealing attention grab.

Bridget:	*Ben could be way, way down at the bottom of the fields and if he thought there was a cup up on that window, he'd come back up…all the way back up. Get that cup. Put it into the dishwasher and go back down the field again. Wouldn't he?*
Edel:	*He would ya. It occupies his mind*
Bridget:	*Ya totally*
Edel:	*He has a set place for everything and that's where everything has to go.*
Bridget:	*That's it full stop.*
Edel:	*You see that's a problem when you're trying to interact with them*
Bridget:	*Ya but you can't do anything about that*
Edel:	*No*
Bridget:	*Not one hope in the wide earthly world have you of getting through to Ben while that's in his head. He's zoned out. Because you have to wait for your chance that they are ready to interact with you.*

(excerpt from family interview. Bridget is Ben and Rose's mother. Edel is their sister in law.)

Figure 5.5 Opportunity Seeking: Ben and Jane



Low interference appeal lessens time spent at this stage. The competing appeal is low and therefore it is effort efficient to attention grab.

5.6.2 Attention Grabbing

An effective attention-grabbing action will draw the partner's attention and establish the connection. This may involve speaking/vocalising, touch or a previously successful strategy. The attention grab does not need to be related to the interaction motivation or engagement activity. Its only purpose is to establish a connection. It must however, hold subjective appeal and/or greater appeal than any interference.

A repertoire of low appeal attention grabbing methods raises the challenge of this stage. This is because the strength of appeal of the attention-grabbing act is a key factor determining a successful outcome of this connection establishment stage. More overt methods have inherently high attention-grabbing appeal. As attention-grabbing methods become more subtle, their appeal factor reduces

accordingly. A method with low appeal may be undetectable to the partner. However, a wider repertoire of attention-grabbing methods does not imply less difficulty. If the partner's receptive repertoire is narrower, the challenge of reconciling repertoires is raised. This further highlights the need to reconcile communication repertoires across the interaction and its functions as the core category.

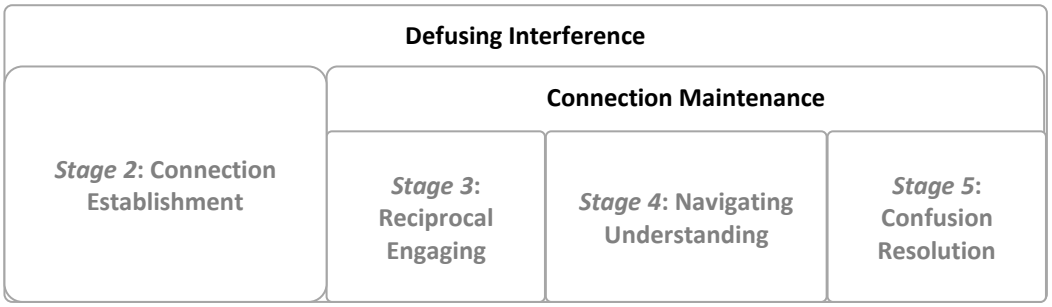
If the attention grab fails to establish a connection, a number of pathways may be followed. The person may opportunity seek again or repeat the attention grab. Similarly, an alternative attention-grabbing act with greater appeal may be used if available. Choosing to try again indicates the motivation strength. The person may decide against pursuing the interaction and resign if interference appeal is deemed too powerful or the repertoire disparity too wide to reconcile. The effort demand is too high. In circumstances where alternative attention-grabbing methods are available, resigning may indicate low motivational strength.

Establishing a connection is a critical juncture as an interaction cannot occur in its absence. Therefore, meeting the motivation and progressing to the next stage requires a successful outcome. A connection exists where both parties are concurrently attentive to each other or a shared activity and the interaction is reciprocal in nature. In this context, a sense of belonging can be nurtured. However, reciprocal engagement relies on the connection being maintained. Consequently, the connection must be maintained by defusing present or potential interference.

5.7 Connection Maintenance

Connection maintenance and reciprocally engaging (para. 5.8) are interdependent. The connection brings about the sense of belonging and provides the platform on which to reciprocally engage (Figure 5.1). Correspondingly, reciprocally engaging while concurrently defusing interferences maintains the connection. Therefore, maintaining the connection is a high priority through the course of the interaction. A highly appealing reciprocal engagement activity where understanding is probable, lessens the effort demand of this dual task. High subjective appeal will hold interest and understanding indicates the repertoires are successfully reconciled. This reduces the risk of disconnection caused by raised effort demand, more appealing interference, frustration from misunderstanding, or difficulties resolving confusion.

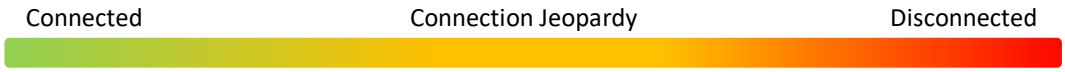
Figure 5.6 Connection Maintenance



The difficulty of maintaining the connection is amplified by its delicacy and fragility. A disconnection can happen at any point, including as soon as it is established. The strength of the connection fluctuates throughout the interaction along a continuum (Figure 5.7) ranging from connected through connection

jeopardising to disconnected. It is influenced by the factors discussed under economising effort (para. 5.4).

Figure 5.7 The Connection Continuum



A strong connection exists when both parties are concurrently attentive to each other or a common interest and are reciprocally engaging. This is sustained while the engagement activity is appealing and effort efficient. The presence of interference, a rise in the effort demand or a weakening of the motivation jeopardises the connection. Interference is caused by environmental, personal and/or interaction-related factors. Environmental factors include distractions external to the interaction that interrupt or interfere with its progression such as one person being called, a sudden sound or the presence of someone/something of interest. Personal factors are individual characteristics that jeopardise the connection such as breadth of communication repertoire, transient factors such as attention and enduring factors such as cognitive and/or physical variables. Interaction-related factors relate to the interaction itself. These include uncomfortable pacing or unappealing reciprocal engagement activity. Although the connection is maintained, these interferences must be defused by raising the appeal of the reciprocal engagement or, if possible, removing the interference. This situation raises the effort demand adding to the risk of disconnection.

Disconnection occurs when the connection no longer exists, and the parties are not attending to each other. It can be purposeful or non-purposeful. A purposeful disconnection or resignation occurs when the person decides to resign from the interaction because the motivation is fulfilled, and the interaction reaches its natural end (as determined in Stage 4: Navigating Understanding). It may be that one person does not want to interact and so terminates the connection (at any stage). Alternatively, it may be that effort demand to maintain the connection and engage is too high (at any stage). Essentially, the person is in control of the disconnection.

A disconnection not controlled by the person is a non-purposeful disconnection. This can occur at any stage after the connection has been established when the motivation to interact has not been met but interference has caused a disconnection. An interference was not defused while the connection was in jeopardy. In this circumstance the person may opportunity seek again or resign if re-establishing the connection is effort inefficient.

The strategies for maintaining a connection or defusing interference are the same for all parties to the interaction. As discussed, differences arise consequent to the repertoire breadth. However, defusing interference is just one strategy to maintain a connection. Reciprocal engagement also supports connection maintenance.

5.8 Stage 3: Reciprocally Engaging

Reciprocally engaging is a sub-core category of reconciling communication repertoires and, as previously mentioned, a dual-purpose strategy that can maintain the connection and nurture a sense of belonging. Connection maintenance and reciprocal engagement are symbiotic and intrinsically linked. If the reciprocal activity has insufficient appeal, the connection is jeopardised. If there is no connection, reciprocal engagement cannot occur. Therefore, the reciprocal engagement activity needs to be appealing and effort efficient with probability for understanding an advantage. Reciprocal engagement encompasses two concepts; activity sharing and conversing.

5.8.1 Activity Sharing

Activity sharing is a means of reciprocally engaging particularly effective in nurturing a sense of belonging and achieving understanding. The need for spoken language is reduced thus reducing the effort demand to reconcile repertoires. It is easier to find a mutual communication space as the repertoire disparity is narrower.

> *But if you gave him something to do, he'll do it. But saying that there… feeding the pigs like, he knows intensely where everything is to go almost. And if you told him to take that down there to the sows… He'd do it alright. Ben does an awful lot of observation. And I think an awful lot of times when he understands you it's based on what he is observing rather than what he is hearing.*
>
> *(Michael)*

Reciprocal engagement through activity sharing is fulfilled by co-operative contribution and/or being present together. Participation can occur on a parallel or collaborative basis. Parallel participating (Figure 5.8) is indicated by engaging in the same activity but independently of each other. A sense of belonging is nurtured by being present with each other.

Figure 5.8 Parallel participating in Shared Activities



Everyone is engaged in the same activity but independently of each other.
A sense of belonging is nurtured by being present with each other.

Collaborative participating (Figure 5.9) involves engaging in an activity that requires co-operation, teamwork and/or turn-taking. A sense of belonging is nurtured in the experience of working together to complete the activity.

Figure 5.9 Collaborative Participating: Linda and David

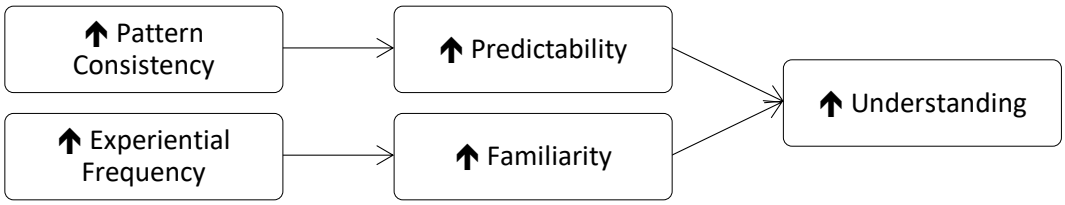


Linda and David played a song together. Linda played along to the beat David set

The practical nature of activity sharing reduces the need for spoken communication methods and the associated challenges to achieving understanding. This is particularly true for routine or patterned activities.

Routine/patterned activities increase probability of understanding, thus strengthening the connection and lowering the effort demand. Predictability of and familiarity with routines enables understanding (Figure 5.10).

Figure 5.10 Impact of Routine on Understanding



Predictability is enhanced by high pattern consistency. Pattern consistency refers to the extent to which a routine's procedure is the same from one occasion to the next. High pattern consistency offers high predictability which consequently

increases the chances of understanding. Inconsistency causes confusion. Familiarity is supported by high experiential frequency. Experiential frequency relates to how often the person is involved in the routine. High experiential frequency supports understanding by increasing familiarity (Figure 5.11). It must be acknowledged that a repertoire for retention and recall are prerequisites to achieving understanding through predictability, familiarity and routine.

Activity participation is an effective way to nurture a sense of belonging. Being present, collaborating and co-operating all foster belonging, inclusion and bonding. Furthermore, when outcomes of the activity are positive, the parties experience achievement and success not only regarding fulfilling the motivation but also in having successfully completed the activity.

Figure 5.11 Routine Activities: Rose



Rose knows the routine of setting the table for dinner as it was a daily activity she took part in. She waited until it was her turn and carried out her part of the task.

5.8.2 Conversing

A second reciprocal engagement strategy, conversing, is commonly used to engage in the typically cyclical way of message sending, receiving and responding. Although theoretically straightforward, this is a challenging and complex process in practice. Reconciling repertoires is difficult and evidenced by infrequent

understanding achievement. Rotation of roles between sender and receiver requires a simultaneous reconciliation of repertoires necessary for each role. Repertoire disparities can relate to expression, attention, reception, interpretation, imagination, understanding and maintaining a connection. Reconciling repertoires to the mutual communication space necessitates significant effort.

Individuals use different strategies to converse. Conversing strategies must be prudently and carefully selected to maintain the connection. Three conversing strategies, subtle hinting, multi-messaging and routine conversing, are now presented. Subtle hinting and multi-messaging tend to be problematic strategies. Routine conversing can be more successful to nurture a sense of belonging and achieve understanding.

5.8.2.1 Subtle Hinting

Individuals with a narrower expressive repertoire tend to use unconventional and/or subtle expressive methods. Subtle hinting (Figure 5.12) is particularly problematic. A subtle hint has two main properties. Firstly, it is not a close representation of the intended message. Secondly, it is easily missed or unrecognised. This directly impacts their potential of being understood by increasing the scope for misinterpretation and/or reducing the chance of recognition. Without recognition, the expression is not received to be interpreted. This situation is connection jeopardising. However, these methods can work when the partner is familiar with and sensitive to their meaning. In other words, if this

sensitivity is in the partner's receptive repertoire a mutual communication space can be found.

Figure 5.12 Subtle Hinting: David



David looked towards staff in the kitchen, stretching his fingers on his left hand and raising it slightly. He tried a second time but still did not attention grab. He revised his method by adding a low, short vocalisation. The staff member responded. David's initial method of grabbing attention was too subtle to be recognised by his interaction partner.

5.8.2.2 Multi-Messaging

Difficulties not only relate to narrow repertoires. A broader expressive repertoire brings about its own challenges. This is because the availability of multiple expressive methods can result in the use of multiple expressive methods. Multi-messaging (Figure 5.13) occurs when two or more messages are inadvertently conveyed; one intentionally (e.g. verbally) and the remainder unintentionally (e.g. a hand gesture). People with a wider communication repertoire tend to multi-message more frequently because they have more skills available. The partner receives, interprets and responds to the expressive method that is closer to the

mutual communication space and their receptive repertoire. If this is the unintended message, confusion ensues.

Figure 5.13 Multi-messaging



Rose turns away when Jen puts out her hand. Although Jen is asking Rose to slow down, her body language and gestures could indicate she is about to take the glass from Rose.

Subtle hinting and multi-messaging are not conducive to connection maintenance, achieving understanding or nurturing a sense of belonging. They both usually imply the conversation is occurring on the peripheries of or outside the mutual communication space. This jeopardises the connection, causes confusion and is effort inefficient. While these strategies demand much effort, one conversing strategy, routine conversing, is particularly successful at nurturing a sense of belonging.

5.8.2.3 Routine Conversing

As with routine activities, the predictability and familiarity of routine conversing support understanding and connection maintenance. It involves following a similar or possibly identical dialogue several times a day or a week. The topic is

usually subjectively appealing and had a positive outcome previously. The content is irrelevant but powerful for reciprocal engagement, connection maintenance and nurturing a sense of belonging. As it is rehearsed and proven and the mutual communication space is already established it is effort efficient.

Julie:	*You ok? Are you watching the telly?*
Rose:	*[Doesn't move or reposition but holds eye contact with her; no change in facial expression; looks Julie up and down; breaks eye contact]*
Julie:	*Are you? Were you at home with Daddy?*
Rose:	*[Looks to the TV and around the room]*
Julie:	*Go out with the cows?*
Rose:	*[Looks around the room and quickly makes eye contact with Julie when she mentions cows]*
Julie:	*Were you?*
Rose:	*[Holds eye contact with Julie]*
Julie:	*Well? Were you milking cows?*
Rose:	*[Looks to Julie and holds eye contact]*
Julie:	*Were you having a good time?*
Rose:	*[Looks down to the belts and then back up to Julie, small smile]*
Julie:	*Oh the smile…were you having a good time? You were, weren't you?*
Rose:	*[Looks at Julie and continues to smile]*

(Routine conversation between Julie and Rose that was repeated on three separate video recorded occasions over one week)

In short, conversing is a more challenging method of reciprocally engaging than sharing activities. However, if the repertoires are reconciled to a mutual

communication space, a sense of belonging and connectedness can be achieved. Although understanding may not occur to the same extent while conversing rather than sharing activities, its achievement strengthens the connection and sense of belonging further.

5.9 Stage 4: Navigating Understanding

Navigating understanding is a sub-core category and fourth stage of the Theory of Reconciling Communication Repertoires. This theory distinguishes two understanding viewpoints. Firstly, understanding as experienced by the person receiving the message. Secondly, understanding as appraised by the person sending the message. These two perspectives of understanding will now be presented.

5.9.1 Experiencing Understanding

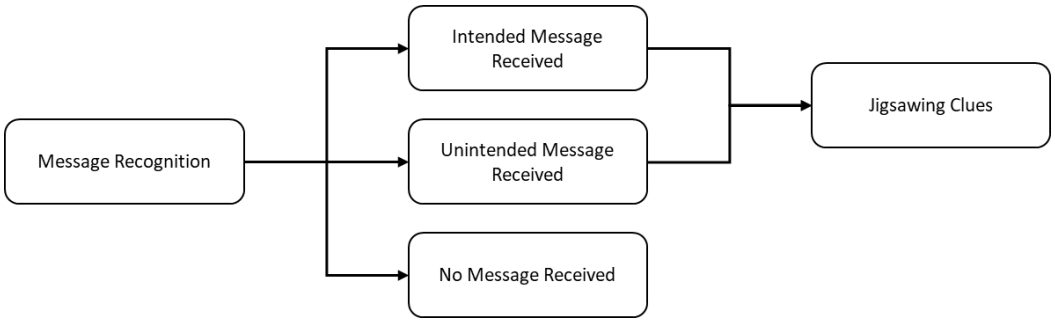
If a connection is maintained, the receiver attends to the sender's expressive behaviours. Understanding these behaviours involves two stages; message recognition and jigsawing clues. It is important to distinguish these as two distinct stages as a message must be recognised before it can be interpreted. Difficulty with either or both skills results in an unsuccessful conversation.

5.9.1.1 Message Recognition

Message recognition happens as the message is expressed. It involves the receiver attending to the expressive behaviours of the sender and recognising the behaviours hold meaning. This is successful when repertoires are reconciled.

