

**The Use of Photovoice as a Methodology to Explore Identity  
Expression Amongst People with Intellectual Disabilities  
who have No or Limited Verbal Communication**

*Portfolio Volume 1: Major Research Project*

Submitted to the University Hertfordshire in partial fulfilment  
of the requirements of the degree of Doctor of Clinical  
Psychology

Emma Krisson

June 2020

Word Count: 31,878

## **Acknowledgements**

I would first like to express my gratitude to the three participants in this project, who not only made this study possible, but permitted me to walk alongside them and share experiences. To their families, carers and support staff at the education centre thank you for guiding me along the way and for your generous storytelling.

Second, to my supervisory team, Dr Maria Qureshi and Dr Annabel Head, thank you for agreeing to go on this journey with me, sharing your expertise and offering words of encouragement. Thank you to Dr Helen Ellis-Caird and Dr Louisa Rhodes, whose valuable input helped inspire the foundations of this project. Additionally, to other members of the DCLINPSY teaching staff and the research department at the University of Hertfordshire, thank you for always having an open door.

Third, a special thank you to my fiancé, family and friends who have been with me every step of the way. Finally, to Cohort 17, who despite the distance were a source of unwavering support.

## Contents

	<b>Page</b>
<b>List of Tables, Figures and Images</b>	<b>8</b>
<b>Abstract</b>	<b>10</b>
<b>Chapter 1: Introduction and Literature Review</b>	<b>11</b>
1.1 Chapter Overview	<b>11</b>
1.2 Epistemological Perspectives and Theories	11
1.2.1 A Social Constructionist Perspective	11
1.3 Definition of Key Concepts	11
1.3.1 Intellectual Disabilities	12
1.3.2 Identity	12
1.4 My Connection to the Topic	14
1.5 Conceptualising Identity	14
1.6 Why is Research with People with ID Important?	15
1.6.1 The Evolution of Integration and Policy	17
1.6.2 Emancipatory and Participatory Practices	18
1.6.3 Ethical Considerations	19
1.6.4 Wider Implications of Research	20
1.6.5 Development of Visual Methodologies	22
1.6.5.1 Photovoice	23
1.7 Systematic Literature Review	25
1.7.1 Identity and ID: A Systematic Review of the Literature	25
1.7.2 Assessing for Quality in Qualitative Research	27
1.7.3 Systematic Literature Review	31
1.7.3.1 Stigma and the ID Diagnosis	31
1.7.3.2 Self-Advocacy and Support	32
1.7.3.3 Change and Transition	34
1.7.4.4 Creative Methodological Approaches	36
1.7.4 Synthesis of Findings	39
1.7.5 Critical Evaluation	40
1.7.6 Rationale for Current Project	41
<b>Chapter 2: Methodology</b>	<b>42</b>
2.1 Design	42
2.1.1 Qualitative vs. Quantitative	42
2.1.1.1 Assessing for Quality in Qualitative Research	43
2.1.2 Adopting a Qualitative Multiple Case Study Approach	44
2.1.3 Layers of Data Collection	45

2.1.3.1 Stage 1: Ethnographic Observations	45
2.1.3.2 Stage 2: Photovoice	46
2.1.3.3 Stage 3: Interviews	47
2.1.3.4 Researchers Reflections	48
2.1.4 Triangulation	48
2.1.5 Reflexive Thematic Analysis	49
2.1.6 Application of Other Methodologies	49
2.1.7 Methodological Considerations and Adaptations	51
2.1.7.1 Issues Relating to Interpretations and ascertaining views	51
2.1.7.2 Research 'with' vs. 'on': Issues Relating to Power	52
2.2 Participants	53
2.2.1 Inclusion and Exclusion Criteria	53
2.2.2 Participant Recruitment	53
2.2.3 Participant Information	54
2.3 Ethical Considerations	55
2.3.1 Ethical Approval	55
2.3.2 Capacity and Consent	56
2.3.3 Building Rapport	57
2.3.4 Anonymity and Confidentiality	57
2.3.5 Dissemination	57
2.4 Procedure	58
2.4.1 A Layered Approach	58
2.4.1.1. Ethnography	58
2.4.1.2 Photovoice Activity	59
2.4.1.3 Interviews	59
2.4.1.4 Reflexive Journal	60
2.5 Data Analysis	60
2.5.1 Analysis in Multiple Case Study Research	60
2.5.2 Setting Up the Process of Analysis	61
2.5.3 Analysis Procedure	62
2.5.3.1 Within-Case Analysis	64
2.5.3.2 Cross-Case Analysis	64
<b>Chapter 3: Results</b>	<b>65</b>
3.1 Introduction to the Section	65
3.2 Within-Case Analysis	65
3.2.1 Case Vignette: Chloe	66
3.2.1.1 Chloe Theme 1: The Richness of Stories: 'A Light Dancing around the Lawn'	66
3.2.1.2 Chloe Theme 2: Facilitating Independence: 'Mum have a Cup of Tea'	67
3.2.1.3 Chloe Theme 3: Embracing Individuality: 'The Sounds were Like the Wind'	68
3.2.1.4 Chloe Case Summary	69
3.2.2 Case Vignette: Oscar	69

3.2.2.1 Oscar Theme 1: Familiarity in the Process: 'He's an Old-Fashioned Chap'	69
3.2.2.2 Oscar Theme 2: Learning Through Being With: 'Comfort in the Routine'	70
3.2.2.3 Oscar Theme 3: Creating Safe Environments: 'Smile and Gently Rock with them'	71
3.2.2.4 Oscar Theme 4: Inviting a Position of Curiosity: 'He Loves his Christmas Socks'	71
3.2.2.5 Oscar Case Summary	72
3.2.3. Case Vignette: Buddy	73
3.2.3.1 Buddy Theme 1: Keeping a Positive Frame: 'Glass Half Full'	73
3.2.3.2 Buddy Theme 2: Blind Spots: 'People Think there's Nothing in his Head'	74
3.2.3.3 Buddy Theme 3: Pictures as a Way of Connecting: 'I Like Seeing him Laugh'	75
3.2.3.4 Buddy Theme 4: Waling in their Shoes: 'Buddy Loves to Dance'	76
3.2.3.5 Buddy Case Summary	76
3.3 Cross-Case Analysis	77
3.3.1 Theme 1: Multidimensional Identity	78
3.3.1.1 Subtheme 1: Identity as a Complex Interaction	78
3.3.1.2 Subtheme 2: We are What we Do	79
3.3.1.3 Subtheme 3: A Disabled Identity	80
3.3.1.4 Subtheme 4: 'You Wonder what they Think About': A Veiled Identity	80
3.3.2 Theme 2: Power Structures	81
3.3.2.1 Subtheme 1: A Safe Relationship	82
3.3.2.2 Subtheme 2: A Wealth of Knowledge	82
3.3.2.3 Subtheme 3: An Enabling Attitude	83
3.3.2.4 Subtheme 4: Facilitating Opportunities	83
3.3.3 Theme 3: Finding the Voice in the Photos	84
3.3.3.1 Subtheme 1: The Role of the Storyteller	84
3.3.3.2 Subtheme 2: Connecting Beyond the Lens	85
3.3.3.3 Subtheme 3: Inviting Curiosity	85
3.3.3.4 Subtheme 4: Balancing Ability, Interest and Familiarity	86
<b>Chapter 4: Discussion</b>	<b>88</b>
4.1 Overview of the Chapter	88
4.2 Summary of Results	88
4.2.1 How do People with ID and Limited or No Verbal Language Express their Identities?	89
4.2.1.1 A Social Constructionist Perspective of Identity	89
4.2.1.2 Identity as a Complex Interaction	89
4.2.2 Can Photovoice be Used as a Research Methodology to Engage People with ID and Limited or No Verbal Language?	90

4.2.2.1 Photovoice: An Evolving and Flexible Methodology	90
4.2.2.2 Awareness of Power Structures	91
4.2.2.3 Can we Learn Anything New about the Person's Identity Through Participation in the Photovoice Activity?	92
4.2.2.4 Can we Learning More about the Person's Identity Through Integrating Ethnographic Ideas, Photovoice and Dyadic Interview Components?	94
4.3 Clinical Implications	94
4.3.1 Overall Implications	94
4.3.2 Specific Clinical Implications	95
4.3.2.1 Implications for Clinical Psychologists	95
4.3.2.2 Conducting Research with People with ID	96
4.3.2.3 Implication for Services for People with ID	96
4.3.2.4 Implications on Wider Policies and Guidelines	97
4.4 Methodological Implications	98
4.4.1 Strengths of Current Study	98
4.4.2 Limitations of Current Study	99
4.4.3 Validating the Methodology	100
4.5 Ethical Implications	100
4.6 Recommendations for Future Research	101
4.6.1 Longitudinal Study	101
4.6.2 Videography	102
4.6.3 Additional Research Exploring Identity of People with Severe and Profound Intellectual Disabilities	102
4.6.4 Other Avenues for Future Research	103
4.7 Conclusions	103
<b>References</b>	<b>105</b>
<b>Appendices</b>	<b>120</b>
Appendix A: Systematic Literature Search	120
Appendix B: Summary of Papers included in Systematic Review	126
Appendix C: Extracts from Reflective Journal	139
Appendix D: Quality Review of Current Study	142
Appendix E: Service Information Sheet	144
Appendix F: Service Consent Form	146
Appendix G: Participant Information Sheet	149
Appendix H: Flyer	152
Appendix I: Photovoice Information Sheet	153
Appendix J: Parent/Carer Information Sheet	154
Appendix K: Ethical Approval	158
Appendix L: British Psychological Society Personal Consultee Forms	161
Appendix M: British Psychological Society Personal Consultee Declaration	162
Appendix N: Family/Carer Consent Form	163

Appendix O: Permission to use Resources	166
Appendix P: Consent Checklist	168
Appendix Q: Extracts from Field Notes	169
Appendix R: Extract from Participant part of Interview	171
Appendix S: Interview Questions	174
Appendix T: Example of Coding Procedure	176
Appendix U: Thematic Mapping Within-Case Analysis	178
Appendix V: Thematic Mapping Cross-Case Analysis	182
Appendix W: Additional Quotes to Support Themes	186

## List of Tables, Figures and Images

<b>Tables</b>	
Table 1: Inclusion and Exclusion Criteria for Systematic Literature Review.	26
Table 2: Quality Measure of Qualitative Papers included in the Systematic Review using Mays and Pope (2000).	28
Table 3: Quantitative Quality Measure for Rekosiewicz (2018) paper using Mixed Methods Appraisal Tool (MMAT; Hong et al. 2018).	29
Table 4: Participant Details	55
Table 5: Table 5: Illustrating the themes, for enabling identity expression, generated during within-case analysis	66
Table 6: Initial Searches of Databases	121
Table 7: Summary of Papers Included in Systematic Review	138
Table 8: Quality Review of Current Study	142
<b>Figures</b>	
Figure 1: Visual Model of the Research Design	45
Figure 2: Diagram illustrating the stages of data collection	58
Figure 3: Diagram of triangulation of data to correspond with the research questions	62
Figure 4: Final Thematic Map	77
Figure 5: Systematic Review Process	123
Figure 6: Literature Review PubMed	124
Figure 7: Literature Review Scopus 1	125
<b>Images</b>	
Image 1: Interview Transcript with initial codes and reflections	176
Image 2 interview transcript with initial codes and reflections (2)	177
Image 3: Picture illustrating the initial construction of theme categories from codes during within-cases analysis for Chloe	178
Image 4: Picture illustrating the process of generating themes during within-cases analysis for Chloe	178

Image 5: Pictures illustrating the final themes generated from within case analysis for Chloe	179
Image 6: Pictures illustrating the final themes generated from within case analysis for Chloe	179
Image 7: Picture illustrating the process of generating themes during within-cases analysis for Buddy	180
Image 8: Picture illustrating the final themes generated from within-cases analysis for Buddy	180
Image 9: Picture illustrating the process of generating themes during within-cases analysis for Oscar	181
Image 10: Picture illustrating the final themes generated from within-cases analysis for Buddy	181
Image 11: Picture illustrating the initial process of combing all codes from all data for cross case analysis	182
Image 12: Picture illustrating the initial process of combing all codes into categories	182
Image 13: Picture illustrating the initial process of combing all codes into categories	183
Image 14: Picture illustrating the initial process of combing all codes into categories	183
Image 15: Picture illustrating the initial process of combing all codes into categories	184
Image 16: Picture illustrating final themes from cross-case analysis – Theme 1	184
Image 17: Picture illustrating final themes from cross-case analysis – Theme 2	185
Image 18: Picture illustrating final themes from cross-case analysis – Theme 3	185

## **Abstract**

People with severe and profound intellectual disabilities are rarely given the opportunity to participate in research. This is despite the development of inclusive participatory practices. A lack of involvement in research can maintain the negative assumptions and biases that surround people with intellectual disabilities and overshadow aspects of their identities. Building on previous research, this project aimed to explore whether an adapted version of photovoice could be used as a methodology to explore the identities of people with severe and profound intellectual disabilities. Informed by Social Constructionist ideas, this project incorporated a qualitative multiple case study approach. Three participants, their families and carers were invited to participate in the project which combined methods of ethnography, photovoice and dyadic interviewing. The data collected from these multiple methods were analysed systematically using a Reflexive Thematic Analysis approach. The findings of this study illustrate the complex processes involved in exploring the multidimensional identities of people with severe and profound intellectual disabilities. Photovoice can offer a flexible and accessible methodology to including visual voices, although there are important facilitating factors that must be considered, not only when conducting research, but when providing support in day to day life.

## **1. Introduction and Literature Review**

*“There is a voice that doesn’t use words. Listen.”*

*(Quote from Rumi).*

### **1.1 Chapter Overview**

This research centres on exploring whether photovoice as a methodology can explore expressions of identity amongst people with intellectual disabilities who have limited or no verbal language. This first chapter will begin by describing the context in which this piece of research sits before moving onto describing key terms. It will then explore how the notion of identity is conceptualised drawing on social constructionist perspectives. It will also review how people with intellectual disabilities have been involved in research, in the past, with a particular focus on the type of methodologies used. The chapter will conclude with a systematic review of the literature on identity and intellectual disabilities before providing a rationale for the current project.

### **1.2 Epistemological Perspectives and Theories**

#### **1.2.1 A Social Constructionist Perspective**

Where we situate ourselves in relation to gaining knowledge and developing an understanding of the world can be thought of as our epistemological position. In essence, an epistemological position is a *‘basic belief system or worldview that guides’* the researcher (Guba & Lincoln, 1994, p.105). These positions we take have important implications when conducting research since they not only determine how we understand and define concepts, but they also guide the research questions we ask, methodological decisions we make, the interpretation of results and the recommendations of policies and practices that follow (Rioux, 1997; Povee, 2014). Therefore, throughout this thesis I will attempt to draw on my epistemological position to reflect this congruency in thought.

The epistemological stance I draw on sits within social constructionist ideas, i.e. the idea that our understandings of the world are socially derived and relevant to cultural and historical contexts. Therefore *‘what we take to be knowledge of the world, and self, finds its origins in human relationships’* and no one perspective is more relevant or accurate than another

(Gergen, 2011, p. 109). The approach emphasises exploring the co-constructed meanings and understandings of the world that are created through language. This position '*challenge[s] the idea, that we can know the world for what it is*' (Gergen, 2015, p. 30) and there is an objective reality. Adopting a social constructionist approach questions the idea that concepts like 'intellectual disabilities' and 'identity' reside solely within people and are fixed entities of their own (Dudley-Marling, 2004; Rioux, 1997). In other words, from a social constructionist viewpoint, intellectual disability is seen as a dehumanising label, given by society rather than the person owning or having an intellectual disability (Kliwer, Biklen, & Kasa-Hendrickson, 2006; McKenzie, 2012). This perception allows focus to shift from the individual to wider social factors (see Clegg, 1993) that impact on a person rather than something that resides within them (Caldwell, 2013).

There are limitations to viewing disability through the lens of social constructionism; such as minimising the impact of living with a disability (Webb, 2014 cited in Head, 2017). Critics would argue that by saying 'intellectual disability' is 'just a social construction' it implies that it does not exist and therefore rejects the reality of people's lived experience (Gergen, 2015; Harper, 2011; Head, 2017). However, as argued by Harper (2011) social constructionist approaches are not saying that notions such as 'identity' and 'intellectual disabilities' do not exist, nor is it saying that people do not experience them, but it is emphasising that what is important is the way it is conceived, across different contexts and throughout history. Therefore, when referring to both identity and intellectual disabilities throughout this thesis, I will not be denying the lived experiences of my participants or their abilities but curious of the way these notions are conceptualised holding in mind the person's social, cultural and historical contexts.