There are three potential outcomes of message recognition (Figure 5.14): the intended message is recognised and received; an unintended message is recognised and received, or no message is recognised. If no message is recognised, and hence none received, progression to jigsawing clues cannot happen and the connection is jeopardised. However, jigsawing can take place regardless of whether the intended or unintended message is recognised, because clues been received.

Figure 5.14 Message Recognition



5.9.1.2 Jigsawing

Jigsawing involves piecing the recognised and received clues together creating a picture from which meaning is drawn. The need to jigsaw demonstrates the clue-based nature of these interactions. Once meaning is drawn, it is reviewed for probability of accuracy. This is a self-check of understanding. A strong correlation strengthens the assumption of correct understanding.

Understanding can be experienced in five different ways (Table 5.1); correct understanding, oblivious understanding, cognisant confusion, oblivious misunderstanding or no-understanding. Correct understanding occurs when the

message is interpreted as the sender intended. The message is received, clues are jigsawed together and the accuracy of the interpretation is high. Oblivious understanding is indicated when the receiver has drawn the correct meaning but is concerned about the accuracy of their interpretation. The receiver experiences doubt regarding their interpretation when reviewing it for probability of accuracy. The message may be expressed out of context causing the receiver to believe they have misunderstood e.g. asking a person if they would like something to eat while in a music room. Cognisant confusion arises when the meaning drawn is not as the sender intended but the misunderstanding is acknowledged. Oblivious misunderstanding occurs when the meaning drawn is not as the sender intended but this is not known. It is believed the interpretation is accurate. No-understanding is indicated when no meaning is drawn.

Table 5.1 Typology of Understanding

	Aware	**Unaware**
Correct Meaning Drawn	Understanding	Oblivious Understanding
Incorrect Meaning Drawn	Cognisant Confusion	Oblivious Misinterpretation
No Meaning Drawn	No Understanding	

The type of understanding the receiver has reached is unknown to the sender until a response is provided. The sender uses the response to appraise understanding. Although the receiver can experience one of several types of understanding, the sender will only appraise understanding as achieved or not.

5.9.2 Appraising Understanding

The sender attends to the receiver's response to appraise understanding. The response is seen to indicate the type of understanding reached. Despite five potential types of understanding (Table 5.1), it will only be appraised as achieved or not based on two criteria; response fit and response delay (Table 5.2).

5.9.2.1 Response Fit

Response fit refers to the extent to which the response relates to the intended message. If the response fits, understanding is assumed. If the response is deemed non-fitting, no understanding is assumed. Responding to seek clarification or express confusion is considered a fitting response. In other words, if understanding is not achieved, it is fitting to express this as a response.

5.9.2.2 Response Delay

Response delay refers to the length of time between expressing the message and receiving a response. A faster response is aligned with an increased likelihood of understanding. This appraisal method is less accurate as a fast response can occur with oblivious misunderstanding. A delayed response is interpreted as difficulty with understanding. The delay is assumed to be as a result of needing more time to interpret the message. Confusion resolution strategies (para. 5.10) may be implemented.

An extended delay indicates a non-response. In this circumstance, a disconnection may have occurred. Alternatively, if the connection is maintained, no-

understanding is assumed except for one situation. When a choice is offered, a non-response may be interpreted as contentment with the status quo; understanding is assumed. This demonstrates where fitting responses and non-responses overlap. The 'non-response' fits with the intended message; choosing to remain as is.

Table 5.2 Matrix of Appraising Understanding

		Response Fit	
		Fitting Response	**Non-Fitting Response**
Response Delay	**Fast/Prompt Response**	Understanding	No Understanding
	Delayed Response	Understanding	No Understanding
	Non-Response	Understanding	No Understanding/ Disconnect

If understanding is appraised, the interaction will either end through resignation or continue with reciprocal engagement. In circumstances of misunderstanding, confusion resolution may be necessary.

5.10 Stage 5: Confusion Resolution

Confusion resolution is only required in contexts of misunderstanding or no-understanding. Effort efficiency and strength of motivation will determine if an attempt will be made to resolve confusion. The ability to reconcile repertoires is tested in this scenario. Consideration needs to be given to the availability of skills necessary to resolve confusion and reconcile repertoires. Sometimes, confusion resolution is not attempted as the person may decide to acquiesce to the

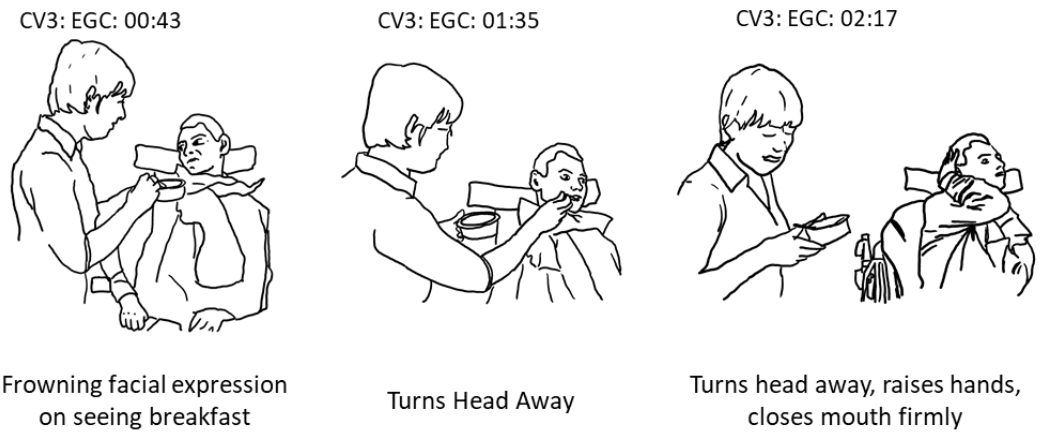
misunderstanding or resign from the interaction altogether. These strategies are now explored in more detail.

5.10.1 Revising

If the communication repertoire allows, the person might revise or modify their communication method (Figure 5.15). Firstly, changing methods necessitates the availability of an alternative. This can significantly hamper those with a narrow repertoire. Secondly, a fundamental problem is that the original method is usually selected because it is considered closest to the mutual communication space. Therefore, when this is unsuccessful, the second-choice method may be further from this space.

Furthermore, revising the methods requires awareness of the problem causing confusion so that it can be amended. Without this awareness, the wrong adjustment may be made e.g. when multi-messaging occurs, an awareness of the unintended conveying method is required to resolve the confusion.

Figure 5.15 Revising: David



5.10.2 Repeating

If an alternative method is not available in the repertoire, the person may choose to repeat their original method. This raises the significance of having a narrower repertoire. Strategic options to resolve confusion may be limited. In these circumstances, the conveying method may be repeated, perhaps with greater intensity or force to magnify the message.

5.10.3 Acquiescing

Resolving confusion is not as simple as attempting to achieve understanding. Acquiescing is a strategy adopted sometimes. This is used when understanding is desirable but unnecessary and the motivation to nurture a sense of belonging is high. Acquiescing occurs when no understanding is appraised but a choice is made to avoid jeopardising the connection by attempting to resolve the confusion. Instead, the misunderstanding is acquiesced to as the method of reciprocal engagement is a connection maintaining tool and not the purpose of the interaction. If the misunderstanding will maintain the connection, there is no need to correct it. This repertoire reconciling strategy tends to be a successful way of maintaining a connection and nurturing a sense of belonging because the process is more important than the engagement activity itself.

Figure 5.16 Acquiescing: Jane and Ben



Jane asked Ben to get gloves from the garden shed. When Ben got a garden chair, Jane did not attempt to resolve his misunderstanding. She continued the interaction by acquiescing to his misunderstanding.

5.10.4 Resigning

Resigning is another strategy people use in the absence of understanding. The person may resign because the motivation is fulfilled. A sense of belonging has been achieved. It may be that resigning is appropriate as the interaction reaches its natural end. Alternatively, to economise effort, the person may choose to resign because the demand to maintain the connection and continue to engage is too high. Regardless of the reason for choosing this strategy, resigning will end the interaction.

> *It happens an awful lot where you want, you want to say something to Rose or Ben and they are… you look at them and you say Oh look she's there looking for her belts. There's no point saying anything to her now. You don't bother.*
>
> *(Michael)*

To summarise, once a decision is made to resolve confusion but maintain the connection, reciprocal engagement will carry on. The method may be revised or repeated but reciprocal engagement continues in this context. The interaction may become effort inefficient or encounter an interference that will cause a

disconnection. Alternatively, the interaction may come to its natural end when the motivation has been fulfilled.

5.11 Conclusion

Interactions involving people with a severe/profound intellectual disability are complex and challenging. This is evidenced by their low frequency and short duration as well as the infrequent achievement of understanding. However, driven by a desire to nurture a sense of belonging, efforts are made to find a mutual communication space. This involves attempting to, at best close, or at least narrow the disparity in repertoires through reconciliation. This Theory of Reconciling Communication Repertoires sets out the strategies people use to nurture a sense of belonging by establishing a connection and maintaining it through reciprocal engagement. Importantly, those with a severe/profound intellectual disability and their partners use the same strategies. However, the extent of their usage is determined by the breadth of their communication repertoire.

Significant effort can be required of both parties and this impacts on the progression of the interaction. Increasing effort demands can result in the interaction ending. However, the strength of motivation can be such that the effort is deemed worthwhile.

This motivation to nurture a sense of belonging is the impetus to attempt establishment of a connection. This is achieved by opportunity seeking and attention grabbing. A successful attention grab signals the establishment of a

connection. This connection is critical to the entire process as it is the platform upon which the motivation is fulfilled. Therefore, once established, the connection must be maintained.

Connection maintenance can be as challenging as it is fragile. It is easily broken by interference. The connection is fluid moving from connected to disconnected through connection jeopardy. It is varied by effort demand and the competing appeal of the reciprocal engagement activity and interferences present. It is maintained by defusing interference and reciprocally engaging through a subjectively appealing activity. Reciprocal engagement methods include activity participation or conversing. Successful reconciliation of repertoires makes connection maintenance easier. Furthermore, understanding is more likely.

The Theory of Reconciling Communication Repertoires recognises that understanding is experienced and appraised. Understanding can be experienced in one of five ways. Yet, understanding is appraised as achieved or not based on a judgement of response fit and delay. When understanding is achieved, reciprocal engagement continues, or the interaction will end if the motivation is fulfilled. When it is not achieved, confusion resolution takes place.

Confusion resolution involves deciding to attempt to reach understanding or not. Strategies used to attempt to resolve confusion include revising or repeating the communication method. If it is decided to not attempt a resolution, there are two options; acquiescence or resignation. When acquiescing, misunderstanding is

recognised but a decision is made to go along with this misunderstanding. This indicates the strength of the motivation to nurture a sense of belonging and the importance of maintaining a connection. A choice is made to maintain the connection and nurture a sense of belonging rather than jeopardise it to reach understanding. Resignation will end the interaction either because it is inefficient to expend the effort necessary to continue or the motivation is fulfilled.

Throughout the interaction, a need to reconcile repertoires is evident as disparities usually exist at each stage. While recognising and acknowledging these disparities, this Theory of Reconciling Communication Repertoires highlights the contribution and ability of both people with a severe/profound intellectual disability and their interaction partners. While it is appreciated that these interactions occur in a context of communication difficulties, the findings suggest that a focus needs to be placed on finding a mutual communication space and interacting in this space. These findings are considered in light of extant knowledge in this substantive area in the following chapter.

Chapter 6 Discussion

6.1 Introduction

There is a plethora of research relating to interactions involving people with severe/profound intellectual disability. However, it generally focuses on specific aspects of the interaction. Researchers examine components of the interaction such as its nature, attentional processes, environmental influences, staff practices, family relationships, the efficacy or impact of interventions to name but a few. This has resulted in discrete findings that contribute to the evidence base surrounding interactions with people with severe/profound intellectual disability. The previous chapter presents a theory that brings these discrete findings together. The Theory of Reconciling Communication Repertoires explains how people navigate such interactions with due consideration of these elements. It identifies the nature of these interactions, recognising the motivation and effort required to engage. A comprehensive explanation of connectedness cognisant of interpersonal, intrapersonal and environmental variables is presented. The dual action of maintaining a connection while reciprocally engaging is detailed in this context. Strategies used to resolve confusion are delineated. Such comprehensive exploration of the interaction in its entirety and integration of variables is limited in the literature. This chapter presents an integrative literature review situating the Theory of Reconciling Communication Repertoires in empirical and theoretical literature

pertaining to interactions involving people with severe/profound intellectual disability.

6.2 The Integrative Review

The integrative review process suggested by Whittemore and Knafl (2005) guided this review (

Table 6.1). This approach was selected as it presents existing evidence in the substantive area, informs research, practice and policy and contributes to theory development (Whittemore and Knafl 2005). It is the broadest type of review and as such can capture the complexity of multiple perspectives. Further, this type of review has been advocated as important for evidence-based practice initiatives in nursing (Hopia et al. 2016).

A limitation of this method relates to the appraisal of the methodological rigour of identified studies. The use of an established quality appraisal tool (for example Crowe et al. 2012; Crowe et al. 2011; Crowe and Sheppard 2011) might have strengthened the quality appraisal of the integrative review. However, Hutchinson and Bodicoat (2015) highlight that when available literature is limited, it is more helpful to critique identified papers and use identified gaps to inform future research. This approach was adopted in the review.

Table 6.1 The Integrative Review Process (Whittemore and Knafl 2005)

Stage	Actions	Purpose	Application to Current Study
Problem Identification	Clear identification of the problem the review is addressing	To differentiate between pertinent and extraneous information in the data extraction stage	Communication/interaction with persons with severe/profound intellectual disability in the context of the Theory of Reconciling Communication Repertoires is the focus of the review
	Determining variables of interest and sampling frame		Keywords were determined. Inclusion and exclusion criteria were developed to guide identification of relevant studies.
Literature Search	Database search	To source relevant literature	CINAHL, Linguistic Collection, Social Science Premium Collection and Education Collection and Scopus were searched using keywords in 16 combinations. See Appendices XI-XIV for search and screening process resulting in identification of 41 articles
	Analysis of reference lists from retrieved reports	To maximise identification of pertinent literature	A bi-directional citation chase identified an additional 66 papers
Data Evaluation	Extraction of specific methodological features of primary studies	To evaluate overall quality	The methodology of each study was reviewed to assess quality. This explained differences in study findings. It distinguished the sometimes-subtle differences in study aims and subsequent findings.
Data Analysis	Data are ordered, coded, categorised and summarised into a unified and integrated conclusion	To achieve a thorough and unbiased interpretation of primary sources and innovative synthesis of the evidence	The articles were reviewed, and findings were coded using the concepts from the Theory of Reconciling Communication Repertoires.
Presentation	Reporting the conclusions	To demonstrate a logical chain of evidence	This chapter reports the findings from this review

6.2.1 Stage 1: Problem Identification

Stage 1 of the integrative review process requires clearly identifying the focus of the review, determining the variables of interest and the sampling frame. The focus of this review is communication/interaction with persons with severe/profound intellectual disability in the context of the Theory of Reconciling Communication Repertoires. In order to identify relevant literature, the following keywords or variables of interest were identified:

1. intellectual disabilit* OR mental retard* OR learning disability* OR developmental disabilit*
2. communicat*
3. interact*
4. sever*
5. profound
6. understand*
7. comprehen*
8. interpret*

A sampling frame was established and inclusion/exclusion criteria were developed to differentiate between pertinent and extraneous information in the data extraction stage. As earlier discussed (para. 2.4), the term severe/profound intellectual disability is adopted in this study to be inclusive of individuals described using the variety of terms ‘severe’, ‘profound’, ‘pervasive’, ‘complex’,

‘significant’ and ‘multiple’ as well as ‘learning disability’, ‘intellectual disability’ or ‘developmental disability’. This review included documents that uses any combination of these terms. The terminology used by referenced authors is maintained. Otherwise, severe/profound intellectual disability is used. Additionally, studies were not limited by age range or life stage of participants. Therefore, studies relating to both adults and children are included. Studies were included if they related to

1. the perspective/experiences of the person with severe/profound intellectual disability and/or their communication partners
2. the substantive area of communication/interactions with people with severe/profound intellectual disability
3. a specific aspect of communication/interaction with people with severe/profound intellectual disability

Studies were excluded if they…

1. were not primary research
2. were prevalence/methodological studies
3. related to mild/moderate intellectual disability
4. related to persons without intellectual disability
5. related to interactions that do not involve persons with severe and/or profound intellectual disability

6.2.2 Stage 2: Literature Search

As per stage 2 of Whittemore and Knafl's (2005) method, databases were searched to identify relevant literature. A bi-directional citation chase of the included literature was subsequently carried out. This section details the process for identifying research included in the final review.

Initially, a search of CINAHL Plus with Full Text using sixteen keyword combinations (Appendix XI) yielded 1134 results. This database has an extensive collection of journals relating to nursing and allied health professions. It provides access to papers from 1937. Removal of duplicates and application of the inclusion/exclusion criteria by title screening and abstract screening refined the article list to 54. Some duplicates were removed if identified at title screening stage. Application of the inclusion/exclusion criteria on reading the studies led to the exclusion of a further 21 articles. Thirty-three studies were included in the final review from this search.

Social Science Premium Collection and Education Collection, which includes ERIC, was searched (Appendix XII) to source literature beyond health-related fields such as education and counselling. Forty-four articles from this search were screened using the inclusion/exclusion criteria. Ultimately, seven articles were selected for inclusion.

Linguistic Collection (Appendix XIII) was also searched. This database combines Linguistics and Language Behaviour Abstracts, Linguistics Database and Proquest.

Many articles returned were excluded due to irrelevance. There appeared to be limited resources relating to severe/profound intellectual disability specifically. Many results related to specific learning disabilities such as dyslexia or attention disorders. A large number of results were returned on some searches. Therefore, the following limiters were used: Last 5 years, peer reviewed, English language. Notably, this database returned the same results for combination searches involving the keywords 'severe' and 'profound'. Therefore, searches with combinations of keyword 5: profound are not included in the table at Appendix XIII. As this was the third database searched, there were many duplicates to the previous searches. Therefore, this search only returned 1 article for inclusion.

Lastly, Scopus was searched as the largest abstract and citation database of peer-reviewed literature (Appendix XIV). All sixteen keyword search combinations were used in this database. However, due to the scale of results, the keyword searches were limited to 'TITLE, ABSTRACT and KEYWORD'. Nine articles were identified on title screening. Removal of duplicates and application of the inclusion/exclusion criteria resulted in no new publications from this database.

Nine of the sixteen combination searches in Social Science Premium Collection and Education Collection, six in Linguistic Collection and eleven in Scopus returned no new results. Therefore, no further databases were searched. This part of the literature search identified forty-one papers for inclusion.

Whittemore and Knafl (2005) recommend analysis of the retrieved reports to identify further pertinent literature. A bi-directional citation chase was completed by screening the reference lists of articles, and using the UCC Library OneSearch "cites/cited by" function and Google Scholar 'cited by' option. According to Hinde and Spackman (2015), this approach is a method that enables identification of published works of relevance that Boolean logic searches do not return. This search identified a further 66 studies deemed suitable for inclusion in the review. Many of these were research studies that were integrated with the review from the database search. Other commentary or discussion papers were used to bolster discussions or provide alternative positions in debated issues. Seminal studies such as Parten (1932) and Maslow (1943) were included due to their identifiable links to specific aspects of the discussion. In total this integrative review comprises 110 papers.

6.2.3 Stage 3: Data Evaluation

In keeping with Whittemore and Knafl's (2005) process, the methodology of each study was reviewed to assess quality. This assessment helped to explain differences in study findings. It distinguished the sometimes subtle differences in study aims and subsequent findings. About half of the included studies adopted a quantitative approach. Three expert commentaries were included. The remaining papers were qualitative including case studies and phenomenological studies as well as Grounded Theory approaches. All included research studies obtained ethical approval and transparently reported the study methods and findings.

Research methods were in keeping with the adopted methodology unless otherwise explained and justified. Limitations of included studies were acknowledged and considered in this review.

The majority of studies were European or Australian. Three papers reported from two studies undertaken in Ireland. A considerable proportion of studies relating to this area are from Europe, namely the Netherlands, Belgium, Germany and the UK. Studies were also sourced from the US, Israel and Malaysia. The cultural context of each of these regions was an important factor to consider when evaluating the studies as study participants and study sites reflected the living arrangements of and service provision to people with intellectual disability. For example, European studies tended to involve both families and paid support staff either from day services or supported living which reflects the service model of community-based living supported by intellectual disability specific service providers. Australian studies had strong family representation reflective of the Individual Support Package service structure. Studies from countries with more institutional based service provision tended to have more paid staff as participants.

There was a broad spectrum of contexts studied including health, social care and education fields. Nurses' perspectives were under-represented. However, the three Irish papers included registered nurses in intellectual disability. This is indicative of the unique role of intellectual disability/learning disability nursing in Ireland and the UK.

6.2.4 Stage 4: Data Analysis

In order to coherently and accurately synthesise the selected articles, each was read, and findings were categorised and coded in accordance with the findings of the Theory of Reconciling Communication Repertoires. The studies were compared and contrasted to provide a thorough and in-depth analysis of the current evidence, cognisant of the evaluation at stage 3. The transparency of reporting study methods and findings enabled informed comparison of studies and identification of the reasons for inconsistencies or differences in findings.

6.2.5 Stage 5: Presentation-Reporting the Conclusions

The remainder of this chapter presents this integrative review and situates the Theory of Reconciling Communication Repertoires in the current body of evidence. It is structured along the core and sub-core categories of the theory.

6.3 The Theory of Reconciling Communication Repertoires and Existing Knowledge

As previously mentioned, the Theory of Reconciling Communication Repertoires weaves discrete research areas into a unified theory that explains the processes and strategies people use to navigate interactions involving people with severe/profound intellectual disability. Such comprehensive exploration of the interaction as a whole is limited in the literature. This integrative literature review positions the Theory of Reconciling Communication Repertoires in current and seminal literature. Findings from the current study and others are discussed under

the concepts from the Theory of Reconciling Communication Repertoires which are communication repertoires, motivation to interact, connectedness, reciprocal engaging, understanding and confusion resolution.

6.3.1 Communication Repertoires

The Theory of Reconciling Communication Repertoires recognises that both parties to an interaction use the same processes to interact but differ in relation to the breadth of their respective communication repertoires. This extends Griffiths and Smith (2017 p.113) assertion that one of the most important ideas to emerge from their study is that people with severe/profound intellectual disability can and do communicate and their communication is comprehendible and interpretable. Similarly, Cascella (2005) found that adults with profound intellectual disabilities have communication skills that enable them to affect their environment, indicate choice and express needs. It was identified that the majority of participants used up to twelve communication forms (Cascella 2005). Reciprocity, despite differences in communication repertoires was also discussed by Bunning et al. (2013) in a study carried out in an educational setting with children. This in-depth, observational study examined the communication interface between students aged 11-14 years with profound intellectual and multiple disabilities and educational staff in the UK. Bunning et al. (2013) found that, despite their severely limited communication repertoire, students were able to contribute to the interactions. However, significant differences were found across several measures with staff dominating the interactions.

The work of Griffiths and Smith (2017; 2016) merits particular attention when considering the Theory of Reconciling Communication Repertoires in the context of existing literature. The current and Griffiths and Smith (2017; 2016) studies observed interactions between adults with severe and profound intellectual and multiple disabilities and their communication partners. However, the present study took the additional step of examining how understanding is attempted, achieved and/or managed. Furthermore, the present study adopted a Classic Grounded Theory methodology from the outset and adhered to it through each stage of the research. Griffiths and Smith (2016) only used Classic Grounded Theory data analysis methods. Theoretical sampling was undertaken in the current study to account for diversity of physical, intellectual and communication ability as well as relationship type i.e. family, friend or professional. Griffiths and Smith (2016) used purposive sampling to recruit two participants with differing physical and communication abilities but only observed interactions with one professional communication partner over one hour each. The present study collected data from three persons with intellectual disability and nineteen people with whom they interact. One hundred and twenty-one interactions were identified although data saturation was reached after analysing forty-five. Additionally, both this study and Griffiths and Smith (2016) used video recordings and field notes to collect and record data. This study interviewed communication partners to offer further insight into the interactions.

Griffiths and Smith (2017; 2016) put forward the Theory of Attuning relating to interactions with people with severe/profound intellectual disability. They state it is a bidirectional, dyadic communication process that calibrates and regulates how individuals respond to each other and each other's behaviours (Griffiths and Smith 2017; 2016). The Theory of Reconciling Communication Repertoires builds on the Theory of Attuning by recognising the strategies adopted to navigate the interaction and accounting for the concept of understanding. In summary, this present study and Griffiths and Smith (2017; 2016) have adopted similar and distinguishing methods that strengthens common and explains differing findings.

Both studies agree that the difference in breadth of communication repertoires is the single factor that distinguishes this type of interaction from others and has most influence on navigating each stage of the interaction. Griffiths and Smith (2016 p. 124) describe the difference as a '*communication gulf*' and highlight the resultant high frequency of misunderstanding in interactions, concurring with the present study. The literature agrees that the impact of the repertoire differential is significant. The Theory of Reconciling Communication Repertoires goes further by explaining how this gulf is managed.

6.3.1.1 Reconciling Communication Repertoires

The gulf or disparity between repertoires requires both parties to find a common 'space' in which to interact. Griffiths and Smith (2016) use the term calibration to describe this attuning process. They (2016 p. 131) describe attuning as a process

that regulates how a person engages in the interaction by reaching a '*common purpose*, *aligning'* or finding a communication space. Neerinckx and Maes (2016 p.574) discuss '*harmonization among behaviours'* in relation to the two-way process of finding joint attention. Joint attention behaviours coordinate attention between interaction partners in relation to objects or events, or to share awareness of the objects or events (Dawson et al. 2002; Mundy et al. 1986). Griffiths and Smith (2016) and Neerinckx and Maes (2016) agree that the extent to which this calibration, attuning or harmonisation is achieved determines the quality and success of the interaction.

The present theory refers to the process as *reconciling* to reflect the continuous fluctuations in and need for responsivity to unpredictable variables (e.g. attention, interference, expressive/receptive abilities) throughout the interaction. This study found that a single adjustment is insufficient to lay a foundation for a successful interaction. Rather it is a continuous and dynamic navigation through multiple variables during the entire interaction. Therefore, The Theory of Reconciling Communication Repertoires extends these findings by recognising the unstable and shifting nature of attunement and harmonisation. Furthermore, it illustrates that even if both parties do not reconcile, they can continue to interact (in the context of acquiescence para. 5.10.3). This is important because it demonstrates that interactions can occur in the absence of attunement or harmonisation and the presence of a willingness to reconcile.

The difference in communication repertoires can require a conscious and sometimes significant effort to reconcile repertoires in order to interact. Effort (para. 5.4) was a notably influential factor in the Theory of Reconciling Communication Repertoires.

6.3.1.2 Effort

Reconciling Communication Repertoires is a complex and complicated task for both parties. The effort required to reconcile repertoires, sustain the engagement and reach understanding impacts directly on the nature of interactions. There is consensus in the literature that interactions between people with severe/profound intellectual disability and their communication partners are infrequent (Bunning et al. 2013; Felce et al. 2000; McConkey et al. 1999; Couchman 1996; Golden and Reese 1996; Felce et al., 1991) and brief (Ware 1990). Descriptors like burdensome and hard (Johnson et al. 2012a), complex and difficult (Forster and Iacono 2008), extensive communication support needs (Hughes et al. 2011) and challenging (Griffiths and Smith 2016) are used in the literature. Forster and Iacono (2014) identified effort as being the most frequently occurring quality in interactions being present in 90.6% (58/64) of them. The Theory of Reconciling Communication Repertoires found that effort is a determining factor in the potential for an interaction occurring, its continued maintenance and the likelihood of an attempt to resolve confusion.

Even though the challenge of these interactions is well recognised, discussion of effort and its impact on interactions is limited in the literature. Two studies, Felce and Perry (1995) and Healy and Noonan-Walsh (2007) discussed how the demands of workloads and time constraints mitigated against the development of relationships and/or opportunities for interaction. Participants in Healy and Noonan-Walsh's (2007) study also identified high resident to staff ratios as constraining the time available for interaction. Felce and Perry (1995) suggest that because people with severe/profound intellectual disability are more dependent, staff perform more tasks to support them. This may explain why higher staff: resident ratios do not necessarily translate into increases in interactions (Felce and Perry 1995). Although these studies recognise the demands on carers, effort was not a central focus of either. Felce and Perry (1995) examined the extent of support for ordinary living provided in staffed housing while Healy and Noonan-Walsh (2007) explored communication strategies adopted by staff nurses in a residential centre. Despite not being a central focus of the studies, the influence of effort as presented in the Theory of Reconciling Communication Repertoires emerged as an influential factor.

In the family context, Johnson et al. (2012a) identify that family members persist for longer than paid staff in clarifying communication attempts, trying alternative communication methods and facilitating communication with the persons with intellectual disability. They suggest this is because of a deeper emotional involvement and greater investment in their happiness. Johnson et al (2012a)

adopted a Constructivist Grounded Theory approach to identify the processes involved in positive relationships among six adults with severe intellectual disability. One parent in this study likened the process of communicating with her son to '*playing high stakes charades'* (p.332). Johnson et al. (2012b) published a second paper drawing from this study identifying the types of social interactions adults with severe intellectual disability had with those whom they had positive relationships with. They discuss how short, less intense, undemanding interactions resulted in delight, joy and/or mutual satisfaction such as hanging out, being present and having fun. Brigg et al. (2016) had similar findings in their observational study of four children with profound intellectual and multiple disabilities. They discuss how the children demonstrated interactional capabilities and engaged in a genuinely mutual exchange through laughter, playfulness and mischief. Brigg et al. (2016) acknowledge the effort taken to achieve this recognising that gentleness, patience and repetitiveness are required. It does, however, illustrate that engagement can be supported even when significant differences in interactional repertoires exist.

While the effort required to reconcile repertoires from staff and family is recognised, there is a notable paucity of literature relating to the effort experience of people with severe/profound intellectual disability in interactions not involving Augmentative and Alternative Communication supports. Halle et al. (2004) discuss the extra effort a child with very significantly limited expressive communication repertoires must expend to gain attention and deliver a message. They

acknowledge that additional effort must be considered in relation to motivational value. Summarising earlier work (including Halle and Drasgow 2003; Mace and Roberts 1993; Horner and Billingsley 1988), Halle et al. (2004) identify five factors that determine response efficiency including response effort, immediacy obtaining a desired outcome, consistency of obtaining a desired outcome, quality of outcomes and lastly punishment which describes any outcome that reduces the likelihood of a response. This work (Halle and Drasgow 2003; Mace and Roberts 1993; Horner and Billingsley 1988) examines effort expenditure in the context of response efficiency or outcome in the area of behavioural support. The Theory of Reconciling Communication Repertoires identifies these factors and recognises additional elements that influence the decision to expend effort including time demands, complexity of the message and management of distractions. However, there is agreement that when each of these factors are considered, the ultimate decision to interact is influenced by the value of the motivation to interact and likelihood of successful/beneficial outcomes (para. 5.4), particularly to nurture a sense of belonging.

6.3.2 Motivation to Interact

The sense of belonging, mutual satisfaction and connectedness that comes when such efforts are expended is identified as a key motivator to interactions involving people with severe/profound intellectual disability in this study. The potential of experiencing isolation consequent to short, intermittent interactions as well as difficulties with mutual understanding amplify the motivation to nurture a sense

of belonging. Having a sense of belonging is recognised as a basic human need (Maslow 1943).

6.3.2.1 Nurturing a Sense of Belonging

The Theory of Reconciling Communication Repertoires identifies nurturing a sense of belonging as a major motivator for interactions involving people with severe/profound intellectual disability. Those with narrower communication repertoires experience greater difficulty establishing and maintaining interactions, which is a considerable concern for those in their network. The effort expended to interact stems from concerns around isolation and loneliness (para. 5.5). Subsequently a motivation to nurture a sense of belonging is experienced. This concern has been echoed in the literature over several decades (Robertson et al. 2001; Krauss et al. 1992; Kennedy et al. 1990; Krauss and Erickson 1988) as research identifies that people with severe/profound intellectual disability have few social relationships and these are mostly with family members and paid workers. McLean et al. (1996) identify the characteristic communication difficulties as contributing to this situation.

6.3.2.2 Benefits of Belonging

There is agreement in the literature that the reciprocity experienced in an interaction brings about a sense of esteem and belonging (Johnson et al. 2012a, b; Maslow 1943). Interaction partners in the study by Johnson et al. (2012a) believed that these interactions instilled trust, showed respect, felt good and provided a

sense of security for persons with severe intellectual disability. Bogdan and Taylor (1998) discussed this in relation to recognising humanness. The importance of having a sense of belonging is repeatedly recognised in the literature including as a core dimension of quality of life (Hostyn et al. 2011b; Petry et al. 2005) and foundational in supportive social relationships (Beauchamp and Anderson 2010). Furthermore, these interactions provide the person with opportunity to express themselves and influence their environment. Kamstra et al. (2017) agree with this view and discuss broader benefits including prevention of the negative health effects related to isolation and loneliness, facilitation of social inclusion and wider participation in society. In support of this, studies have shown that close relationships benefit subjective well-being (Karelina and De Vries 2011), increase coping ability (Hartup and Stevens 1997), positively impact mental and physical health (Karelina and De Vries 2011; Umberson and Montez 2010; Cohen 2004; Lincoln 2000) and support cognitive and language development (Canevello and Crocker 2010; Hartup 1989). A narrow communication repertoire can negatively impact on these variables (Griffiths and Smith 2016).

6.3.2.3 Difficulties around Nurturing a Sense of Belonging

Reciprocity however, is noted as unclear and difficult to maintain in these interactions (Johnson et al. 2012a). Griffiths and Smith (2016) discuss how even skilled communicators can be challenged in such interactions particularly in the areas of enrichment and reciprocity. In their Dutch study which analysed the content of individual support plans with respect to the social contacts of people

with profound intellectual and multiple disabilities, Kamstra et al. (2017) found that 41.7% of the plans mentioned difficulties and obstacles to establishing social contacts. Positively, Individual Support Plans for sixty people were analysed and all included information about social contacts. Earlier work by Kamstra et al. (2015), however, identified that informal social networks of people with profound intellectual and multiple disabilities are small, averaging only five informal contact persons per year, of which 80% is a family member. The issues identified by Johnson et al. (2012), Griffiths and Smith (2016) and Kamstra et al. (2017; 2015) reinforce the participants' concerns regarding isolation and loneliness in this present study.