### **1.3 Definition of Key Concepts**

#### **1.3.1 Intellectual Disabilities**

In response to changes in social attitudes and values, there have been many changes in the language and terms used to describe particular impairments or disabilities over the years (British Institute of Learning Disabilities; BILD, 2019). Up until recently, '*Learning Disability*' was the term most commonly used in the UK to describe a person with a significant impairment in intellectual functioning; a significant impairment of adaptive/social

functioning; and onset before adulthood (British Psychological Society; BPS, 2010). However, in an updated report, the BPS now refer to the same criteria as *'intellectual disabilities'* (BPS, 2015). Whilst both terms are still being used interchangeably across the UK, I will use the term intellectual disabilities throughout this thesis, to reflect the change in terminology used by the BPS (2015). This change also mirrors ones being made in revised versions of diagnostic criteria manuals including the International Statistical Classification of Diseases and Related Health Problems (ICD-11; World Health Organisation; WHO, 2018) and Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-V; American Psychiatric Association; APA, 2013).

DSM-V defines intellectual disability as a neurodevelopmental disorder that begins in childhood and characterised by intellectual disabilities as well as difficulties in conceptual, social and practical areas of living. The DSM-V diagnosis of intellectual disabilities requires satisfaction of three of the following criteria:

1. Deficits in intellectual functioning (reasoning, problem solving, planning, abstract thinking, judgement, academic learning and learning from experience) confirmed by clinical evaluation and individualised standard IQ testing.
2. Deficits in adaptive functioning that significantly hamper conforming to development and sociocultural standards for the individual's independence and ability to meet their social responsibility.
3. The onset of these deficits occurring during childhood.

The DSM-V (APA, 2013) also identify severity codes that reflect the clinician's impression of the severity of adaptive functioning. They are 'profound', 'severe', 'moderate' and 'mild'. These categories are not rigid, nor are there clear dividing lines between the different groups (Mietola, Miettinen, & Vehmas, 2017). In the United Kingdom, these terms are determined by society and we use them to make distinctions between levels of need (Povee, 2014; BILD, 2019). For example, people with more severe and profound intellectual disabilities are likely to experience cognitive difficulties, are likely to use nonverbal forms of communication and unable to take care of their own basic needs (WHO, 1992). Previous research has distinguished between level of need by using terms 'profound and multiple learning disabilities' or 'severe and profound intellectual disabilities'. Participants invited to take part in this project, have limited or no verbal communication abilities. Therefore, in this thesis, I

will be using the terms ‘people with intellectual disabilities’ and ‘people with severe and profound intellectual disabilities’ to reflect the varying levels of need.

### 1.3.2 Identity

The word ‘identity’ is often used in everyday discourse, yet it is difficult to provide a succinct summary that captures the range of its meanings (Fearon, 1999; Beart, Hardy, & Buchan, 2005; Vignoles, 2017). Whilst the dictionary may define it as ‘*who a person is, or the qualities of a person or group that make them different from others*’ (Cambridge Dictionary, 2019), this does not fully capture the meaning(s) of ‘identity’ (Fearon, 1999). This has resulted in numerous definitions and conceptualisations of the word across different disciplines and professions (Vignoles, 2017). For the purposes of this thesis, I will draw on my epistemological position to conceptualise identity. Firstly, from a social constructionist perspective, identity can be thought of as constructed through social interactions with others and the environment, rather than something that occurs naturally. Secondly, it is something that is considered multiple and changing, rather than static and stable (Rattansi & Phoenix, 2005). Lastly, the construction of identities relies on the use of social tools, most favourably, language (Khokhar, Memon, & Siddique, 2016). Therefore, identity can be ‘*seen as fluid across time and space and contextual in nature*’ (Kamlager, 2013, p.60). I will expand on this definition of identity and accompanying theoretical frameworks, in future sections.

## 1.4 My Connection to the Topic

My connection to this topic reflects experiences that cross both personal and professional aspects of my life. I have a younger brother whose identity has often been overshadowed by his diagnosis of Autism, i.e. ‘he’s Autistic’. I have also supported young adults whose identities have been characterised by their behaviours that challenge. Similarly, I have observed labels used to characterise a set of mental health symptoms become a person’s identity ‘he’s a schizophrenic’. Often this has extended throughout their life; past, present and future. Over time this has made me question how a person, specifically with intellectual disabilities, accepts or denies these identities, whether they have the capability to do so, or whether we have just assumed they do not without evidence. The identities we hold, often represent the choices we make in defining ourselves. For people with severe and profound intellectual disabilities, they often do not get the opportunity to accept or deny their identities. Reflecting

on this made me curious to explore new ways for people with severe and profound intellectual disabilities to express their identities.

### 1.5 Conceptualising Identity

The notion of identity is notoriously difficult to define (Fearon, 1999; Beart et al., 2005; Vignoles, 2017). In its simplest form, it can be thought of as the response to the question 'Who am I?' (Vignoles, 2017). Yet, the reply can reveal layers of complexity, that cross both personal and social processes. Meaning, there is a 'paradox' in the frequency of its use in everyday life and the understanding of the notion itself (Beart et al., 2005). This has meant that there have been '*contradictory arguments and conceptualisations*' (Beart et al., 2005, p.47) across numerous disciplines and professions where it has served a popular focus of exploration.

Common amongst most definitions of identity is the idea it refers to expressions of individuality along with a reference to the groups in which people belong, therefore combining both personality and social roles (Dunn & Burcaw, 2013). A distinction is therefore often made between personal identity and social identity; the former relating to some distinguishing characteristics that are mainly unchangeable and the latter referring to a social category that can be distinguished by rules, characteristics or features (Fearon, 1999). Yet this distinction has also been contested (see Beart, et al., 2005; Vignoles, 2017), with scholars arguing personal and social identity are related and '*mutually reinforce and shape each other*' (Vignoles, 2017, p.2). This argument comes from the idea that a person cannot be separated from their social context but instead, derive their identities from social interaction (Beart et al., 2005; Burkitt, 2008). Therefore, identity has a '*double sense*' and can be thought of as both '*social categories and ... sources of an individual's self-respect or dignity*' (Fearon, 1999, p.2).

As outlined in Dorozenko, Roberts and Bishop's (2015) paper, they acknowledge much of what we know and understand about identity has come from a positivist frame with psychology naturally favouring these individualistic interpretations of identity. These ideas can be captured in the early work of Erik Erikson (1968). As a prominent developmental theorist in the 1950s, Erikson explored the notion of identity as part of his psychosocial model of human development. In a review of his work, McLeod (2018) outlines how Erikson was

influenced by psychodynamic approaches, favouring internal processes and seeing identity as something that was static, only occurring during adolescence. His conceptualisation of identity also neglected to consider the impact of social situations on the development and maintenance of identity. Viewing identity through this lens; as a process that lies solely within the individual, has meant that people with intellectual disabilities have often been regarded to be 'less than human' and considered to have 'stigmatised identities' (Povee, 2014; Kamlager, 2013). These views focus on the limitations of the impaired individual and neglect to consider the impact of social and political barriers and perceptions.

In contrast to this view, sociologists typically viewed identity (the self) as something that is constructed in the context of social and power relations (Gergen, 2015; Dorozenko et al., 2015). In his book, *Mind, Self and Society*, George Herbert Mead (1934 cited in Gergen, 2015, p.99) put forward the idea that *'there is no thinking or indeed any sense of being a self, that is independent of social process'*. Mead (1934 cited in Povee, 2014) proposed that identity develops through a process of experiential social relations and transitions, rather than being fully present at birth. Mead's ideas are captured in a term coined by Herbert Blumer; 'Symbolic Interactionism'. Blumer (1969 cited in Carter & Fuller, 2015) outlined the following underpinnings of Symbolic Interactionism;

- Humans interact with things based on meanings ascribed to those things,
- The ascribed meanings of those things come from our interactions with others and society,
- The meanings of those things are interpreted by a person when dealing with things in specific circumstances.

These ideas emphasise the importance of the interaction between individuals, social processes and contexts. Symbolic Interactionism aims to provide a perspective of society from the 'bottom-up' or micro-level, rather than a, 'top-down' or macro-level perspective operates (Carter & Fuller, 2015). In line with this, rather than focusing on how social structures 'impose and constrain' individuals, micro level perspectives centre on face-to-face interactions and how these can be used to explain how society operates (Carter & Fuller, 2015). This is very much in line with Gergen's (2015, p.99) idea of human interdependence; the idea that we *'draw our sense of self from others, we are thoroughly interconnected'*. In addition to this, a

central concept of symbolic interactionism is the idea that people use language and symbols (gestures, vocal sounds, facial expressions and gaze) as methods of communication between one another and to make sense of their social worlds (Carter & Fuller, 2015; Gergen, 2015; Luman, n.d.).