According to Baumeister and Leary (1995), individuals are internally motivated to develop and maintain positive and special relationships with others. Dreyfus (2012) agrees, concluding that such relationships are equally important for someone who does not use speech to communicate. Reassuringly, the Theory of Reconciling Communication Repertoires demonstrates that a sense of belonging can be achieved. Kamstra et al. (2017) also assert that people with severe/profound intellectual disability are capable of building and maintaining meaningful relationships. Furthermore, Vandesande et al. (2019) found that parents believe the development of secure relationships with their children is challenging but possible. Parents in this study reiterated the importance of taking and making time to connect and engage with their children.

According to the Theory of Reconciling Communication Repertoires, a sense of belonging, is achieved through connecting with another person. Connecting is foundational to an interaction. The establishment of a connection determines whether an interaction will even occur. This aspect of the Theory of Reconciling Communication Repertoires will now be explored in relation to existing literature.

6.3.3 Connectedness

The Theory of Reconciling Communication Repertoires sets out a two-stage connection establishment process (para. 5.6); firstly, opportunity seeking and subsequently attention grabbing. Dreyfus (2012 p.257) uses the term *'aligning'* to describe this process. Successful connection is essential as an interaction can only occur in this context. Attention and connectedness are interwoven and being connected is the foundation upon which an interaction takes place. Establishing a connection involves acting strategically to gain the attention of the identified partner on two fronts. Firstly, identifying an opportune moment to attention grab and secondly performing an appropriate attention-grabbing act. Both the person with severe/profound intellectual disability and their communication partner use this process, although the communication repertoire determines the extent to which it can be navigated successfully. This can be a significant challenge regardless of who is attempting to establish the connection as the evidence suggests breakdowns are frequent (Dincer and Erbas 2010).

Over the last number of years, Munde et al. (2015; 2012; 2009a; 2009b) have carried out research relating specifically to attention and alertness among people with profound intellectual disability. The findings of this work and others are now presented in relation to the person with severe/profound intellectual disability as initiator followed by their interaction partner as initiator.

6.3.3.1 Person with Severe/Profound Intellectual Disability as Initiator

Initiation is one of the core problems in interactions for people with severe/profound intellectual disability (Hetzroni and Shalev 2017; Munde and Vlaskamp 2015; Bunning et al. 2013). In their exploratory study of attention processes in interactions between people with profound intellectual disability and staff, Hostyn et al. (2011a) showed that participants with intellectual disability are limited in the extent to which they initiate interactions. Antaki et al. (2017) discuss how strategies typically used to initiate an interaction are not available to this group. Physical disabilities hinder attention-grabbing acts such as waving or touching (Houwen et al. 2014; van der Putten et al. 2005). These findings are in keeping with this study. When theoretical sampling was undertaken to account for physical disability, it was found that as severity of physical disability increases, the communication repertoires narrows. Neerinckx et al. (2014) also highlight low rates of attention-grabbing success among people with profound intellectual and multiple disabilities. These authors suggest this finding may be because these skills are generally learned at a later developmental stage than many people with this disability reach. This Belgian study coded video observations of twenty-eight

support-worker/service-user dyads using partial interval coding. The sample size of twenty-eight participants is noteworthy as many studies in this area have much smaller samples.

It must be recognised that although they experience challenges, people with severe/profound intellectual disability do attempt to initiate interactions and repair connection breakdowns. The evidence suggests that eye contact, gaze shifts (Neerinckx and Maes 2016) and looking (Healy and Noonan-Walsh 2007) are frequently used. More overt indicators may also be used such as withdrawal, excitement or behaviours that challenge (Hostyn et al. 2011a). However, Forster and Iacono (2014) noted that attempts are often subtle, unremarkable, idiosyncratic or open to interpretation. Consequently, there is a reliance on the interaction partner to be sensitive and responsive to the person's initiation attempts. Halle et al. (2004) discuss the issue of responsivity in the context of communication breakdowns. They argue that connection breakdowns are commonplace for people with narrow repertoires and their capacity to repair a breakdown is critical. Non-acknowledgements or a partner not responding to a connection attempt in a reasonable amount of time is particularly difficult.

Forster and Iacono (2008) state this implies a different communication experience for people with severe/profound intellectual disability as they do not experience the same frequency of responses as those without such difficulties. This is not to suggest that only those with severe/profound intellectual disability experience

difficulties establishing a connection. Those with a broader repertoire can experience challenges.

6.3.3.2 Interaction Partner as Initiator

There is discussion in the literature relating to the specific challenge of establishing a connection with persons with severe/profound intellectual disability. Mattie and Kozen (2007) discuss the challenge brought about by biophysical factors associated with this level of intellectual disability. Visual or hearing impairments and slow reactions impede initiation attempts (Brown et al. 2001; Guralnick 1999). This is supported in earlier commentary from Guess et al. (1993) and Arthur (2004) who recognise that many people with severe/profound intellectual disability are not in a state of optimal alertness for engagement. Furthermore, the same attention-grabbing stimulus directed towards a person with severe/profound intellectual disability can result in a broad variety of reactions (Munde et al. 2009a, b). Munde et al. (2012) identified that alertness levels in people with profound intellectual and multiple disabilities changes in waves of about twenty seconds from 'active' to 'passive' alert. A time-window sequential analyses for two minutes following four different stimuli was conducted on video-recordings of twenty-four people with profound intellectual and multiple disabilities during one-to-one interactions with staff. In keeping with the findings of Healy and Noonan-Walsh (2007), Forster and Iacono (2014) and Neerinckx and Maes (2016), Munde et al. (2012) identified that reactions are subtle. This compounds the challenge experienced by staff as they try to interact and provide

activities. A Danish case study by Dammeyer and Køppe (2013) of a boy and his teacher exemplifies this situation. In a two-minute episode, the teacher spends the first thirty seconds trying to establish a connection with the boy by calling his name, gaining eye contact and touching his hands. When this is considered in relation to Munde et al.'s (2012) findings of twenty second waves of alertness, the difficulty of establishing and maintaining connections is evident.

Research involving family interactions has found mixed results. Parents are reported to have similar difficulties to staff. They expressed difficulties gaining and maintaining their son/daughter's attention and wished for more successful ways of connecting (Wilder et al. 2004). In their study of parents' perspectives on the communication skills of their children with severe disabilities, Stephenson and Dowrick (2005) identified inconsistencies in relation to communication between school and home. These challenges do not seem to be reflected in research involving siblings.

More recently, Nijs et al. (2016) found that siblings could support the person in interactions although successful connections were short-lived. This study involved thirteen children and young people with profound intellectual and multiple disabilities, their sibling and a peer with profound intellectual and multiple disabilities. Descriptive, comparative and sequential analyses were conducted on video recordings of interactions. It was concluded that persons with profound intellectual and multiple disabilities interacted with siblings more than peers as it

is more motivating and encouraging. Furthermore, siblings mainly used non-verbal attention-grabbing behaviours such as physical support. Verbal attempts were simple comments and vocalisations. These types of attention grabs are closer to the communication repertoire of persons with severe/profound intellectual disability. Therefore, it supports the finding that when repertoires are reconciled, interactions can be successful and reciprocal engagement can occur.

6.3.4 Reciprocal Engaging

In the Theory of Reconciling Communication Repertoires, reciprocal engaging refers to the interaction that occurs on the foundation of the established connection (para. 5.8). It is the point in the interpersonal process where both people attend to each other or a common activity. The parties navigate the course of their interaction by sharing activities, using established routines or conversations while concurrently maintaining the connection

6.3.4.1 Activity Participation

Participating in activities together was one of the most likely methods of achieving understanding in the Theory of Reconciling Communication Repertoires. Phelvin (2013) cautions that identification of activities the person enjoys may be informed by subjective interpretations and so should be evaluated on a continual basis. Across the literature, sharing activities is referred to in different ways such as '*being with*' (Firth et al. 2010 p. 58), hanging out (Johnson et al. 2012b) and spending time together (Forster and Iacono 2008). Firth et al (2010 p. 58) describes

the scenario as '*symmetrical sociability*'. Dreyfus (2012 p.260) describes this type of activity as a '*cherished experience*' where the person with intellectual disability and their interaction partner can share joy. The experience of participating together in an activity fulfils the motivation of nurturing a sense of belonging.

Additionally, participants in the study by Forster and Iacono (2008) believed that participating in activities increased their own communication skills with the person as they could learn their particular/unique communication methods. Such knowledge makes reconciling repertoires easier. Less effort is required to interact and the likelihood of achieving understanding and nurturing a sense of belonging is increased.

Johnson et al. (2012a) discuss how sharing activities resulted in mutually enjoyable interactions and emotional reciprocity. As outlined earlier, these researchers aimed to identify the processes involved in positive interactions with adults with severe intellectual disability. In their follow up publication to this study, Johnson et al. (2012b p.330) highlight the importance of '*hanging out'* and particularly laughing and comedy. Such interactions are undemanding and nurture a sense of belonging. Brigg et al. (2016) assert a similar stance suggesting that laughter and involvement in humorous interactions enable children to express themselves and develop relationships. Johnson et al. (2012a) agree and stress the importance of sharing activities that do not rely on speech. It is acknowledged that such activities require imagination from interaction partners to create an opportunity for fun and

joking that does not rely on spoken language. This study found that this makes achievement of understanding more likely (para. 5.8.1).

The nature of these activities, as outlined in The Theory of Reconciling Communication Repertoires is reflective of the parallel and associative categories in Parten's (1932) Theory of Social Participation. Parten (1932) observed forty-two children (without intellectual disability) in a nursery school over a school year from October to June. She identified several categories of social participation in play activities, but the aforementioned parallel and associative play resonate with the present study. Both categories tend to be associated with earlier stages of development. Therefore, the emergence of this tentative link between Parten's work and the present study is interesting from a developmental perspective.

Parten defined parallel activities as those where children play independently but the activity is such that they are alongside others. The children play with similar toys but do not influence or modify each other's activity. The children play '*beside rather than with´* their peers (Parten 1932 p. 250) and are unaffected by the presence or absence of each other. Parten used play around a sandbox to demonstrate. The children played independently but in close proximity. Associative play involves children playing with each other in a common activity (Parten 1932). There is an interaction or agreement about the activity and an exchange of props and toys. This is more interactive than parallel play, but an element of independence remains. Using parallel and associative type activities is

identified as a strategy likely to be successful in interactions motivated by a desire to nurture a sense of belonging in the Theory of Reconciling Communication Repertoires. A sense of belonging and inclusion is created by being present with others and sharing activities. Understanding the activity or expectations is not a prerequisite as each person can participate independently but, most importantly, together.

6.3.4.2 Routine

The second type of reciprocal engagement identified in the Theory of Reconciling Communication Repertoires is routine. Understanding is achieved in the predictability of routines. This type of interaction is acknowledged by some researchers in the literature although not to any great extent. Griffiths and Smith (2016) refer to this as learned understanding of patterns. Similarly, Bunning et al. (2013) found teachers used preparatory moves to cue children with severe to profound and multiple intellectual disability to attend and prepare for participation in activities. Essentially, teachers used consistent and thus predictable behaviours (routines) to communicate with and involve the children in class activities. Bruce and Vargas (2007) found that familiar routines facilitate intentional communication and interaction. Cascella (2004) found that individuals with significant intellectual disability appeared to have relatively stronger skills for comprehension of single-step in-context directions and recognise that specific and tangible objects represent certain routines. Cascella (2004) measured the receptive communication skills of fourteen adults with significant intellectual

disability living in community settings in the US. The findings relating to contextual and artefact clues informing the interpretations is in keeping with the Theory of Reconciling Communication Repertoires. However, this theory provides further detail regarding the routine related factors that support understanding including pattern consistency and predictability and experiential frequency and familiarity (Figure 5.10).

Johnson et al. (2012a) provide some detail relating to routine as a context for social interactions. They noted the personal and idiosyncratic nature of such interactions. Routine interactions were a repeated physical and/or vocal interaction that occurred in a pleasurable way. The present study identified routine conversations as a type of interaction that is regularly used. It found they are a particularly effective way of interacting to achieve understanding. This makes these unique from other types of conversation. Dreyfus (2012) provides an example of such conversation in her case study. The person with severe intellectual disability uses an idiosyncratic sign to express that he has a sore finger even though it isn't sore. Once he initiates this interaction, he expects the partner to sympathise with his fictitious predicament. Both know his finger is not sore, but the routine conversation provides a bonding opportunity.

Routine conversations also emerged in a case study undertaken by Johnson et al. (2010). This case study explored the social interactions of Sandra, a young lady with severe intellectual disability. Sandra's interaction partners were able to

describe interactions and conversations in step by step detail, identifying what Sandra expected them to do or say and predicting her responses. Johnson et al. (2010) also identified social bonding or closeness as the purpose of this type of interaction.

The power of routines to enable understanding needs to be maximised to support people with severe/profound intellectual disability to understand issues or events in their lives. Opportunities to role play or simulate situations supports the person and affords them time to process, explore and understand abstract concepts or situations at an individually appropriate pace.

6.3.4.3 Conversations

Conversations in the context of the Theory of Reconciling Communication Repertoires (para. 5.8.2), are generally two-way exchanges that incorporate both verbal and non-verbal communication methods, where the verbal includes both idiosyncratic and conventional language.

These were found to be the least successful methods of achieving understanding. The verbal and symbolic element of conversations tend to be problematic for people with severe/profound intellectual disability. Hogg et al. (2001) asserts that verbal communication is not typically in their communication repertoire. There is mostly a reliance on gestures, facial expressions, body movements and vocalisations (Stephenson and Dowrick 2005). Atkin and Perlman Lorch (2016) go a step further stating that people with profound intellectual disability are unable

to produce conventional gestures or vocalisations to communicate, instead using subtle, fleeting behaviours that can be difficult to observe, identify and capture.

These are the same issues previously discussed in relation to initiating an interaction or connectedness. However, even when attention is gained the subtle nature of communicating continues to be problematic. Grove et al. (1999) agree acknowledging that the communication attempt may be undetected by others or its meaning unrecognised. Bunning et al. (2013) found that a high proportion of student communicative behaviours were undetected by adults with less than 10% being acknowledged communicatively.

Despite this well documented issue, interactions with persons with severe/profound intellectual disability tend to involve a disproportionate amount of symbolic and/or spoken communication considering this group tend to communicate at a pre- or proto-symbolic developmental stage (Hostyn and Maes 2009; Goldbart 1994). Bunning et al. (2013), for example, found that teachers generally favoured speech in their interactions with students. Foreman et al. (2007) and Healy and Noonan-Walsh (2007) both reported discrepancies between what is known to be an effective interaction method and the method that are practiced or used. Although participants were aware of the most effective communication approached, these were not necessarily the methods used in practice. One suggested explanation for this is that use of verbal communication is underestimated while use of non-verbal communication is overestimated by

communication partners (Bradshaw 2001). The present study also found communication partners use symbolic communication methods which tended to be less successful in achieving understanding. This is not to suggest that the spoken word should not be used in such interactions. Rather, the extent to which it is used is disproportionate to the frequency with which it is effective or understood. McLean and McLean (1999) argue that failure to adjust communication methods adds to existing communication difficulties.

The combination of the repertoire gulf (Griffiths and Smith 2016) and the infrequency with which it is reconciled explains the rarity of understanding being achieved in these types of interactions. This study found that understanding is assumed as achieved more often than it actually is. While the achievement of understanding is a recognised difficulty in these interactions, this finding suggests that it is achieved less frequently than realised.

6.3.5 Understanding

The Theory of Reconciling Communication Repertoires makes the distinction that understanding is a phenomenon experienced by one party to the interaction and appraised by the other. This is important as it recognises both perspectives in uncovering the nuances of achieving understanding in these encounters. The impact of the breadth of the communication repertoire is considerable at this stage of the interaction. Therefore, the following discussion presents the literature in relation to understanding as an experience and understanding as appraised

from the perspectives of persons with severe/profound intellectual disability and their interaction partner.

6.3.5.1 Experiencing Understanding

The Theory of Reconciling Communication Repertoires presents a typology of understanding as an experience (Table 5.1). Griffiths and Smith (2016) suggest that rather than a typology, interpretations exist along a continuum from fully shared interpretation to lack of any shared interpretation. The typology offered in the Theory of Reconciling Communication Repertoires delineates a further three states from understanding through oblivious understanding, cognisant confusion and oblivious misunderstanding to no understanding. These are indicated by accuracy of the interpretation and awareness of this accuracy. Regardless of which position is preferred, the achievement of understanding is one aspect of interpersonal communication that continues to see debate and discussion in the literature.

6.3.5.1.1 Understanding Experience of the Person with Severe/Profound Intellectual Disability

The nature of a severe/profound intellectual disability makes gaining the person's experience of understanding others quite difficult. Therefore, such discussion tends to be developmentally focussed. It does not extend to any great degree beyond the comprehension expectations of early developmental stages. Nakken and Vlaskamp (2007) discuss how people with profound intellectual disability have

difficulty understanding others' communication because of the nature of their disability. This difficulty is evident in the low rates at which understanding seems to be achieved.

During data analysis in the present study, it was clear that participants with intellectual disability correctly understand some messages or elements therein. However, their response is appraised as misunderstanding or not understanding. This was an inaccurate appraisal. It became particularly evident when interactions were examined in three second intervals for both verbal and non-verbal communication methods. When multiple communication methods are used (e.g. speech, facial expressions and gestures) the person with intellectual disability may appropriately respond to one method but this does not fit with the intended message. This occurs when interaction partners are incongruent in the communicative methods they use. It exemplifies McLean and McLean's (1999) assertion that failure to adjust communication methods adds to existing communication difficulties.

6.3.5.1.2 Understanding Experience of Interaction Partner

People without a disability also experience difficulty due to the idiosyncratic and pre-symbolic expressive methods used by the person with severe/profound intellectual disability (Grove et al. 1999). Communicative behaviour is often ambiguous (Halle et al. 2004) or the person may use the same methods to express different messages (Dreyfus 2012). Difficulties consequent to unconventional

communication methods are considered a significant barrier to establishing understanding (Hetzroni and Shalev 2017; Atkin and Perlman Lorch 2016; Dammeyer and Køppe 2013). Interpretations are drawn from very subtle communication attempts (von Tetzchner and Jensen 1999). Forster and Iacono (2008) found that staff frequently ascribe meaning to rather than understand the expressive communicative behaviours of those with severe/profound intellectual disability. Ascription of meaning based on best guess has been suggested by others (Halle et al. 2004; Olsson et al. 2004; Grove et al. 1999; Detheridge 1997). Porter et al. (2001) use the term inference and discuss the difficulties and risks of this strategy. This can cause interaction partners to question the accuracy of their interpretations (Koski et al. 2010) as there can be a high degree of uncertainty (Blain-Moraes and Chau 2012).

Hogg et al. (2001) examined this issue specifically. This study aimed to examine the extent to which a staff group agreed on an interpretation of communication by adults with profound intellectual and multiple disabilities. Twenty-four staff rated twelve video samples of four adults with profound intellectual and multiple disabilities they were familiar with, in relation to interpretation of an expression and their confidence in their interpretation. Hogg et al. (2001) found considerable individual variation in interpretations but a good level of consistency across observers. The researchers concluded that, over time, communication partners gather and use information about the person with intellectual disability to inform their interpretations. Interpretation of a behaviour may be influenced by

knowledge of the person's typical preferences (Hogg et al. 2001). Ware (1997) cautions that if there is variation in interpretation of the person's behaviour, they are likely to receive inconsistent responses when they communicate. This will exacerbate any confusion experienced in the interaction.

In keeping with Nijs et al. (2016), siblings in a study by Luijkx et al. (2016) report that they can understand what their brother or sister wants, means or feels. However, they also referred to times when they have difficulty understanding. This Dutch study used a qualitative descriptive design to describe the positive and negative aspects of having a sibling with profound intellectual and multiple disabilities from the child's perspective. Eighteen children aged six to thirteen years participated. Some participants discussed how they would like if their brother or sister could understand them more. Despite this, the study found that siblings are able to understand their brother or sister's behaviour and communicative intentions. Therefore, Luijkx et al. (2016) recommended more detailed study of the knowledge siblings possess about interacting with their brother or sister with severe/profound intellectual disability.

Research has identified that familiarity with and individualised knowledge of persons and their communication methods can increase the likelihood of reaching understanding. Petry and Maes (2006) undertook observational analysis of video data to identify expressions of pleasure and displeasure by persons with profound and multiple disabilities. Six participants with intellectual disabilities were

recruited. Their caregivers (parents and paid support staff) also completed a questionnaire. Petry and Maes (2006) found that caregivers gradually accumulate knowledge in recognising the person's individual and often subtle communication methods. These researchers also found that caregivers who were more familiar with the person with intellectual disability were more selective in identifying behavioural signals that could be communicative and noticing intentional communication acts than an independent observer. However, nonfamiliar respondents noticed more socially motivated behaviours which, Petry and Maes (2006) concluded, pointed to their open-mindedness. Singh et al. (2015) undertook an observational study of interaction of pre-symbolic children with developmental disabilities with their mothers and siblings in Malaysia. It was found that mothers and siblings adapted and familiarised themselves with the child's (with intellectual disability) communication methods through frequent interactions. This enabled them to identify and respond to communicative behaviours. This concept of familiarity is recognised in the literature as supporting understanding (Singh et al. 2015; Martin et al. 2012).

Each of the issues identified thus far emerged in the Theory of Reconciling Communication Repertoires. Idiosyncratic communication makes understanding difficult, but familiarity increases the likelihood of its achievement. Familiarity through routines and routine conversations supported understanding for both the person with intellectual disability and their interaction partners. However,

understanding as an experience is only one side of two-pronged concept. Understanding as appraised is the second property of this concept.

6.3.5.2 Appraising Understanding

With regard to understanding appraised as achieved or not, Griffiths and Smith (2016) argue that interpretations cannot be categorised as correct or incorrect. In the context of the Theory of Reconciling Communication Repertoires, understanding is appraised as achieved or not for the purposes of resolving confusion. It is the sender's judgement of whether or not a message has been understood as intended (para. 5.9.2). This appraisal determines whether the interaction will proceed to the confusion resolution stage or not.

6.3.5.2.1 Interaction Partner Appraising Understanding

It is well established in the literature that interaction partners have difficulty appraising the comprehension ability of persons with severe/profound intellectual disability. Banat et al. (2002) investigated carers' perceptions of the verbal comprehension ability of adults with severe intellectual disabilities. This study found that staff misjudge comprehension ability by either over or under-estimation. Similar findings have been reported elsewhere although the sample in these studies included the full range of intellectual disabilities (McConkey et al. 1999; Purcell et al. 1999; Bartlett and Bunning 1997; van der Gaag 1989). Banat et al.'s (2002) findings raise questions around the earlier discussion of the influence

of familiarity. It was found that more experienced staff were not more likely to accurately judge comprehension ability.

Essentially, this may indicate that the person with severe/profound intellectual disability's capabilities are largely unknown to those in their network. The implications of this are considerable from their perspective of feeling or being understood.

6.3.5.2.2 Person with Severe/Profound Intellectual Disability Appraising Experience

Hetzroni and Shalev (2017) argue that persons with severe/profound intellectual disability are more likely to develop learned helplessness due to the difficulties their interaction partners have in understanding them. According to Carter (2002), learned helplessness develops when there is limited correspondence between the persons' communication attempt and the response they receive. This is in keeping with the methods used to appraise understanding as per the Theory of Reconciling Communication Repertoires. The response is judged in terms of the extent to which it fits with the original message.

Others have argued that these experiences result in a learned passivity or lack of desire to communicate (Wilkinson 1994). Detheridge (1997) discusses how individuals may not understand how they can influence their environment due to inexperience or difficulty exerting such influence. Kiernan et al. (1987) described several prerequisites to communication; one being the belief that communication

will be responded to. Repeated failure of gaining desired responses, any response or being understood may decrease the likelihood that the person will attempt to express themselves (Carter and Iacono 2002). Furthermore, Singh et al. (2015) argue that excessive directiveness by mothers and siblings suppresses children's initiations and results in passivity. Compounding this further, Detheridge (1997) and Antaki et al. (2017) discuss how the extended time a person with severe/profound intellectual disability takes to express themselves, coupled with their interaction partners impatience and/or time demands deters the person from attempting to communicate. Again, this can contribute to passivity.

The evidence as discussed above suggests that the experience of persons with severe/profound intellectual disability of being understood is negative. A downward spiral of expressing, not being responded to or understood, becoming demoralised or passive results in fewer communication attempts in a context where interactions are already short and infrequent. Inevitably, this curtails the potential for communication skill development or repertoire expansion through experiential learning. This type of behaviour emerged to some extent in the Theory of Reconciling Communication Repertoires. Disconnecting or ending the interaction is one strategy used when understanding is appraised as not achieved. However, this strategy is used by both parties to the interaction; not just the person with severe/profound intellectual disability. This raises the question of why people with intellectual disability are described as passive while their interaction partners are not? It is recognised that one of the reasons for infrequent and short

interactions is the difficulty both individuals have connecting with one another; an issue frequently cited in the literature (Stephenson and Dowrick 2005; Harwood et al. 2002). This question has been addressed in the literature in relation to persons with severe/profound intellectual disability. It merits attention and exploration from the perspective of their interaction partners.

It must be acknowledged that one reason why a person decides to end the interaction relates to the availability of strategies in the communication repertoire to resolve confusion. In other words, if the strategies or skills to resolve the misunderstanding are not available a decision is made to end the interaction. However, this is just one strategy that is used to address misunderstandings or resolve confusion.

6.3.6 Confusion Resolution

Confusion resolution is a stage of the Theory of Reconciling Communication Repertoires that is only necessary when understanding is appraised as not achieved (para. 5.10). Any attempt to resolve confusion requires the availability of suitable strategies in the communication repertoire. Hetzroni and Shalev (2017 p.439) refer to this as having communicative competence or ability *'to both understand the mechanism of the communication breakdown and to devise a repair strategy with the required modifications'*. Halle et al. (2004) agree acknowledging the additional cognitive and communication demands of this situation. As with the present study, Weiner (2005) and Dincer and Erbas (2010)

showed that people with limited communication repertoires can resolve confusion and address misunderstanding. Strategies to support the achievement of understanding are discussed under the subthemes repetition and revision. However, the Theory of Reconciling Communication Repertoires identifies that action may not be taken to resolve the confusion. As discussed above, the person may choose to end the interaction and thus not address the misunderstanding. This issue is discussed under the subtheme of resignation. Secondly, they may choose to continue the interaction but not resolve the confusion by acquiescing to the misunderstanding.

6.3.6.1 Resignation

Hetzroni and Shalev (2017) undertook a quantitative study examining the repair strategies used by students with severe intellectual disabilities in their interactions in an Israeli school. A five-category coding system informed by the literature on communication breakdowns was developed for this study. One of these categories, communication arrest, is a non-repair strategy that involves termination of the interaction. This strategy has been found in other studies (Dincer and Erbas 2010; Meadan et al. 2006; Ohtake et al. 2005). It was used in 12.5% of communication breakdowns in Hetzroni and Shalev's (2017) study. These authors suggest this strategy may be used in the absence of other repair strategies. They also propose it could be a result of limited support provision around attempting a repair and/or concluding that the effort is futile. This reinforces the above discussion around passivity. Halle et al. (2004) concur stating

that the motivational value of a communication attempt may be considered insufficient to merit a repair attempt. This is in keeping with the findings of this study. Participants decide to end the interaction when strategies to resolve confusion are not available in their communication repertoire and/or the motivational value for the interaction is low. However, while Hetzroni and Shalev (2017) only identified one non-repair strategy, the Theory of Reconciling Communication Repertoires distinguishes another, acquiescence.

6.3.6.2 Acquiescence

As discussed (para. 5.10.3) acquiescence is a conscious and deliberate decision to continue to interact in the context of misunderstanding/no understanding in order to remain connected and interactive. This facilitates fulfilment of the original motivation to create a sense of connectedness and belonging. One person will acquiesce and reconcile to the receptive repertoire of the other, maintaining the connection and engagement. There is a paucity of research relating to this strategy. Hetzroni and Shalev (2017) discuss 'topic shift' but this does not correspond with the nature of acquiescence. With a topic shift, the interaction partner remains attentive and continues the interaction but their response results in further confusion (Meaden et al. 2006). Acquiescence, on the other hand, involves remaining attentive and continuing the interaction but recognising the misunderstanding and choosing to not address it. Therefore, instead of exacerbating confusion (as in topic shifts), the person recognises the misunderstanding and acquiesces to it. This indicates a preference to interact in a

context of misunderstanding rather than not interact at all; highlighting the motivational strength to nurture a sense of belonging.

Research on acquiescence in this context is scant. It emerged as a frequently used strategy in interactions in this study as it was a means of successfully sustaining interactions. It is unique in that there is generally a desire to understand and be understood in interpersonal interactions. However, understanding is not prioritised if this strategy is used. Interacting, connectedness and bonding are prioritised. While it is a non-repair strategy, it is also an interaction sustaining strategy. Other strategies that sustain the interaction but attempt to resolve confusion include repetition and revision.

6.3.6.3 Repetition

In keeping with previous studies (Brady et al. 1995; Erbas 2005; Ohtake et al. 2005), the present study and Hetzroni and Shalev's (2017) study identified repetition as a commonly used repair strategy. According to Halle et al. (2004) repetitions are an exact reiteration of an expression and a basic strategy evident in early language development. As such, it is an effective strategy for those with severe/profound intellectual disability particularly. Hetzroni and Shalev (2017) argue that the dominance of repetition may be due to difficulties identifying the cause of misunderstanding in interactions. Concurring with this study, Halle et al. (2004) and Dreyfus (2012) discuss how a repetition may include an increase in

intensity, force and/or emotion. This informs the communication partner that their interpretation is appraised as inaccurate.

The Theory of Reconciling Communication Repertoires explains that while this strategy is effective in an emphatic sense, it is problematic in that the original message was misunderstood so repeating it does not offer further detail or clues that may support understanding. In these circumstances, a revision or modification may be required.

6.3.6.4 Revision/Modification

Halle et al. (2004) define modifications as any change to the original expressive methods. Johnson et al. (2012a) discuss how interaction partners adjust their message or communication method to connect more effectively with those with profound intellectual disability. Methods like simplifying the message, allowing extra time, using routine and phrasing questions to yes/no format were identified (Johnson et al 2012a). Bunning et al (2013) reported that teachers adopted a directive and instructional style of communicating that enabled students to respond and contribute despite their restricted repertoire such as smiling, laughing and other vocal behaviour. However, in their study, Johnson et al (2012a) noticed a difference in communication adjustment across partner groups. For example, family members rarely used augmentative strategies, but most paid staff used basic strategies such as objects of reference (van Dijk 1989), key word signing (Windsor and Fristoe 1991) and pictures. Similarly, Bunning et al. (2013) found that

teachers demonstrated flexibility in the range of modalities they utilised to communicate with and involve students in class such as touch, singing and objects; adapting to the multi-sensory experience of communicating. However, they noted the importance of having knowledge of the person's repertoire in order to ascribe meaning to their communicative acts.

Although the need to adjust interaction method is well recognised in the literature, implementation of this knowledge appears to be problematic. It has been found that even if staff adjust their communication method, it still may not fall within the ability of the person with intellectual disability (Bradshaw 2001); they do not reconcile repertoires. Healy and Noonan-Walsh (2007) also identified that communication strategies were mismatched to the needs of persons with severe/profound intellectual disability. Furthermore, a mismatch was noted between what participants reported in the interview stage and what they enacted in the observation stages of the study. Participants discussed the importance of making adaptations such as speaking slower, repeating, rephrasing, using simpler language, body language adjustments but these were not observed by the researchers. This could indicate that while adjustment and adaptation strategies are known, implementation of these is an entirely different matter. Despite these findings, such strategies were observed in this study. Some participants adjusted successfully, some less so but, as above, some not at all.

In their study, Hetzroni and Shalev (2017) found that students used substitution, addition and reduction strategies. Substitution refer to replacing all or most of the original expressive methods (Dincer and Erbas 2010). It requires a greater communication repertoire and can require greater cognitive effort. While repetition and substitution were used more, addition and reduction strategies were in the students' repertoire (Hetzroni and Shalev 2017).

In the course of data analysis, Hetzroni and Shalev (2017) noticed another strategy used by students; 'partner shift'. This involves the student seeking out a new partner to interact with. While the interaction with the original partner terminates, it continues with a new partner. As the original interaction was unsuccessful, the student turns to a new partner in an effort to fulfil the interaction motivation. This is an interesting finding that once again demonstrates the ability of those with intellectual disability to resolve confusion.

To summarise, confusion resolution is a stage in the interaction that requires further effort and adds interactional and cognitive demands for both parties. It incorporates non-repair and repair strategies that can be used to sustain the interaction. Although the strategies identified in the Theory of Reconciling Communication Repertoires have been noted in the literature, acquiescence has received little attention. Furthermore, it is evident that these strategies are available to both people with severe/profound intellectual disability and their

interaction partners. This is an important consideration in terms of expectations and recognition of potential in people with severe/profound intellectual disability.

6.4 Conclusion

This chapter has situated the Theory of Reconciling Communication Repertoires in existing literature pertaining to the substantive area of interpersonal interactions with persons with severe/profound intellectual disability using Whittemore and Knafl's (2005) Integrative Review method. The literature was examined in relation to the concepts that emerged in the theory, namely communication repertoires, motivation to interact, connectedness, reciprocal engaging, understanding and confusion resolution. While literature exists relating to each concept, it is evident that each concept is studied in isolation. This theory brings these discrete research areas together in a coherent and connected way. Therefore, this study addresses this issue by offering a systematically derived, integrated and explanatory theory of a process that is well documented as challenging.

This theory concurred with the findings of some studies but contributes to the debate on other issues. There is a long-established acceptance that having a sense of belonging is an important part of a person's overall well-being. The Theory of Reconciling Communication Repertoires echoes this perspective and highlights its role as a key motivator in interactions. Additionally, it concurs with existing discussion and debate that interactions of this nature are challenging and difficult. Importantly, however, the Theory of Reconciling Communication Repertoires

highlights the ability of people with severe/profound intellectual disability in interactions. It demonstrates, with support from the literature, that this ability exists but is often unrecognised or undetected. This is important because in a context where misunderstanding and confusion are frequent, increasing awareness of ability and missed opportunities for interaction and understanding could positively impact on outcomes for all.

The concept of understanding as experienced and appraised has been delineated recognising the perspective of both parties to the interaction. From this a new debate regarding passivity of interaction partners has been proposed. This can be linked with opportunity seeking, an indicator of motivation to interact, where a person considers the potential outcomes of an interaction before deciding to initiate it. While the literature recognises this from the perspective of persons with severe/profound intellectual disability, similar work relating to their interaction partners is scant.