These ideas are particularly suited to a project such as this because they emphasise that identity is a fluid concept, developed within contexts of ongoing relational experiences with others and they consider nonverbal methods of communication between people and the meanings ascribed to them. Through applying this approach to understanding identity, it is hoped this project can broaden our understandings of identity and hopefully impact the way intellectual disabilities is viewed within society. To do this, we need to consider the methods we adopt within academia and research to ensure they are inclusive and not exclusive of the needs of people with severe and profound intellectual disabilities.

## **1.6 Why is Research with People with intellectual disabilities Important?**

Intellectual disability is '*commonly conceptualised as a stigmatising identity*' (Dorozenko et al., p. 1345) and a '*master status that overrides all other identities and social roles a person may have*' (Povee, 2014, p. 232). Yet, this contradicts what a label is meant to be used for, i.e. to describe an aspect of a person, not embody them (Rix, 2006). For people with intellectual disabilities, the embodiment of these labels has resulted in a broad range of biases and social assumptions being made about a person's competence, abilities and access to opportunities (Davies & Jenkins, 1997; Beart et al., 2005; Rix, 2006; Povee, 2014) as well as their morals and social roles (Craig, Craig, Withers, Hatton & Limb, 2002). Whether it be 'intellectual disabilities', or previous labels such as 'mental retardation', 'mentally handicapped', 'moron' or 'feeble-minded', they have all been found to not only impact how a person is perceived but also how they are treated in society (BPS, 2015; Cluley, 2018; Rix, 2006). This has often left people with intellectual disabilities being discriminated against and excluded from things that have a direct impact on their quality of life (Cluley, 2018).

### 1.6.1 The Evolution of Integration and Policy

Prior to 1980, it was '*unusual for people with intellectual disabilities*' to be included in research (Boxall & Ralph, 2010, p. 174) and if they were, the approach was '*very much research on rather than research with*' (Kiernan, 1999, p.44). Much of this was underpinned by the way people with disabilities were viewed within society. Prior to 1980, disabilities were predominately viewed through a medical model lens; seeing disability as a 'problem', that belongs to and lies within a person (Kamlager, 2013). An alternative perspective towards people with intellectual disabilities was born, initially, out of the work of Robert B. Edgerton (1963 cited in Beart et al., 2005; Kamlager, 2013; Koltz, 2004; Walmsley, 2001). Edgerton challenged the dominance of professional perspectives within the literature and treatment of people with intellectual disabilities as well as the way it pathologized and objectified people with the diagnosis leaving them considered 'less than human' (Kamlager, 2013). Offering a sociological alternative to quantitative and statistical approaches, Edgerton drew on a range of social theories (symbolic interactionism, stigma, power and labelling) as well as his training as an anthropologist and approached the field of intellectual disabilities from an ethnographic stance (see Beart et al., 2005; Kamlager, 2013; Koltz, 2004; Walmsley, 2001).

In a review provided by Koltz (2004) Edgerton's work mainly centred on experiences of people with intellectual disabilities in secure hospitals, stigmatisation, dehumanisation and de-institutionalisation. It was highly influential in the sociocultural study of intellectual disabilities; however, Edgerton has been criticised for overlooking the social and cultural reasons behind *why* people with intellectual disabilities are viewed in such a way (Koltz, 2004; Walmsley, 2001). Koltz (2004) reviews how Robert Bogdan and Steven Taylor built on Edgerton's work to explore the social and cultural views underlying the stigma towards people with intellectual disabilities. Whilst again influential, most of the approaches by both Edgerton, Bogdan and Taylor centre on capturing the social experiences and perceptions of those with mild to moderate intellectual disabilities and failed to consider those with more severe and profound intellectual disabilities. Therefore, failing to '*exhaust the full possibilities of what it means to be intellectual disabled*' (Koltz, 2004, p.98).

Influenced by the epistemological and methodological approaches utilised by Edgerton, Bogdan and Taylor, John Gleason (1989, 1994 cited in Koltz, 2004) and David Goode (1980, 1984, 1990, cited in Koltz, 2004) set out to gain insight into the everyday worlds of people

with severe and profound intellectual disabilities through naturalistic observation and interaction. In their work, Goode and Gleason emphasised the '*centrality of interactions and relatedness*' to joining with people with severe and profound intellectual disabilities (Koltz, 2004, p.99). They emphasised the importance of observation, interaction and behaviour mimicking as a way of gaining insight to a person's communication strategies and lived experience. As summarised by Koltz (2004, p.101) we not only need to accept people with severe and profound intellectual disabilities as authors in their own lives but acknowledge their behaviours as meaningful and refrain from making them conform to '*normative social practices...as a means for their social inclusion and acceptance*'.

In the last couple of decades, following the combined efforts of academics and government initiatives, more interest and investment has gone into involving people with, varying degrees, of intellectual disabilities in research. This has subsequently led to the development of policies and practices. One influential initiative was the Valuing People, White Paper (Department of Health; DoH, 2001). Constructed by the Department of Health, it promoted the rights, independence, choice and inclusion of people with intellectual disabilities. As outlined by Walmsley (2004) the initiative was underpinned by social model theorists, who argued that people with intellectual disabilities must be actively involved in research rather than passive recipients and that research should be pursued in their (people with intellectual disabilities) best interests.

With the aim of empowering people with intellectual disabilities and reducing social exclusion, poverty and inequality, the white paper influenced the promotion of what is commonly known as Person-Centred Care (PCC). As outlined in Mansell & Beadle-Brown (2004) paper PCC emphasises the importance of adopting an individualised approach to the development of services and policies. PCC centres on developing goals set by the person rather than the service and focuses attention on what can be achieved through the integration of resources e.g. family and wider services.

### **1.6.2 Emancipatory and Participatory Practices**

The Social Model of Disability focuses on the environmental and societal barriers experienced by disabled people, as well as the impact of anti-discrimination legislation (Durrell, 2016). Informed by these social model ideas, it was down to researchers within the field of disability

studies to find ways of involving and empowering people with intellectual disabilities (Walmsley, 2004). Out of this came the development of 'Inclusive research', an umbrella term for emancipatory and participatory research practices. These approaches emphasised service user involvement, endorsing the idea that research should be conducted *with* and not *on* people with intellectual disabilities; making them active participants and facilitators of research (Walmsley, 2004). Through involving people with intellectual disabilities as co-researchers, these approaches attempt to empower people with intellectual disabilities and promote '*valued social roles and positive images*' (Walmsley, 2001, p.202-203). As a result of this, it soon became an expectation of research to be inclusive of people with intellectual disabilities (Cluley, 2016). Despite these development in policy and practice, a similar pattern emerged to earlier efforts, as people with severe and profound intellectual disabilities continued to be rarely involved in research (Boxall & Ralph, 2010; Mietola et al., 2017; Cluley, 2016).

Influenced by the writings of Boxall and Ralph (2010), Mietola et al. (2017, p.264) described people with severe and profound intellectual disabilities as '*probably the most marginal group of disabled people in both society and in research*'. In both papers they argue that regardless of the efforts of inclusive research, people with severe and profound intellectual disabilities continue to be excluded from theoretical, methodological and empirical discussions. Researchers have made several speculations as to why this is. For example, Cluley (2016) argues that the epistemological parameters of traditional research methods are not inclusive of people who have severe and profound intellectual disabilities. In other words, through using interviews and focus groups (methods typically used within inclusive research) there is an implicit expectation that participants have certain cognitive and communicative capacities or 'intellectual skill' that are less accessible for people with severe and profound intellectual disabilities (Kiernan, 1999; Durell, 2016; Mietola et al., 2017). There have also been concerns regarding whether it is possible to ascertain the views of people with severe and profound intellectual disabilities (Cluley, 2016; Ware, 2004; Boxall & Ralph, 2010), particularly when participants are communicating at a pre-intentional level. Therefore, it is important that researchers be aware of the communication abilities of their participants, acknowledge the degree to which inferences are being made, and the limits of what can be achieved (Ware, 2004; Porter, Ouvry, Morgan, & Downs, 2001).