Furthermore, gaps in the research have been highlighted particularly in relation to the influence of effort, the experiences of persons with severe/profound intellectual disability of understanding and being understood and a generally un-researched concept, acquiescence. Each of these merit further investigation and exploration if the challenges to interaction and barriers to the achievement of understanding are to be overcome. In light of the findings of this study and this

integrative review, the next chapter discusses the implications of this study and concludes the thesis.

Chapter 7 Implications and Conclusions

7.1 Introduction

This study set out to explore and explain the methods and processes people use to communicate with and understand each other in interactions involving people with severe/profound intellectual disability. The philosophical underpinnings (Chapter 3) and methods (Chapter 4) that guided this study have been detailed. It was undertaken to increase knowledge and understanding of these interactions against of backdrop of a rights agenda as well as policies and strategies that aim to improve individual's quality of life. These agendas are underpinned by principles of person centredness, inclusion, empowerment and self-determination as discussed in Chapter 2. The Theory of Reconciling Communication Repertoires has been generated (Chapter 5) and adds to existing knowledge and evidence as discussed in the previous chapter (Chapter 6). In view of these findings and cognisant of existing evidence, implications of this study for practice, policy, management, education and research are discussed in this chapter. These need to be considered in the context of the study's strengths and limitations which are clearly outlined. However, for this study to have impact, its findings must be shared. A dissemination plan is presented that clearly identifies target audiences and strategies that will enable communication of these findings. An outline of future opportunities stemming from this research follows. Firstly, the implications for practice are presented.

7.2 Practice Implications

The Theory of Reconciling Communication Repertoires can contribute directly to practice as it captures and explains an issue encountered daily in interactions involving individuals with severe/profound intellectual disability. It can inform practice by supporting understanding and awareness of the nature of interactions, the facilitators and barriers to successful interactions and understanding attainment. It also offers insights to the experiences of persons with severe/profound intellectual disability.

This theory has brought subtle and often unrecognised issues relating to each step of the interaction to light. Marsham (2009) asserts that awareness is necessary to bring about change. With appropriate dissemination of the findings, it can raise awareness of these issues among communication partners. Accordingly, these subtle and often unrecognised issues should be noticed and recognised more frequently.

In a landscape where person-centredness, quality of life, choice, self-determination and rights are emphasised and advocated across policy, practice, education and research, measures must be taken to ensure they are realised in individuals' lives. This theory recognises ability in a context where disappointment consequent to disability is often experienced (Ogundele 2018; Soltani et al. 2011). It is hoped that the findings of this study will highlight the critical role communication partners play in recognising and responding to individual's

communication attempts and in creating and providing opportunities to express themselves and their choices. Being aware of the impact of their own communication style on the possibilities and limitations of an interaction (Neerinckx et al. 2014) is an important step towards fulfilling their role as facilitators and enablers of successful, quality interactions. Similarly, interaction partners need to be aware of and understand the person's ability to communicate, the extent of their communication repertoire and the factors that facilitate or limit the person in using that repertoire such as stimuli, time, attention (Munde et al. 2011), context, partner sensitivity (Neerinckx and Maes 2016) and responsivity (Brigg et al. 2016). The study may have an impact on the knowledge, attitudes and interactional competencies (Hostyn and Maes 2013) of communication partners. They may be encouraged to explore other ways of interacting, become self-reflective and consider the impact of their approaches and practices.

The Theory of Reconciling Communication Repertoires identifies strategies and approaches to supporting successful communication and the achievement of understanding, thus facilitating inclusion and negating isolation. Practical ways such as establishing routines, sharing activities and routine conversations can engage people with severe/profound intellectual disability and become the basis for a positive and high-quality interaction. This needs to be a practice culture in services, where contexts are created for active engagement. The importance of spending time with the person has been highlighted in research (Johnson et al. 2012a, b) and practice guidelines (Goldbart and Caton 2010). It is advocated in

Active Support (see Mansell and Beadle Brown 2012) and Positive Behavioural Support (see Carr et al. 2002) approaches. These measures can create a culture where interaction and communication are central. This is critical to fulfilling policy and strategic goals of inclusion and person-centredness.

7.3 Policy Implications

Intellectual disability service provision has been shaped by the philosophical drivers and policy agenda of any given era. There has been a shift from asylums, retreats and eugenics to de-institutionalisation and normalisation to community living (Burrell and Trip 2011). Person centredness and respect for personhood, empowerment and recognition of rights are values and principles currently guiding support and care. Coinciding with this, there has been a gradual shift from associating intellectual disability with incompetence to maximising potential (Aldridge 2010). This study demonstrates the need to recognise ability in order to maximise potential. The Theory of Reconciling Communication Repertoires identifies that this population has abilities that are unrecognised and/or underestimated. Some authors argued that inappropriate responses are exacerbating existing disabilities (Bunning et al. 2013; Halle et al. 2004; Grove et al. 1999). Therefore, one of the key recommendations emerging from this study is that supports offered or provided to individuals with severe/profound intellectual disability are through a lens that recognises ability and seeks to maximise not only potential but maximise ability.

Chapter 2 (para. 2.8) has discussed the policy context of this study. Its relevance to informing implementation of these strategies and goals was outlined. In Ireland, *New Horizons* is particularly influential regarding how people with intellectual disability spend their time, shaping employment, further education and training, and activation services. This programme particularly notes the challenges to meeting its goals for people with severe/profound intellectual disability. This study, as well as some previous studies (Brigg et al. 2016; Johnson et al. 2012b), suggest that policies, programmes and strategies allow carers and practitioners time, space and resources to positively and meaningfully engage with people with severe/profound intellectual disability. Measures must be taken to ensure such relationships are valued for their contribution to quality of life and the provision of high-quality care and services. The value of this aspect of care needs to be articulated (Johnson et al. 2012b) and interactions that support individuals to express themselves promoted and advocated in strategies and programmes.

7.4 Management Implications

Management have a crucial role in designing and creating environments and encouraging practices that meet policy and strategy goals. They have a role in motivating staff and establishing conditions that support a level of commitment, staff competence and monitoring (Felce and Perry 1995) so that the recommendations offered here and in the literature are operationalised. Managers can build commitment, motivate staff, reinforce and encourage appropriate and suitable approaches by providing positive feedback for engaging

with people with intellectual disability in these ways. Additionally, these could be highlighted as good practice (Forster and Iacono 2014) by encouraging staff to share their experiences and the impact of adopting this approach through local or national practice development initiatives such as newsletters, symposia and conference presentations or posters. This would further encourage staff to engage with the evidence base underpinning their practice.

Furthermore, managers need to support staff in developing their competence by supporting and facilitating engagement in education and training opportunities. Supporting staff to develop and hone their skills can encourage participation in education and practice development and potentially boost confidence in relation to this complex area of practice.

7.5 Education Implications

Education and training of communication partners has the potential to support their personal development, including confidence, during interactions, develop and maintain skills and consequently, improve the quality of life of people with intellectual disability (Healy and Noonan-Walsh 2007). A training programme developed in collaboration between third level educational institutes, service providers and advocacy groups that increases staff awareness of their non-verbal communication methods and sensitivity to subtle communication methods is recommended. Such training needs to include a practice element with a mentor who could support and facilitate students to develop and hone their skills as well

as support them to be reflective and self-aware in their practice. Although Koski et al. (2014) found that mentoring cannot ensure maintenance of skills or continuation of practices after training, it was found to be beneficial during the training. There is evidence that training, in and of itself, may be insufficient to impact staff communicative practices (Purcell et al. 1999). Ager and O'May (2001) noted that addressing thought processes and challenging thinking habits can result in more long-term maintenance of learning and skills and changes to practice. Therefore, it is important that any training programme not only teaches communication practice but provides students with an opportunity to consider their own assumptions and expectations of interaction involving people with severe/profound intellectual disability (Koski et al. 2010). Reflective practice needs to be intrinsic. Griffiths and Smith (2017) and Hostyn and Maes (2013) contend that education can be enhanced by analysing videoed interactions as a catalyst for group and individual reflection. Approaches such as Video Interaction Guidance (Kennedy et al. 2011) may be useful.

Responsivity is a key issue that needs to be included in such education or training programmes on two fronts. Firstly, partners sensitivity and responsiveness to the individual's communication attempt (Halle et al. 2004; Coupe O'Kane and Goldbart 1998) and secondly, increasing partners' repertoires of behaviours that can influence the individual's responsiveness (Forster and Iacono 2008). Munde and Vlaskamp (2015) further advocate education that trains the partner to look for and recognise the individual's alertness in order to interact more appropriately. Such

an approach highlights and recognises that the person with intellectual disability has communication skills and abilities but partners need to act in ways that enables rather than limits the extent of their communication repertoire.

7.6 Research Implications

The Theory of Reconciling Communication Repertoires has explained the strategies people use to navigate interactions involving people with severe/profound intellectual disability. In so doing, it has highlighted areas that warrant further exploration and research. People with severe/profound intellectual disability experiencing short and infrequent interactions is a particular concern. Further study is warranted to identify and create opportunities to increase the frequency of interactions. This study identified some barriers and facilitators during interactions. However, research that specifically focuses on the barriers and facilitators to the frequency of interactions, strategies to break those barriers and to augment and strengthen those facilitators is required. In this study, for example, the competing variables of effort and time demands were found to influence the frequency of interactions. This is in keeping with Felce et al. (1991) and Felce and Perry's (1995) findings from over twenty-five years ago where higher staff: individual ratios did not impact on frequency of interactions due to the intensity of support needs. Similarly, participants in Forster and Iacono's (1998) study, over twenty years ago, reported that organisational policy and practices were a barrier to their preferred methods of interacting. Research is required that will provide guidance to organisations on removing systemic barriers

to interpersonal interactions. This research should inform the design and development of services and systems of work that recognise, prioritise, foster and value interpersonal interactions as a critical element of high-quality care. This would be valuable to inform practice, policy, management and education.

Secondly, this study explored interactions in a social context where understanding was deemed secondary to the primary motivation of nurturing a sense of belonging. A study of interactions where understanding and comprehension is a primary concern e.g. expression of personal choice or preference, assessment of well-being or pain, is merited. While studies have been undertaken in these areas (Kankkunen et al. 2010; Zwakhalen et al. 2004; Stancliffe and Abery 1997; Lancioni et al. 1996) an observation study of the interaction process itself has the potential to provide important knowledge about the contribution of the person with severe/profound intellectual disability and interactional barriers and facilitators to successfully navigating these interactions. It could provide valuable knowledge of the ways in which people with severe/profound intellectual disability can be included, self-determining and empowered.

Lastly, this study has demonstrated how insights into the experiences of persons with severe/profound intellectual disability can be gained. While gaining such perspectives is difficult, it is not impossible. Novel and innovative approaches to research can ensure the voices of people with this ability are heard while maintaining research standards to ensure reliable and trustworthy findings. This

study is one example of how the processes to ensure rigorous research can be adhered to while including this group as participants. Therefore, it is recommended that researchers continue to include people with severe/profound intellectual disability in research as their perspectives and experiences are invaluable in informing person-centred care, service and policy. To extend this further, innovative ways of including people with intellectual disability in informing research need to be explored. In Ireland, the NDA (2002) published *Guidelines for Including People with Disabilities in Research*. This publication presents a number of models to including people with different disabilities in research. However, it is important that their inclusion and contribution is genuine, respectful and non-tokenistic (Romsland et al. 2019; Snow et al. 2018; McLaughlin 2010).

7.7 Strengths and Limitations

In considering the recommendations and suggestions discussed it is important to acknowledge the strengths and limitations of this study. Measures taken to ensure its quality have been discussed in Chapter 4 (para. 4.10). From a limitations perspective, it must be recognised that this study was undertaken by a novice Classic Grounded Theory researcher. Many processes and methods were new but supervisory expertise, advice and guidance and engagement with original texts ensured the methodology and methods were rigorously adhered to.

While the sample of twenty-two participants is a strength for a study of this nature, this includes only three participants with severe/profound intellectual disability. However, concurrent data analysis informed recruitment of these participants to address gaps in the study. Data analysis, and more specifically saturation, informed the need for further sampling and recruitment of participants. As saturation was reached, sampling and recruitment of more participants with severe/profound intellectual disability was unnecessary.

The outcome of this study is a theory that is abstract of time, place and people. While this is an advantage in some regards, others have highlighted that it does not capture the individual experience or perspective (Richards and Farrokhnia 2016) as would be expected with the data type. This study does not claim to offer individual perspectives but provide an indication of their experience. It explains what people do and how people navigate interactions involving people with severe/profound intellectual disability.

Additionally, this theory is confined to one substantive area. Application to other contexts, situations or groups requires further development to a formal theory. However, this has been clear throughout this thesis and the recommendations and suggestions made relate only to the substantive area of interactions involving people with severe/profound intellectual disability.

One of the strengths of this study lies in the rigorous adherence to Classic Grounded Theory methods. The theory generated captures and explains what

happens in these interactions. This theory is a parsimonious integration of rich and dense concepts that have the potential to inform practice, policy, research and education.

A further strength lies in the meaningful inclusion of people with severe/profound intellectual disability as participants. The methodology was selected due to its ability to guide the study towards meeting its aim which included gaining insight into the experiences of people with a severe/profound intellectual disability. The inclusion of this group as participants in research has been noted as difficult. Coons and Watson (2013) discuss the ethical and practical implications of including participants with intellectual disability in qualitative research. However, despite these challenges it is particularly important that this group are included in research that explores their experiences and efforts are taken to avoid proxy reporting. Lloyd et al. (2006) assert the value of gaining experiences and perspectives from an individual directly. This study is an example of how people with severe/profound intellectual disability can participate in research and the value of their contribution to research and knowledge. Their inclusion in this study strengthens the findings as issues related to proxy reporting do not apply.

7.8 Dissemination Plan

To ensure the findings of this study inform practice and thereby maximise the benefit to people with a severe/profound intellectual disability, the following dissemination strategy has been developed for translating this knowledge into

practice (Appendix XV). According to Gagnon (2011), a dissemination plan should consider what knowledge should be translated, to whom, how and with what effect. There are five key audiences for this research study including…

1. Individuals with an intellectual disability, their families and carers, advocacy and representative groups
2. Frontline staff supporting individuals and their families
3. Managers who co-ordinate and design service provision and resources at local and service-wide levels
4. Statutory organisations such as HIQA, Irish Human Rights and Equality Commission, National Disability Authority
5. Educators and researchers

Dissemination of this study has begun. I presented an excerpt of the theory at a Grounded Theory seminar in London in November 2016 as a troubleshootee. I also presented an oral paper at the IASSIDD World Congress in Glasgow in August 2019 titled *Classic Grounded Theory as an Approach to Research involving Participants with Severe/Profound Intellectual Disability* (Appendix XVI). This conference is the leading international research and practice meeting in the field of intellectual disability with participants from diverse professions and career levels as well as those with intellectual disability and their families (IASSIDD 2019). Furthermore, I am a member of the Profound Intellectual and Multiple Disabilities Special Interest Research Group (PIMD-SIRG) in IASSIDD. I attended this groups roundtable meeting in Berlin in March 2020. I presented a paper titled *People with*

Severe/Profound Intellectual Disability as Research Participants: Ethical Considerations at the Early Careers Researchers Meeting scheduled with this roundtable. This issue generated much discussion following the presentation at the World Congress. This was an opportunity to share this aspect of the study in more detail and provide other researchers in the field with ideas and suggestions for meeting ethical obligations in their work.

Going forward, I believe the findings of this study are of multi and interdisciplinary relevance nationally and internationally. Therefore, I hope to present oral papers at relevant conferences and seminars that will provide opportunity to reach diverse audiences and increase the impact of the findings. Presentations will need to be tailored according to the audience. For example, if the audience is family or frontline staff, the presentation will be tailored towards practice-based findings and strategies whereas presentations to those with a remit in policy and strategy development will be framed in this context.

I plan to publish subject and methodology articles from this study. I will target publication of the theory and integrative review in the *Journal of Intellectual Disability Research* (impact factor of 1.941) and the *Journal of Applied Research in Intellectual Disabilities* (impact factor 1.769). The target audience of these journals include families, carers, frontline professionals and researchers in the area of intellectual disabilities generally. This would ensure wide dissemination of the findings to those can use and benefit from this knowledge. *PMLD Link* would be a

suitable journal to publish a paper on the application and implementation of the findings. *PMLD Link*, particularly, is dedicated to sharing ideas, information and good practice around supporting individuals with profound intellectual and multiple disabilities with families, carers and professional across a variety of settings. Therefore, this journal will support dissemination of the findings directly to those interacting with people with severe/profound intellectual disability daily.

There is also an opportunity to publish articles relating to the methods adopted in this study to include people with severe/profound intellectual disability in research. Therefore, I plan to write an article on the application of Classic Grounded Theory in this study targeting *The Grounded Theory Review*.

This dissemination strategy will maximise the impact of this study and provide a springboard to raise awareness of this issue going forward. It is important that research and development continues in this field.

7.9 Conclusion

In conclusion, this Classic Grounded Theory study has examined interactions involving people with severe/profound intellectual disability and explained the strategies used to navigate such interactions. The challenges and difficulties of these interactions are well recognised and documented. These create barriers to fulfilment of the rights of people with severe/profound intellectual disability to communicate, express themselves and understand those around them. It negatively impacts their rights to inclusion and self-determination and hinders

their empowerment. The achievement of goals of national and international policies, programmes and strategies relies on the perspectives of people with severe/profound intellectual disability being heard and understood. Person-centredness, choice, inclusion, respect and self-determination fundamentally require listening to the person with severe/profound intellectual disability. Successful communication is required. Furthermore, experiencing high-quality and successful interactions are a determinant of a good quality of life. It is in this context that this study has examined interactions involving people with a severe/profound intellectual disability.

A Classic Grounded Theory methodology was used in order to generate a theory that explains the methods and processes people use to communicate with and understand each other in these interactions. Through rigorous adherence to the methods of this approach, the Theory of Reconciling Communication Repertoires emerged. This theory explains and makes visible the processes and strategies individuals use to navigate their interactions. It presents a five-stage process moving from motivation to interact to establishing a connection, reciprocally engaging, navigating understanding and confusion resolution. Successful interactions rely on effectively reconciling communication repertoires and maintaining the connection on which the interaction occurs. This can be demanding and therefore individuals economise their effort by considering the motivation strength and probable outcome.

This theory has unified discrete areas of research in the substantive area of interaction and communication involving people with severe/profound intellectual disability and their communication partners without a disability. It contributes to existing knowledge and evidence. Furthermore, in light of these findings and in consideration of existing literature, suggestions and recommendations have been offered in relation to practice, management, policy development, research and education fields. Each suggestion and recommendation is made with a view to improving the lives of people with severe/profound intellectual disability and those with whom they interact. Effective and successful communication is a determinant of a good quality of life. This is and must continue to be a key driver of care, support and service delivery for, to and with people with intellectual disability because, unquestionably and undeniably, people with a severe/profound intellectual disability have a right to and deserve a good quality of life.

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Appendices

Appendix I Ethical Approval from UCC Social Research Ethics Committee

ucc
Coláiste na hOllscoile Corcaigh, Éire
University College Cork, Ireland

Oifig an Leas - Uachtaráin Taighde agus Nuálaíochta
Office of the Vice President for Research and Innovation

Urlár 4, Bloc E,
Áras na hEolaíochta Bia,
Coláiste na hOllscoile Corcaigh,
Bóthar an Choláiste,
Corcaigh, Éire.

4th Floor Block E,
Food Science Building,
University College Cork,
College Road, Cork, Ireland

T +353 (0)21 4903600
E vpresearch@ucc.ie
www.ucc.ie

Anne-Marie Martin,
School of Nursing and Midwifery

8th August 2013

Dear Anne-Marie,

Thank you for submitting your research (project entitled: **The Meaning Making Process Between Adults With A Severe/Profound Intellectual Disability And Their Communication Partners: A Grounded Theory)** to SREC for ethical perusal. I am pleased to say that we see no ethical impediment to your research as proposed and we are happy to grant approval.

We wish you every success in your research.

Yours sincerely,

S Hammond

Sean Hammond
Chair of Social Research Ethics Committee

Príosún Ardú, Uachtarán Coláiste na hOllscoile Corcaigh
Vice President for Research and Innovation

Ollscoil na hÉireann, Corcaigh
National University of Ireland, Cork

Appendix II Ethical Approval from Service Provider 1

Martin, Anne-Marie

From: [redacted]
Sent: 07 January 2014 12:16
To: Martin, Anne-Marie
Subject: PhD Study

Follow Up Flag: Follow up
Flag Status: Completed

Categories: PhD

Dear Ann Marie,

I wish to follow up on [redacted] letter dated 7 November 2013 regarding your PhD Study.

As advised by telephone today, [redacted] has given permission for you to proceed with your study. Apologies for the delay in contacting you.

I would be obliged if you could resend a brief of your proposal to me by email. I am unable to access the full content due to problems with our internal server at present.

[redacted]
Ireland
+353 21 4643242

1

Appendix III Ethical Approval from Service Provider 2

[redacted]

Phone: [redacted] E-mail: [redacted]
Fax: [redacted] Web: [redacted]

Ms. Anne-Marie Martin,
School of Nursing and Midwifery,
Brookfield Health Sciences Complex,
College Road,
Cork.

11 September 2014.

Re: Application to [redacted] Research Ethics Committee.

Dear Anne-Marie,

We are happy to inform you that ethical approval to carry out your research in [redacted] has been approved. We thought that the inclusion of the work on Intensive Interaction and the literature on vicarious/proxy consent would enhance an otherwise excellent proposal.

We wish you well in your endeavour and look forward to your findings.

Signed [redacted]

Chairperson
On behalf of [redacted] Research Ethics Committee.

COMPANY LIMITED BY GUARANTEE NUMBER [redacted]: CHARITY NUMBER [redacted]
HONORARY DIRECTORS: Chairperson: [redacted] Vice-Chairperson: [redacted] Secretary: [redacted]
Assistant Secretary: [redacted] Treasurer: [redacted] Assistant Treasurer: [redacted]
[redacted]

Appendix IV Proxy Information Sheet and Consent Form

Information Sheet for Person Providing Proxy Consent on behalf of Person with Severe/Profound Intellectual Disability

Purpose of the Study.

As part of the requirements for PhD in Nursing at UCC, I am carrying out a research study. The study is concerned with communication between people with a severe/profound intellectual disability and their communication partners. I will be studying how both people come to understand each other when they communicate.

What will the study involve?

As part of the study I will be carrying out interviews and observations of _____ communicating with people s/he meets regularly. I will make sure that it will be at a time and date convenient to _____.

Why has _____ been asked to take part?

_____ is being asked to take part as his/her involvement will provide the information needed to enhance and inform communication supports for people who require them. As _____ has an intellectual disability and experiences communication impairment s/he is a suitable participant for this study.

Do you have to take part?

Participation in this study is voluntary and _____ has the option to withdraw at any stage. If it becomes clear in the course of the study that _____ does not want to engage, this will be respected.

Will participation in the study be kept confidential?

Anonymity will be maintained throughout the thesis. No information that will disclose _____ identity will be included in the final thesis. Pseudonyms will be used in relation to any extracts or quotes.

What will happen to the information which you give?

The data will be kept confidential for the duration of the study. On completion of the thesis, they will be retained for a further seven years and then destroyed.

What will happen to the results?

The results will be presented in the thesis. They will be seen by my supervisor, and examiners appointed by the University. The thesis will be kept in the library, where it can be accessed by other students and staff of the University. The study will be published in a research journal.

What are the possible disadvantages of taking part?

I don't envisage any negative consequences for you in taking part. It is possible that talking/thinking about experiences in this way may cause some distress. If this occurs, I can be contacted to discuss this distress and if necessary supports will be arranged as appropriate.

Who has reviewed this study?

Approval has been granted by the Social Research Ethics Committee in UCC.

Any further queries?

If you need any further information, you can contact me:

Anne-Marie Martin

School of Nursing and Midwifery, UCC,
Brookfield Health Sciences Complex
College Road,
Cork.

☎ 021-4901451

a.martin@ucc.ie

If you agree to _____ taking part in the study, please sign the consent form overleaf.

Consent Form

I …… agree to …… participating in the research study, *The Meaning Making Process Between Adults with Severe/Profound Intellectual Disability and their Communication partners: A Grounded Theory*.

The purpose and nature of the study has been explained to me in writing.

I am providing this consent voluntarily.

I give permission for the interview to be digitally recorded and observations to be noted and/or recorded.

I understand that _____ can withdraw from the study, without repercussions, at any time, whether before it starts or while I am participating.

I understand that _____ can withdraw permission to use the data within two weeks of the interview, in which case the material will be deleted.

I understand that anonymity will be ensured in the write-up by disguising _____ identity.

I understand that disguised extracts from _____ interview may be quoted in the thesis and any subsequent publications

Print Name: _____

Relationship to _____: _____

Signature: _____

Date: _____

Appendix V Information Sheet and Consent Form for those Self-consenting

Information Sheet for Communication Partner of Person with Severe/Profound Intellectual Disability

Purpose of the Study.

As part of the requirements for PhD in Nursing at UCC, I am carrying out a research study. The study is concerned with communication between people with a severe/profound intellectual disability and their communication partners.

What will the study involve?

As part of the study I will be carrying out interviews and observations of communication between _____ and you. This may occur on more than one occasion, but I will make sure that it will be at a time and date convenient to you.

Why have you been asked to take part?

You have been asked because you communicate with _____.

Do you have to take part?

Participation in this study is voluntary and you have the option to withdraw at any stage.

Will your participation in the study be kept confidential?

You will remain anonymous throughout the thesis. No information that will disclose your identity will be included in the final thesis. Pseudonyms will be used in relation to any extracts or quotes you provide.

What will happen to the information which you give?

The data will be kept confidential for the duration of the study. On completion of the thesis, they will be retained for a further seven years and then destroyed.

What will happen to the results?

The results will be presented in the thesis. They will be seen by my supervisor and examiners appointed by the university. The thesis will be kept in the library, where

it can be accessed by other students and staff of the university. The study will be published in a research journal.

What are the possible disadvantages of taking part?

I don't envisage any negative consequences for you in taking part. It is possible that talking about your experience in this way may cause some distress. We can speak about how you are feeling and if you subsequently feel distressed supports will be arranged for you as appropriate.

Who has reviewed this study?

Approval has been granted by the Social Research Ethics Committee in UCC.

Any further queries?

If you need any further information, you can contact me:

Anne-Marie Martin

School of Nursing and Midwifery, UCC,
Brookfield Health Sciences Complex
College Road,
Cork.

☎ 021-4901451

a.martin@ucc.ie

If you agree to take part in the study, please sign the consent form overleaf.

Consent Form

I……agree to participate in the research study, *The Meaning Making Process Between Adults with Severe/Profound Intellectual Disability and their Communication partners: A Grounded Theory*.

The purpose and nature of the study has been explained to me in writing.

I am participating voluntarily.

I give permission for my interview to be recorded and observations to be noted and/or recorded.

I understand that I can withdraw from the study, without repercussions, at any time, whether before it starts or while I am participating.

I understand that I can withdraw permission to use the data within two weeks of the interview, in which case the material will be deleted.

I understand that anonymity will be ensured in the write-up by disguising my identity.

I understand that disguised extracts from my interview may be quoted in the thesis and any subsequent publications

Print Name: _____

Signature: _____

Date: _____

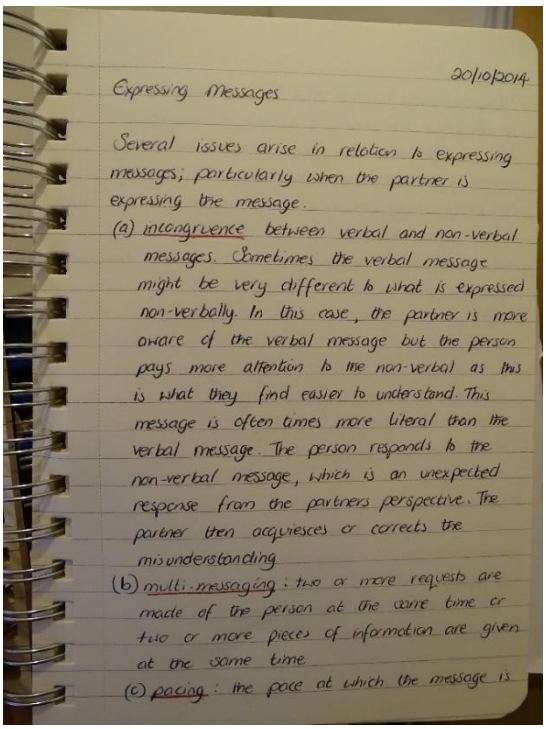
Appendix VI Observational Data Bank

Coded	Data Source	Clip Scenario	Participants	Clip Timing mm:ss:ms	Clip Length mm:ss

Appendix VII Blank Video Transcript

Recording Name:_____ Timing:_____ Clip Title:_____ PwID: _____ Comm. Partner: _____									
Time	**Verbal Content**				**Non-Verbal Content**				**Notes**
	PwID	**Comm. Part.**			**PwID**	**Comm. Part.**			
		Name 1	***Name 2***	***Name 3***		***Name 1***	***Name 2***	***Name 3***	
00:00:03									
00:00:06									
00:00:09									
00:00:12									
00:00:15									
00:00:18									
00:00:21									
00:00:24									
00:00:27									
00:00:30									
00:00:33									
00:00:36									

Appendix VIII Sample Memos



20/10/2014.

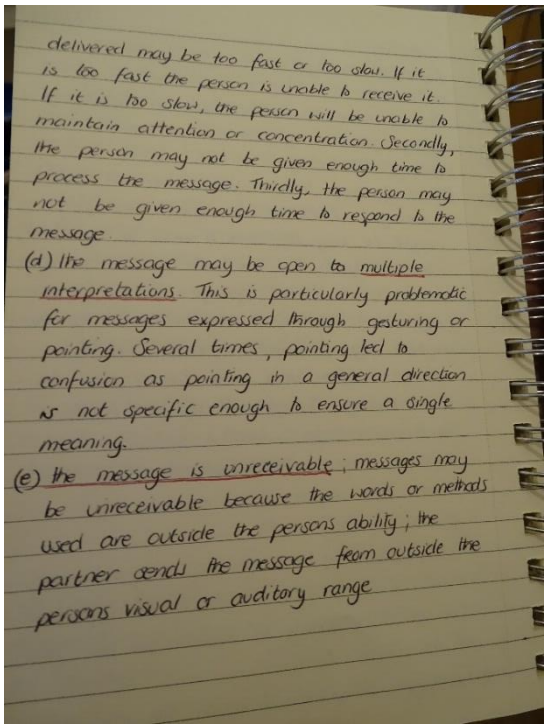
Expressing Messages

Several issues arise in relation to expressing messages; particularly when the partner is expressing the message.

(a) incongruence between verbal and non-verbal messages. Sometimes the verbal message might be very different to what is expressed non-verbally. In this case, the partner is more aware of the verbal message but the person pays more attention to the non-verbal as this is what they find easier to understand. This message is often times more literal than the verbal message. The person responds to the non-verbal message, which is an unexpected response from the partners perspective. The partner then acquiesces or corrects the misunderstanding.

(b) multi-messaging: two or more requests are made of the person at the same time or two or more pieces of information are given at the same time.

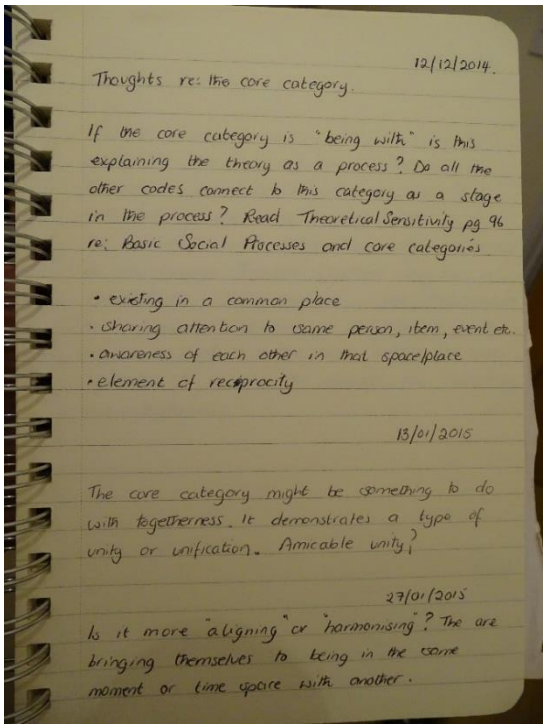
(c) pacing: the pace at which the message is



delivered may be too fast or too slow. If it is too fast the person is unable to receive it. If it is too slow, the person will be unable to maintain attention or concentration. Secondly, the person may not be given enough time to process the message. Thirdly, the person may not be given enough time to respond to the message.

(d) the message may be open to multiple interpretations. This is particularly problematic for messages expressed through gesturing or pointing. Several times, pointing led to confusion as pointing in a general direction is not specific enough to ensure a single meaning.

(e) the message is unreceivable; messages may be unreceivable because the words or methods used are outside the persons ability; the partner sends the message from outside the persons visual or auditory range.



12/12/2014.

Thoughts re: the core category.

If the core category is "being with" is this explaining the theory as a process? Do all the other codes connect to this category as a stage in the process? Read Theoretical Sensitivity pg 96 re: Basic Social Processes and core categories.

- existing in a common place
- sharing attention to same person, item, event etc.
- awareness of each other in that space/place
- element of reciprocity

13/01/2015

The core category might be something to do with togetherness. It demonstrates a type of unity or unification. Amicable unity?

27/01/2015

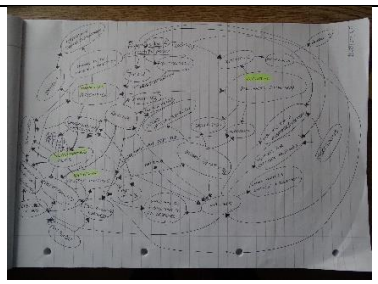
Is it more "aligning" or "harmonising"? The are bringing themselves to being in the same moment or time space with another.