### 1.6.3 Ethical Considerations

Boxall and Ralph (2009, p.45) argue these uncertainties and concerns regarding ascertaining the views of people with severe and profound intellectual disabilities are *'further compounded'* by developments in research governance and ethical review in the UK. They specifically reflect on the impact of the Department of Health's Research Governance Framework for Health and Social Care and the Mental Health Capacity Act, 2005. Both these frameworks have led to stricter protocols and tighter administration of ethical committees on research. In their paper, Boxall and Ralph (2009) question whether the tightening of ethical measures will extend towards limits being placed on the application of *'untested creative methodologies'* that are required to involve people with severe and profound intellectual disabilities in research e.g. visual methodologies (Boxall & Ralph, 2009, p.45). There is of course, an important role for these frameworks within disability research. Yet it is important this does not prevent or prohibit studies being completed with people with intellectual disabilities, but support and facilitate them instead. As noted by Mietola et al. (2017, p.263) there is a need for ethical processes to *'account for the disparities of cognitive ability and power between researcher and participants'*.

Boxall and Ralph (2009) acknowledge that researchers themselves do hold uncertainties around how to conduct ethical and reliable research when it comes to involving people with intellectual disabilities. To support researchers applying to ethical committees, guidance has been developed in relation to conducting research with people with severe and profound intellectual disabilities (BPS, 2008). For example, the BPS (2008) has developed guidance around how to conduct research with people who have intellectual disabilities taking into account challenges around capacity and consent. In her paper, Walmsley (2004) explores the role of non-disabled researchers, arguing for the need of transparency of processes (i.e. what role did the participants have) and the central role of reflexivity of the non-disabled researcher (Durrell, 2016). In addition to this, Cameron and Murphy (2007), amongst others, have developed guidelines for researchers to consider how to include people with severe and profound intellectual disabilities in research, specifically in relation to capacity and consent.

#### 1.6.4 Development of Visual Methodologies

Researchers have argued that continuing to exclude people with severe and profound intellectual disabilities from research would remove the opportunity to gain insight into their subjective experiences and ideas of how to promote well-being (Tuffrey-Wijne, Bernal, & Hollins, 2008). Over the last decade, several studies have set out to explore how to directly involve people with severe and profound intellectual disabilities in research (Brewster, 2004; Boxall & Ralph, 2010; Cluley, 2016; Robinson & Eagle, 2018; Rojas & Sanahuja, 2011). Utilising visual methodologies (such as photovoice, drawings or videography), these studies have actively involved participants in research and offered the *'opportunity to voice their worlds visually'* (Cluley, 2016, p.42). Considered useful in engaging and empowering participants who are typically excluded from research the findings from these studies emphasise the importance of equal and exclusive participation (Robinson & Eagle, 2018). They also stress the need for the acceptance of visual methodologies as a *'medium to explore, know and understand'* (Rojas & Sanahuja, 2011, p. 36) more about people with severe and profound intellectual disabilities and have their voices heard (Robinson & Eagle, 2018).

Yet, studies using visual methods also acknowledge the limitations of such approaches. As noted there have been criticisms in relation to involving participants in research who are unable to provide their own or validate accounts made by those around them (Ware, 2004). As Brewster (2004, p. 166) notes, the interpretative nature of such visual approaches does run the risk of *'putting words into their mouths'*. Whilst inviting family members to participate allows the opportunity to draw on wider experiences, their accounts must not be considered *'absolute'* (Cluley, 2016). Rather the process of ascertaining views should be considered an on-going process (Brewster, 2004), one that utilises multiple sources of data and adopts methods to *'critically probe'* responses from carers and family members (Cluley, 2016). Furthermore, the studies stress the importance of holding realistic expectations of, not only, the abilities of people with intellectual disabilities (Ware, 2004) but also the questions asked by researchers themselves (Cluley, 2016). Ultimately, it is important that not only researchers take responsibility for conducting mediated approaches, but ethical bodies and academics accept that *'facilitating voices are sometimes necessary'* (Cluley, 2016, p.45) to avoid the exclusion of people with intellectual disabilities in research.

**1.6.5.1 Photovoice.** One form of visual methodology, that has a growing literature base, is photovoice (Booth & Booth, 2003; Cluley, 2016; Povee, Bishop, & Roberts, 2014; Shumba & Moodley, 2018). Conceptualised by Caroline Wang and Mary Ann Burris in the early 1990s, it was originally termed Photo Novella, meaning ‘picture stories’. They developed the method as a participatory action research tool to gain insight into the perspectives of health of rural women in China. As a result of this research, it was redefined by Wang and Burris (1997), to ‘Photovoice’ and described as ‘*a process by which people can identify, represent and enhance their community through a specific photographic technique*’ (Wang, 1999, p. 185). It has been applied in range of areas including, education (Strack, Magill, & McDonagh, 2004; Tomar & Stoffel, 2014), public health (Catalani & Minkler, 2010), the elderly (Spasiani, Meisner, Chacra, Heller, & Hammel, 2019) and disability studies (Booth & Booth, 2003; Sutton-Brown, 2014; Cluley, 2016). The approach centres participants in the study and offer’s ‘*greater decision-making agency than traditional researcher-directed studies*’ (Sutton-Brown, 2014, p. 171). This is important to meet the aims of inclusive research and researching *with* people who have intellectual disabilities rather than researching *on* people with intellectual disabilities (Cluley, 2016; Ellis, 2014).

Shumba and Moodley (2018, p.121) completed a scoping review of the application of photovoice and found there is a ‘*small but increasing interest*’ in the use of photovoice as a disability research method. Yet this review focused broadly on the use of photovoice with both physical disabilities and intellectual disabilities. In a specific review, focusing on the use of photovoice within intellectual disabilities research, Overmars-marx, Thomese and Moonen (2018), identified 11 papers, written between 2003 and 2014. They found variation across how photovoice was applied (i.e. additional forms of data collection, type of camera, length of time and number of photographs taken), the level of intellectual disabilities of people involved in the research and the way in which participants were recruited into the projects. They also found that the effectiveness of the approach varied with the needs and capabilities of the participants themselves.

Of the research completed with people who have intellectual disabilities, a limited number of these have included participants with more severe cognitive disabilities. Photovoice as a method, ‘*emphasises action over cognition*’ (Booth & Booth, 2003, p. 432) as it provides the opportunity for participants to ‘*voice their worlds visually*’, therefore making it accessible to

participants who have limited linguistic ability (Cluley, 2016, p. 42). However, some have argued that photovoice is not suitable for participants who are unable to communicate verbally (Jurkowski, 2008; Overmars-marx et al., 2018). This has mainly been due to the challenges faced in gaining participants' reflections on their photographs during the interview stage of the process (Overmars-marx et al., 2018). Of the studies reviewed, two included participants with limited or no verbal communication abilities (Aldridge, 2007; Povee et al., 2014). Participants were supported to point at the pictures, use gestures and facial expressions to convey their answers during the interview stage (Overmars-Marx et al., 2018).

In another study, published following this review, Cluley (2016) outlines how photovoice can be successfully used to include people with severe and profound intellectual disabilities in research. Whilst the project involved participants with a range of disabilities, the paper specifically focused on those with severe and profound intellectual disabilities, asking the research question, 'how is learning disability understood by both people with and without learning disabilities?' Cluley (2016) emphasised the importance of a flexible approach to inclusive research that accommodates for a range of abilities to avoid unwarranted claims, generalisations or further marginalisation of people with intellectual disabilities. Cluley (2016) also stresses the importance of being realistic about the type of research questions asked and acceptance that the structure and outcomes will be different from research involving those that do not have an intellectual disability. Cluley (2016, p. 44) advocates for the involvement of carers as coresearchers or '*allies*' and stresses that the importance of the '*plurality of voices is a necessary condition*' when including people with PMLD in research. If applied, Cluley (2016) concludes that it would be possible to conduct inclusive research that is accessible to people of all cognitive abilities and focuses limitations of methodology rather than individual limits.

In summary, there has been a growing interest in the application of visual methodologies as a way of directly involving participants with intellectual disabilities in research. This participation can support people with intellectual disabilities to tell their own stories and change the way in which they are, not only supported day to day but, viewed within society. Researchers acknowledge the challenges faced with utilising photovoice (and other visual methodologies) with participants who cannot provide their own accompanying story and meaning making (Aldridge, 2007; Jurkowski, 2008). Yet as Ware (2004, p. 178) states this does

not mean the inclusion of people with profound and multiple learning disabilities '*should be abandoned*', instead there needs to be flexibility in approaches and realistic expectations around the types of questions that can be asked and outcomes achieved. At present, there is limited research involving people with more severe and profound intellectual disabilities. Arguably, it is people with severe and profound intellectual disabilities, whose identities are more likely to be misrepresented due to the inability, for them, to confirm or deny the narratives that surround them. Therefore, identifying creative ways of involving participants with severe and profound intellectual disabilities in research, through giving them a visual voice, could help encourage people to re-evaluate how they perceive people with such needs and challenge the idea of being seen 'less than human' (Kamlager, 2013).

The following section will present the findings of a systematic literature review detailing how the notion of identity has been explored with people with intellectual disabilities. It will also review how photovoice can contribute to this field of research.

## **1.7 Systematic Literature Review**

Conducting initial searches for this literature review revealed there was very little research that explored the notion of identity, amongst people with intellectual disabilities, using a photovoice method, with only one paper being identified (Dorozenko et al., 2015). Therefore, the decision was made to broaden out the search to focus on how identity has been explored and what methods have been utilised to explore identity amongst people with intellectual disabilities. Therefore, the search criteria became 'intellectual disabilities' (alternatives: 'learning disabilities', 'learning disability', 'neurodevelopmental disability', 'neurodevelopmental disabilities') and 'identity' (alternatives: 'identities'). By doing this, it allowed for a more in-depth review of how identity has been explored amongst people with intellectual disabilities. For more details of the process involved in the systematic literature review please see Appendix A and B.

### **1.7.1 Identity and intellectual disabilities: A Systematic Review of the Literature**

The studies included are inclusive of anyone with intellectual disabilities rather than just people with severe and profound intellectual disabilities. The inclusion and exclusion criteria used for the systematic review, are displayed in table (1) below. A total of 15 studies were included in this literature review, with all, except two, adopting a qualitative design. Of the

two non-qualitative papers, one utilised a quantitative design and the other a mixed methods design. Seven of these papers were based in the United Kingdom (Craig et al., 2002; Dickinson & Hutchinson, 2019; Jahoda, Wilson, Stalker, & Cairney, 2010; McClimens et al., 2008; Moya, 2009; Monteleone, & Forrester-Jones, 2017; Salt, Melville, & Jahoda, 2019) and nine outside of the United Kingdom including, Sweden, Brazil, Poland, Australia and Norway (Dorozenko et al., 2015; Leite & Monteriro, 2008; Midjo & Aune, 2018; Mineur, Tideman, & Mallander 2017; Rapley, Kiernan, & Antaki, 1998; Rękosiewicz, 2018; Tideman & Svensson, 2015). One paper gathered participants from both in the United Kingdom and Australia (Anderson & Bigby, 2017).

All the papers included in the review identified their participants as having an intellectual disability with six, identifying 'mild to moderate' difficulties, three noting participants were 'unable to communicate verbally' and six not specifying but indicating participants were able to participate in a semi-structured interview.

Inclusion Criteria	Exclusion Criteria
<ul style="list-style-type: none"> <li>- People aged above 18 years with a diagnosis of intellectual disabilities.</li> <li>- People with intellectual disabilities participated as active participants in research.</li> <li>- Papers that set out to explore identity of people with intellectual disabilities; whether that be construction of identity, factors impacting on identity or identity expression.</li> <li>- Original research and not reviews</li> </ul>	<ul style="list-style-type: none"> <li>- Adults without a diagnosis of intellectual disabilities</li> <li>- Papers that focus on the experiences of those around the person with intellectual disabilities (e.g. mothers of people with intellectual disabilities or experiences of nurses or carers)</li> <li>- When the focus of the paper is not central to exploring participants identities rather the findings of the study explore identity</li> <li>- Disorder specific research i.e. Downs syndrome or Autism. Research only focusing on these participants experiences</li> </ul>

	<ul style="list-style-type: none"> <li>- Systematic reviews / meta-analyses</li> <li>- Editorials.</li> <li>- Books.</li> </ul>
--	---

*Table 1: Inclusion and Exclusion Criteria for Systematic Literature Review*

### **1.7.2 Assessing for Quality in Qualitative Research**

Assessing for quality in research is just as important for qualitative research, as it is for quantitative research. Mays and Pope (2000) argue that the same concepts of validity and relevance can be assessed but they just need to be operationalised differently. For example, methods of reflexivity, triangulation and clearly detailing methods of data collection, are just some ways validity can be assessed in qualitative research. Similarly, relevance can be assessed through the extent to which findings can be generalised and whether findings add to or increase confidence in existing knowledge (Mays & Pope, 2000). All the qualitative papers included were assessed for quality using a set of questions developed by Mays and Pope (2000). Papers were assessed in relation to whether there was sufficient evidence of the criteria (✓), partial evidence of the criteria (?) or a lack of evidence of the criteria (X).

The quantitative paper included in the literature review was also assessed for quality using a different tool. The Mixed Methods Appraisal Tool (MMAT) developed by Hong et al. (2018) was used because it was designed for systematic reviews and centres on assessing the quality of the methodological approach of papers which seemed important to the nature of the present study.

Paper / Quality Item (Mays and Pope, 2000)	Worth or Relevance	Clarity of Research Question	Appropriateness of the Design to the Question	Context	Sampling	Data Collection and Analysis	Reflexivity
Anderson and Bigby (2017).	✓	✓	✓	?	✓	✓	?
Craig et al. (2002)	✓	✓	✓	✓	?	?	?
Dickinson and Hutchinson (2018).	✓	✓	✓	✓	✓	✓	✓
Dorozenko et al. (2015).	✓	✓	✓	?	?	✓	?
Jahoda et al. (2010).	✓	✓	✓	?	?	✓	?
Leite and Monteiro (2008).	?	✓	?	✓	?	?	?
McClimens and Gordon (2008).	✓	✓	✓	?	?	?	?
Midjo and Aune (2018).	✓	✓	✓	✓	✓	?	?
Mineur et al. (2017).	✓	✓	✓	✓	✓	✓	?
Monteleone and Forrester-Jones (2016).	✓	✓	✓	✓	✓	✓	✓
Moya (2009).	✓	✓	✓	✓	?	?	?
Rapley et al. (1998).	✓	✓	✓	?	?	?	X
Salt et al. (2019).	✓	✓	✓	✓	✓	✓	?
Tideman and Svensson (2015).	?	?	✓	✓	?	✓	?

Table 2: Quality Measure of Qualitative Papers included in the Systematic Review using Mays and Pope (2000).

Methodological Quality Criteria	Yes	No	Can't tell	Comments
Is the sampling strategy relevant to address the research question?	✓			The paper provides a clear rationale for sampling and the procedure. Both of which are relevant to addressing the research questions.
Is the sample representative of the target population?	✓			The paper describes the target population and explains the reason why they were chosen in line with theory. The respondents that took part were in line with the target population.
Are the measurements appropriate?			✓	The questionnaire used in the study had been previously used in studies that tested its reliability and validity. The paper references these papers and gives a rationale for its application in the present study. Although, the present study uses an adapted form of the questionnaire to include people with intellectual disabilities, therefore, in it's current form the questionnaire had not been tested.
Is the risk of nonresponse bias low?			✓	The paper provided some details relating to participants that withdrew during the process of recruitment and data collection. It also gives some reasoning behind these but there is only limited information given

Is the statistical analysis appropriate to answer the research question?	✓			The paper provides a detailed description of the analysis process as well as the additional tests conducted and the reasons why. The statistical tests conducted were also relevant to the research question since an ANOVA is meant to explore variation amongst and between groups.
--	---	--	--	---

*Table 3: Quantitative Quality Measure for Rekosiewicz (2018) paper using Mixed Methods Appraisal Tool (MMAT; Hong et al. 2018)*

The next section will outline the studies included in the literature review. These papers have been systematically grouped according to their area of interest in relation to identity. Four key areas were identified 'stigma', 'self-advocacy and support', 'change and transition' and 'creative approaches'.

### **1.7.3 Systematic Literature Review**

**1.7.3.1 Stigma and the intellectual disabilities diagnosis.** As previously noted, intellectual disability is thought of as a master status; a label that embodies the whole person. Four studies included in this review directly explored the extent to which this is true for people who are diagnosed with an intellectual disability, the impact it has on their identity and other areas of their lives. Monteleone and Forrester-Jones (2017) interviewed 15 adults with intellectual disabilities, in the United Kingdom, with the aim of exploring how they experience their own disability and if there were any implications for their self-esteem, stigma and social interactions. Using an Interpretative Phenomenological Analysis (IPA; Smith, Flower, & Larkin, 2009 cited in Monteleone & Forrester-Jones, 2017), three major themes were identified; pressure to behave in a socially normative way, tendency to produce personal definitions of disability and limited knowledge of and discomfort around disability terminology. They found that participants clearly experienced feelings of difference and the way the label of intellectual disabilities was understood and utilised could negatively impact on their self-esteem, support systems and behaviour in society.