Appendix IX Blank Interview Transcript

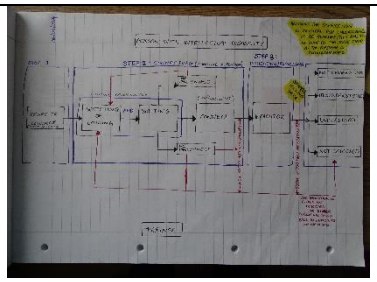
Interview:_____ Date:_____ Time:_____ Length:_____ **Interviewees: _____**		
Name	**Dialogue**	**Notes**

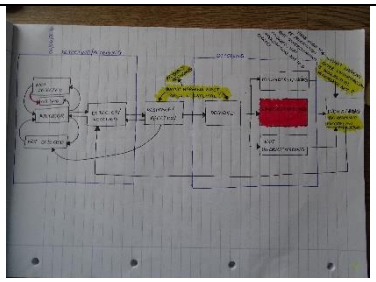
Appendix X Photographs of Sorting

May 2014



June 2014



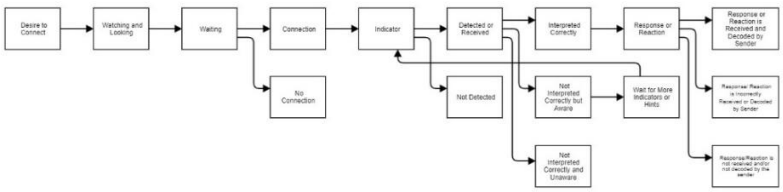


October 2014

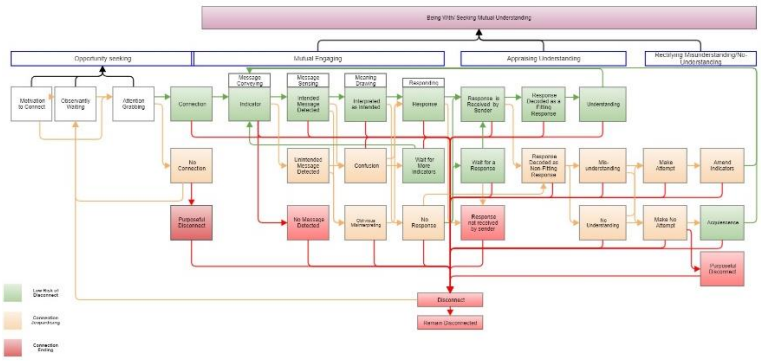




November 2014



February 2015



Appendix XI CINAHL Search

Keywords	Limiters	Database Results	Screening				No. of Papers Included
			Title Review	Duplicates*	Abstract Review	Article Review	
1 AND 2 AND 5	English language	103	23	(-0) 23	(-12) 27	(-12) 28	28
1 AND 2 AND 4		199	26	(-10) 16			
1 AND 3 AND 4		84	13	(-8) 5	(-7) 13		
1 AND 3 AND 5		63	25	(-10) 15			
1 AND 4 AND 6		165	17*	0	(-8) 9	(-8) 1	1
1 AND 2 AND 4 AND 6		25	12*	(-9) 3	(-3) 0	0	
1 AND 5 AND 6		80	17*	(-6) 11	(-7) 4	(-1) 3	3
1 AND 2 AND 5 AND 6		18	4*	(-4) 0			-
1 AND 4 AND 7		99	12*	(-4) 8	(-7) 1	1	1
1 AND 2 AND 4 AND 7		21	6*	(-5) 1	(-1) 0		-
1 AND 5 AND 7		22	5*	(-4) 1	(-1) 0		-
1 AND 2 AND 5 AND 7		4	0*	(-4) 0			-
1 AND 4 AND 8		180	3*	(-3) 0			-
1 AND 2 AND 4 AND 8		19		(-19) 0			-
1 AND 5 AND 8		41	1*		1	(-1) 0	-
1 AND 2 AND 5 AND 8		11		(-11) 0			-
Totals		1134	164	83	54	33	**33**

Appendix XII Social Science Premium and Education Collection Search

Keywords	Limiters	Database Results	Screening				No. of Papers Included
			Title Review	Duplicates*	Abstract Review	Article Review	
1 AND 2 AND 5	None	139	15*	(-1) 14	(-10) 4	4	4
1 AND 2 AND 4	Peer reviewed; 2009-2019	218	15*	(-5) 10	(-6) 4	(-1) 3	3
1 AND 3 AND 4	Peer reviewed; 2009-2019	220	9*	(-2) 7	(-4) 3	(-3) 0	0
1 AND 3 AND 5	Peer reviewed; 2009-2019	28	0*				
1 AND 4 AND 6	Peer reviewed; 2009-2019	110	2*	(-1) 1	(-1) 0	-	
1 AND 2 AND 4 AND 6	Peer reviewed; 2009-2019	30	0*				
1 AND 5 AND 6	Peer reviewed; 2009-2019	29	0*				
1 AND 2 AND 5 AND 6	None	15	1*	(-1) 0			
1 AND 4 AND 7	Peer reviewed; 2009-2019	123	1*	(-0) 1	1	(-1) 0	0
1 AND 2 AND 4 AND 7	Peer reviewed; 2009-2019	33	0*				
1 AND 5 AND 7	None	35	0*				
1 AND 2 AND 5 AND 7	None	6	0*				
1 AND 4 AND 8	Peer reviewed	128	1*	(-0) 1	1	(-1) 0	0
1 AND 2 AND 4 AND 8	None	42	0*				
1 AND 5 AND 8	None	32	0*				
1 AND 2 AND 5 AND 8	None	8	0*				
Totals		1196	44	34	13	7	**7**

Appendix XIII Linguistics Collection Search

Keywords	Limiters	Database Results	Screening				No. of Papers Included
			Title Review	Duplicates*	Abstract Review	Article Review	
1 AND 2 AND 4	None	17	(-11) 6*	(-4) 2	(-2) 0		
1 AND 3 AND 4	None	47	(-10) 37*	(-12) 25	(-24) 1	1	1
1 AND 4 AND 6	Last 5 years; peer review; English language	342	0*	(-5) 0			
1 AND 2 AND 4 AND 6	Last 5 years; peer review; English language	201	0*				
1 AND 4 AND 7	Last 5 years; peer review; English language	410	0*				
1 AND 2 AND 4 AND 7	Last 5 years; peer review; English language	97	0*				
1 AND 4 AND 8	Last 5 years; peer review; English language	246	0*				
1 AND 2 AND 4 AND 8	Last 5 years; peer review; English language	13	0*				
Totals		1373	43	27	1	1	**1**

Appendix XIV Scopus Search

Keywords	Limiters	Database Results	Screening				No. of Papers Included
			Title Review	Duplicates*	Abstract Review	Article Review	
1 AND 2 AND 5	Keyword search limited to TITLE-ABS-KEY	72	3*		(-3) 0		
1 AND 2 AND 5 AND 6		14	0*				
1 AND 2 AND 5 AND 7		6	0*				
1 AND 2 AND 5 AND 8		4	0*				
1 AND 2 AND 4		178	3*		(-3) 0		
1 AND 2 AND 4 AND 6		19	0*				
1 AND 2 AND 4 AND 7		17	0*				
1 AND 2 AND 4 AND 8		8	0*				
1 AND 3 AND 4		128	1*		(-1) 0		
1 AND 3 AND 5		52	1*		1	(-1) 0	0
1 AND 4 AND 6		76	1*		1	(-1) 0	0
1 AND 4 AND 7		141	0*				
1 AND 4 AND 8		80	0*				
1 AND 5 AND 6		41	0*				
1 AND 5 AND 7		14	0*				
1 AND 5 AND 8		15	0*				
Totals			9	-	2	0	**0**

Appendix XV Detailed Dissemination Plan

Dissemination of this study has begun. The study, its methods and preliminary findings have been presented and discussed in diverse fora. I presented an excerpt of the theory at a Grounded Theory seminar in London in November 2016 as a troubleshootee. There was a diverse audience at this seminar from within and beyond health-related fields including physiotherapists, occupational therapists, speech and language therapy, teachers, computer programmers and information technologists. While the substantive area was only of interest to some attendees, the application of the methodology and implementation of the methods was of interest to all as researchers and educators.

I also presented an oral paper at the IASSIDD World Congress in Glasgow in August 2019 titled *Classic Grounded Theory as an Approach to Research involving Participants with Severe/Profound Intellectual Disability* (Appendix XVI). This conference is the leading international research and practice meeting in the field of intellectual disability with participants from diverse professions and career levels as well as those with intellectual disability and their families (IASSIDD 2019). Representation of all five target audiences listed at para. 7.8 attended this conference. I was grateful to receive the Carla Vlaskamp Award (Appendix XVII) and College of Medicine and Health Travel Bursary (Appendix XVIII) to support my attendance. The presentation generated discussion around meeting ethical obligations when including people with severe/profound intellectual disability as

participants, the rigour and robustness of Classic Grounded Theory and coding observational data.

I am a member of the Profound Intellectual and Multiple Disabilities Special Interest Research Group (PIMD-SIRG) in IASSIDD. Through the World Congress, I have extended my peer network in health and education fields with a specific interest in this substantive area. I attended the PIMD-SIRG Roundtable meeting in Berlin in March 2020. I presented a paper titled *People with Severe/Profound Intellectual Disability as Research Participants: Ethical Considerations* at the Early Careers Researchers Meeting scheduled with this roundtable. This issue generated much discussion following the presentation at the World Congress. This was an opportunity to share this aspect of the study in more detail and provide other researchers in the field with ideas and suggestions for meeting ethical obligations in their work.

During the IASSIDD World Congress, I met with peers in attendance and we have connected in the interim period. Opportunities for collaboration, particularly with Clinical Nurse Specialists and Practice Development Officers at a national level have arisen following this congress.

Furthermore, in May 2019, I co-presented a masterclass titled '*Communicating with Persons with Severe/Profound Intellectual Disability*' with Prof. Juliet Goldbart (Appendix XIX). This masterclass drew great interest with tickets selling out in a matter of days. More than 220 people attended from a variety of fields including

health, social care, education, advocacy and policy development. Prof. Goldbart and I explored the development of communication skills and how people with severe/profound intellectual disability are likely to communicate. The importance of supporting comprehension and understanding was discussed and strategies to support communication and interaction were proposed. Reviews of the session were very positive. Some comments from attendees include:

> *'The enthusiasm for the subject and the expertise of both speakers was very evident in the presentation. It gave me a renewed sense of energy.'*

> *'The presenters were experienced and a pleasure to listen to as they kept us interested. They were so passionate about the individuals with intellectual disability!! Fabulous to see and hear especially from a multi-disciplinary perspective and a mixed audience of attendees. Thanks for including so many different professions.'*

It is envisioned that this will become an annual event on communicating and interacting with people with intellectual disability with multiple presenters including those with intellectual disability, family and carers, professionals from across disciplines and fields and researchers exploring aspects of communication or interactions with this group.

I provided feedback and progress updates to the service providers who granted access for this study. It has been very well received and both services have requested I deliver further presentations on this study to the staff once completed. Both services were impressed with the respectful and inclusive approach and methods to include participants with intellectual disability and the

depth of analysis. They stated the findings of the study captured people's experiences accurately and commended the work in light of the challenges to including this population. They suggested opportunities for collaboration to extend this work in the areas of staff education and training and further research development.

I plan to publish subject and methodology articles from this study. I will publish the findings and discussion in journals relevant to the field specifically targeting the *Journal of Intellectual Disability Research* (impact factor of 1.941) and *Journal of Applied Research in Intellectual Disabilities* (impact factor 1.769). There is also an opportunity to publish articles relating to the methods adopted in this study to include people with severe/profound intellectual disability in research. I plan to write an article on the application of Classic Grounded Theory in this study targeting *The Grounded Theory Review*. This journal is interdisciplinary and open access and thus has reach beyond intellectual disability or health related fields to researchers and those with a methodological interest.

I intend to continue to undertake research in this area. Communicating with people with severe/profound intellectual disability is challenging. However, the value to and impact on their quality of life merits unravelling the complexity and intricacies of the challenges, breaking the barriers to interaction, developing and refining strategies to support communication and subsequently contributing to the well-being of this group, their quality of life and that of their loved ones. I want to use research and knowledge in my teaching to educate and inspire future

nurses to recognise, appreciate and understand the significance of communication in the lives of the people they will support and care for, the importance of communication in their practice and the value of high-quality interactions to the realisation of high-quality care.

Appendix XVI Acceptance of Oral Paper for IASSIDD World Congress



The World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities

6 - 9 August 2019

SEC, Glasgow, Scotland, UK

Dear Anne-Marie,

Thank you once again for submitting an abstract for IASSIDD 2019 – with more than 1150 accepted Oral and Poster Presentations, we are looking forward to an informative, successful and educational World Congress!

Please find below an overview of your accepted Oral Presentation. **If you are not the presenting author** for this Oral Presentation, please forward this email to the presenter for information:

- **Classic Grounded Theory (CGT) as an approach to research involving people with severe/profound intellectual disability**
  Presenting Author: Anne-Marie Martin
  Presentation Day: Wednesday
  Session Details: Session F7: Qualitative research in PIMD, starting at 11:30
  Your Presentation Time: from 11:45 to 12:00
  Room: Alsh 2

Important Note
The presenting author for each presentation must register for the Congress. If the presenting author does not register, the presentation may be withdrawn.
We recommend registration prior to the Early Bird Registration Deadline (Monday, 10 June 2019) to benefit from the reduced rate.
Further information on Registration can be found here.

Presentation Guidelines
In preparation for your presentation, please carefully read our Presentation Guidelines which contain all necessary information, such as presentation length, format and requirements.
To view the Presentation Guidelines, click here.

Congress Programme
To view the full Congress Programme, visit our website www.iassidd2019.com or click here.

If you have any questions about your presentation or the World Congress, please contact us at iassidd2019@in-conference.org.uk or telephone +44 (0) 131 336 4203.

We look forward to welcoming you to Glasgow in August!

Kind regards

IASSIDD 2019 Congress Secretariat

IASSIDD 2019 c/o In Conference Ltd

E-mail: iassidd2019@in-conference.org.uk
Tel: +44 (0) 131 336 4203

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Appendix XVII Awarding of Carla Vlaskamp Award



International Association for the Scientific Study of Intellectual and Developmental Disabilities

Dear Anne-Marie,

Thank you for applying for the 2019 SIRG Travel Awards. I am pleased to inform you that you have been chosen as the successful recipient of the **Profound Intellectual and Multiple Disabilities** SIRG Travel Award.

You will be receiving **$1000** to help with travel to Glasgow, please fill out the attached form with your banking details and send back to admin@iassidd.org.

On behalf of IASSIDD and the SIRG leaders I would like to thank you for taking the time to prepare your application and wish you the very best with your travels to the 2019 World Congress in Glasgow.

Kind Regards,

Bea Maes
PIMD SIRG Head

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Appendix XVIII Awarding of College of Medicine and Health Bursary

UCC
University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

College of Medicine and Health
GRADUATE SCHOOL

10th April 2019

Dear Ann-Marie Martin,

On behalf of the College of Medicine and Health I am delighted to inform you that you have been awarded a College of Medicine and Health doctoral student travel bursary.

The general purpose of these awards are twofold:

1. **To facilitate students in obtaining training in support of their academic development which they cannot otherwise receive in UCC.**
2. **To facilitate students to attend and present at an international conference.**

You have been awarded a bursary which covers the expenses to the maximum amount as outlined in your application, €1,000. Expenditure will be reimbursed to each student on the basis of a fully vouched expense claim and receipt of a report (Appendix 1) within one month of travel. The Travel Bursary cannot be claimed in advance of the conference/course. Students who are attending a conference will also have to present evidence of presenting (oral or poster presentation) at the pertinent conference. Students attending training courses must supply evidence of having attended the course (as outlined in their application).

I would like to take this opportunity to wish you well with your doctoral studies.

Yours sincerely,

Eileen Savage

Professor Eileen Savage PhD MEd BNS RGN RCN
Vice Dean Graduate Studies
College of Medicine and Health, UCC

CC Jane Hurley, Executive Assistant, Graduate School College of Medicine and Health

Appendix XIX Masterclass: Communicating with Persons with Severe/Profound Intellectual Disability



Masterclass

Communicating with Persons with Severe/Profound Intellectual Disability

Mon. May 13th, 2019, 13.00-15.00
Brookfield, 2.25, UCC
Register for free at Eventbrite:
https://communication-persons-intdis.eventbrite.ie

This masterclass will explore:

- The development of communication skills
- How people with severe/profound intellectual disability are likely to communicate
- The importance of supporting comprehension/ understanding particularly in the healthcare context
- Communication strategies for interactions involving people with severe/profound intellectual disability

Manchester Metropolitan University

Prof. Juliet Goldbart
Professor of Developmental Disabilities
Faculty of Health, Psychology and Social Care,
Manchester Metropolitan University, UK



Juliet's research addresses the communication challenges experienced by children and adults with profound intellectual disabilities or complex physical disabilities. She has worked on establishing the evidence base for communication interventions for children and adults with profound intellectual disabilities.

She has a particular interest in appropriate service delivery for families with a child or adult with complex needs, whether in relatively advantaged contexts or in lower and middle income countries.

Juliet has been a lecturer in higher education for almost 40 years!

Ms. Anne-Marie Martin
Lecturer and Programme Leader
BSc Nursing (Intellectual Disability)
School of Nursing and Midwifery, UCC



Anne-Marie undertakes research in the area of communication and interaction involving persons with severe/profound intellectual disability. Her expertise in communication has led to her involvement in national and international research exploring the experiences of persons with intellectual disabilities, their families and Registered Nurses (Intellectual Disability) in various contexts.

She is currently completing her PhD titled 'The meaning making process between adults with a severe/profound intellectual disability and their communication partners: A Grounded Theory'.

Catherine McAuley
SCHOOL OF NURSING AND MIDWIFERY
UCC
University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

Attendees at Masterclass



An article was included in the UCC College of Medicine and Health Newsletter. This newsletter is circulated to 10,000 recipients