Craig et al. (2002) also explored the relationship that people with an intellectual disability have with their diagnosis but they also thought about what influence services have on this relationship. Unlike the previous study, Craig et al. (2002) utilised a mixed method design, which incorporated an audit of referrals, a focus group for service-users and a questionnaire for service-providers. They found, that whilst the audit of referrals to Clinical Psychology did not include requests for support in relation to identity conflict, the focus group identified that people with intellectual disabilities were aware of the stigma associated with the diagnosis and appeared uncomfortable with discussions that alluded to this identity. This was evident in participants tendency to portray themselves as non-intellectually disabled or draw on 'better than' comparisons with less able service-users. They concluded that their findings may indicate an unmet need in services and that careful consideration is needed with regards to how services manage identity.

Similarly, Jahoda et al. (2010) highlighted the importance of social and interpersonal factors in managing identities and roles for people with intellectual disabilities. Recruiting 15 young adults with mild to moderate intellectual disabilities, they explored how these young people experienced stigma and the impact of transitioning between childhood and adulthood on developing identities. Unlike many of the other studies, they utilised innovative methodologies, such as the use of video diaries and photographs, to support how the participants shared their experience. They concluded that stigma might increase a person's vulnerability to emotional and interpersonal problems. Yet the participants in this study were experiencing additional emotional difficulties. Residing within specialist mental health services, the generalisability of these findings, as acknowledged by the researchers, has to be taken into consideration.

Common amongst all three papers discussed so far, is a consensus that an intellectual disabilities label can be '*an aversive and toxic one*' (Rapley et al., 1998, p. 807). However, an earlier study conducted by Rapley et al. (1998) argued that rather than this identity being a static characteristic of a person, there is instead a fluid and dynamic nature to the identity that a person with intellectual disabilities can disown and negotiate depending upon the situation. Through using qualitative-interviews the researchers explored the quality of life perceptions of people with mild to moderate intellectual disabilities. They also interviewed primary caregivers. They explored the person's awareness of their disability and the consequences on their lives. They found that people were able to hold an understanding of their social standing and consequences, evident in two key themes; mobilisation of other people's perceptions and management of different identities for themselves.

**1.7.3.2 Self-Advocacy and support.** The following group of papers reflect the role self-advocacy and support services have on developing and maintaining identities of people with intellectual disabilities. Three studies explored the role of self-advocacy groups among people with intellectual disabilities. Self-advocacy can be thought of as the opportunity to create a 'self-authored' space, for people to have a say or develop skills to do so (Anderson & Bigby, 2017; Goodley, 2000; 2005). As noted by Mineur et al. (2017, p.1) '*the ability to express opinions and preferences is fundamental to all people*'; yet it is often a novelty for people with intellectual disabilities due to living '*highly constrained lives*' (Anderson & Bigby, 2017). In addition to this, the identities of people with intellectual disabilities are often impacted by

stigma, which can also (as noted above) have a detrimental impact on a person's self-esteem, relationships and emotional well-being (Anderson & Bigby, 2017; Craig et al., 2002; Monteleone & Forrester-Jones, 2017; Jahoda et al., 2010; Rapley et al., 1998). Self-advocacy groups can have an important role in addressing these difficulties, through enhancing the control they have over their own lives and supporting the development of a more positive self-perception, thereby increasing their health and well-being (Mineur et al., 2017; Tideman & Svensson, 2015). In addition to this, they aim to address and influence the disparities and attitudes towards people with intellectual disabilities at a social and political level (Tideman & Svensson, 2015).

The overarching aim of all three studies was to explore the effects of membership to self-advocacy groups on the lives of people with intellectual disabilities. Collectively, they explored the role of self-advocacy groups on a person's identity, the meaning and importance of their membership as well as the impact on a person's sense of independence. All the studies utilised semi-structured interviews, as the main method of data collection. Two of the studies (Mineur et al., 2017; Tideman & Svensson, 2015) also incorporated ethnographic approaches in the form of participant observations. The studies all recruited from multiple self-advocacy groups. Two of the studies were based in Sweden (Mineur et al., 2017; Tideman & Svensson, 2015) whilst one was based across both the United Kingdom and Australia (Anderson & Bigby, 2017). Only one study (Tideman & Svensson, 2015) utilised a longitudinal design, to explore the role of self-advocacy on people with intellectual disabilities and their experience in the Swedish welfare system, over a 10-year period.

The findings from all three studies support the view that self-advocacy 'can be a pathway to empowerment' (Miller & Keys, 1996, cited in Anderson & Bigby, 2017). There was a consensus, across all three studies, that self-advocacy groups could enable people with intellectual disabilities to develop positive identities. For example, Anderson and Bigby (2017) found that self-advocacy groups had an important impact on developing positive identities, such as being an 'expert' or 'business-like-person'. Similarly, Mineur et al. (2017) found that participants of self-advocacy groups felt more skilled and more socially confident. Tideman and Svensson (2015) note that the self-advocacy groups enabled people to develop alternative identities that were in opposition to those they would have been assigned by

society, highlighting the importance of a positive identity on the health and wellbeing of the person.

Another important finding was that membership of self-advocacy groups enabled people to develop a sense of independence (Anderson & Bigby, 2017). Across both the United Kingdom and Australia, participants of self-advocacy groups described being able to take ownership and control of their groups. Similarly, participants in Tideman and Svensson's (2015) study referenced their collective solidarity, the power and control to determine their needs, power to be able to think independently and control the resources that exist around them. On a wider level, a couple of the papers referenced the potential impact of self-advocacy groups on societal perceptions and treatment provision (Mineur et al., 2017) and countering the stigmatising labels that have obstructed acceptance in communities (Anderson & Bigby, 2017). Yet, Tideman and Svensson (2015) emphasise the need to specifically explore the impact of self-advocacy, over a longer period, to explore the wider effects.

In addition to the three papers that centred on self-advocacy groups, I have also included one additional paper that considers the role of support groups on identities of people with intellectual disabilities. This study explored membership of a theatre company group and the impact of the group on understandings and perceptions of intellectual disabilities. Adopting a qualitative design, Dickinson and Hutchinson (2019) conducted semi-structured interviews and focus groups for members of the theatre company, significant others and community supporters. Like the findings outlined above, membership of the theatre group for people with intellectual disabilities provided them with increased connectivity, a sense of being included and a sense of growth. Dickinson and Hutchinson (2019) concluded that these outcomes have important implications for changing how people with intellectual disabilities are viewed by society.

**1.7.3.3 Change and transition.** Three papers explored the impact of change and transition on a person's identity. These papers primarily focused on people with mild intellectual disabilities and their experiences during the transition from adolescence to adulthood. Generally considered a '*dynamic period in someone's life*', with changes in opportunities, responsibility and protection (Salt et al., 2019). Yet, as noted by Midjo and Aune (2018), there are additional social challenges on the 'path to adulthood' for people with intellectual disabilities, due to the stigmatising nature of the diagnosis and the tendency for

it to stick and overrule any other preferred identities. The three papers utilised a mixture of both qualitative and quantitative methods and were completed across a range of countries including Poland, Norway and the UK.

Adopting a qualitative design, Midjo and Aune (2018) utilised semi-structured interviews to explore the self-constructions of identity of people in late adolescence (18-24 years), in Norway. Rather than directly asking participants how they construct themselves, they focused on exploring what constructions of the self came out of narratives told about everyday life and aspirations for the future. They also interviewed parents and professionals, about the process of transition, to explore how they ascribe social identity to the young adults. The paper interestingly found a high degree of difference between groups and a high concordance within groups in relation to identity constructions, conceptualisations and descriptions of experiences. For example, the young adults referred to their position as '*autonomous actors in their own lives*' (Midjo & Aune, 2018, p.43). Whilst there were gender differences within this group, (with young men considering themselves in dependent positions and young women, already in independent positions) it was a theme identified across all discussions with young people. Within the parent and professional groups, they were both found to influence the young person's path and experience into adulthood. They identified that mothers typically constructed a more complex picture of the person's identity, highlighting a need for assistance and tendency to place the person in a position of dependency, out of concern. Professionals on the other hand, spoke of finding it difficult to balance the needs of the young person and requests made by parents. Midjo and Aune (2018) concluded that if people with intellectual disabilities are to develop their own resources, it is important they are given the opportunity to explore and express their social identities.

Using a similar approach, Salt et al. (2019, p. 901) specifically explored how people with mild intellectual disabilities '*conceptualise, relate to and experience the process of transition*'. Interviewing eight people with mild intellectual disabilities in the UK, they focused on topics of adulthood, and adult identity. Interpretative thematic analysis was chosen to study the data beyond the semantic content, to latent themes; as a principal goal was to gain interpretative depth rather than thematic saturation. They found themes that represented aspirations that were generally very similar to those of people without a diagnosis of intellectual disabilities, such as self-perceived maturity, a reluctance to adopt roles and

responsibility, wanting to feel in control and a desire to be shown trust and respect. As noted by Salt et al. (2019), these findings might reflect the emphasis that is placed on 'equal rights and opportunities'; therefore, it is not surprising there is an expectation from young people that they will lead 'ordinary lives'. Yet, despite this and the significant challenges and obstacles faced by people with intellectual disabilities, there remains limited research directly exploring how young people think and feel about growing up and adulthood.

The final paper, in this theme, adopted a quantitative approach, asking 127 participants, living in Poland, to complete a Dimensions of Identity Development Scale questionnaire. Drawing on the work of Erik Erikson, Rekosiewicz (2018) utilised Luyckx et al's Dual Cycle model of identity formation. It set out to explore changes in identity of individuals with mild intellectual disabilities in late adolescence and emerging adulthood. It was interested in whether there are specific changes in identity during certain developmental periods and whether these changes are similar regardless of whether people have a diagnosis intellectual disability. Like Salt et al. (2019), Rekosiewicz (2018) found that people with mild intellectual disabilities take a similar approach in making choices, the assessment of these choices and whether they feel good with the choices they make. This finding goes against the assumption that people with mild intellectual disabilities differ in respect to identity changes, during transition to emerging adulthood, from people without a diagnosis.

**1.7.3.4 Creative Methodological Approaches.** There were four studies in this review, that adopted alternative approaches to exploring identity amongst people with intellectual disabilities. Directly involving people with intellectual disabilities in research requires an element of flexibility when it comes to research design. As discussed above, Jahoda et al. (2010) utilised visual methods to explore how participants experience and manage stigma during emerging adulthood. Not too long ago, such innovative approaches would not have been so readily accepted, due to the assumption they lack academic rigour (Liebenberg, 2018). Researchers also struggled to identify ethical ways of including people, with intellectual disabilities, in research (Boxall & Ralph, 2009). This meant that much of the research conducted during the early 2000s involved those who were closely connected to the individual.

One example of this is Moya's (2009) study, exploring the use of Life Story Books and the construction of identities. Life story books originated in UK Social Service settings for use with

children, yet their use expanded to other areas, such as work with the elderly and people with intellectual disabilities (Moya, 2009). The project involved exploring how the books could be used in the transition of six people from a long stay hospital back into the community. None of the participants were able to communicate verbally so accounts were taken from nursing staff, in both the long stay hospital and community home. Moya (2009) was interested in how identities of people with complex support needs were maintained across the transition. Using discourse analysis, she found that despite the books being used differently, there was an over reliance on what was written in the book was a direct representation of the person. She also found they supported keeping the person's history alive, challenged care staff to seek alternative perspectives and encouraged readers to view the person as a *'human being rather than 'object' or 'subject''* (Moya, 2009, p.150).

In another innovative study, McClimens and Gordon (2008) explored how people with intellectual disabilities manage their identity as they engage in the blogosphere. The study explored the means and methods in which people with a diagnosis of Downs Syndrome manage their online and offline identities. With the increase in blogging as a method of communication there has been a growth of interest in exploring these forums. However, much like other areas of research, people with intellectual disabilities are 'absent from the debate' (McClimens & Gordon, 2008). The study utilised a variety of different methods including, signing participants up to a blogging site, adopting ethnographic observations of participants interactions, involving participants in a structured focus group and getting them to complete some self-reported questionnaires. The researchers themselves also kept a reflective journal as a space to note down memos and thoughts related to their observations.

The study found participants experienced difficulties expressing themselves and communicating across the blogosphere. Typically, a blog is an interactive process that involves creating a dialogue with other anonymous individuals. The reciprocal nature of blogging was missing from participants communication, meaning the interaction became more of a monologue without the anticipated feedback. This limited how well participants could co-construct their online identities and emphasised the importance of interaction with others. Drawing on sociological explanations of identity McClimens and Gordon (2008) reflected this study emphasises the importance of interaction, context and environment in expressing and constructing our identities.

The previous two studies are examples of how creative approaches can be utilised to involve participants with intellectual disabilities in research. As discussed earlier in the section, since the introduction of emancipatory and participatory practices, researchers have started to consider more visual based approaches to involving participants, with intellectual disabilities in research. The final study included in this review illustrates how photovoice, a type of visual methodology, can be used with participants with intellectual disabilities. Dorozenko et al. (2015)<sup>1</sup> conducted a photovoice study, in Australia, to explore the social construction of identity and social roles of people with intellectual disabilities. The study involved a group of 18 participants from an advocacy service, all with a range of intellectual disabilities; some who were unable to communicate verbally. Participants were positioned as co-researchers, with the opportunity to make decisions and exert control whenever possible. This involved being included in the identification of a theme for the project. Adopting a contextualist perspective, Dorozenko et al. (2015) utilised a photovoice methodology and conversational interviewing to explore participants experiences in relation to the picture they had taken. They utilised a causal layered analysis to deconstruct the data and explore deeper and more complex levels of meaning, such as world views, values, mythologies and culture.

Contrary to some views, the findings of the study suggested the participants' identities were derived from broader social contexts and social relations (such as relationships, leisure and work), with the label of intellectual disabilities being a salient identity. There were, however, these underlying worldviews that *'dehumanised and othered the members, constructing them as incompetent, a burden and innately different'* (Dorozenko et al., 2015, p.1360). They concluded the study has an important role in raising awareness of the larger social processes of dehumanisation.

As noted above, there is an increasing body of research exploring the use of photovoice as a creative, visual methodology. It has proven a popular method for including participants with intellectual disabilities because it's accessible, engaging and offers empowerment and

---

<sup>1</sup> Dorozenko et al. (2015) published several papers under two different names (one being a pre-marital). The other paper is referenced as Povee et al. (2014). These papers all reference the same data set. Dorozenko et al. (2015) is used in the literature review since it is the main paper published about the study.

inclusion of participants through direct participation in research (Booth & Booth, 2003; Povee et al., 2014).

#### **1.7.4 Synthesis of Findings**

Reviewing the literature above, illustrates there are layers of complexity to exploring and trying to make sense of the notion of identity. Of the studies reviewed, the majority draw reference to the social processes involved in the construction and management of identities and the impact a person's perceived identity can have on their own sense of self, self-esteem and opportunities available to them (Craig et al., 2002; Dorozenko et al., 2015; Jahoda et al., 2010). The collection of studies on self-advocacy demonstrate the importance of including people with intellectual disabilities in activities as this opens up opportunities for interdependence and can evoke changes in power relations for the person with intellectual disabilities (Anderson & Bigby, 2017; Mineur et al., 2017; Tideman & Svensson, 2015).

Many of these papers utilise semi-structured interviews as a method of collecting data. As discussed above interviews can limit the opportunities available to include people with more severe forms of intellectual disabilities. This can be demonstrated in the fact only three papers identified they involved participants who were unable to communicate verbally; illustrating the continued marginalisation of people with severe and profound intellectual disabilities in research (Jahoda et al., 2010; Moya, 2009; Dorozenko et al., 2015). Of these three studies, all drew on more creative methods of data collection and involved the people around the participant to support in the telling of their stories. This illustrates how adopting the use of creative approaches can generate new opportunities for people with severe and profound intellectual disabilities to be directly included in research.

All the papers elude to the challenges involved with conducting research, with people with intellectual disabilities. Yet, as noted above, this does not mean we should '*abandon*' (Ware, 2004, p.178) the opportunities to involve people with intellectual disabilities in research. Rather, through the combination of, research governing bodies accepting the use of more creative approaches and researchers, holding realistic expectations of what can be achieved and taking responsibility for conducting ethical research, people with severe and profound intellectual disabilities can be included in research (Boxall & Ralph, 2009; Ware, 2004). This

highlights the importance of identifying and trialling different creative methodologies as a way of involving people with severe and profound intellectual disabilities in research.

### **1.7.5 Critical Evaluation**

Of the fifteen studies included in this literature review, only three (Dickinson & Hutchinson, 2018; Dorozenko et al., 2015; Moya 2009) included participants with severe and profound intellectual disabilities. These studies utilised approaches that were inclusive of participants needs and allowed them to be involved in the research. Three other studies (Jahoda et al., 2010; McClimmens & Gordon, 2008; Mineur et al., 2017) utilised ethnographic approaches but only included participants with mild to moderate intellectual disabilities. The remaining studies utilised focus groups or semi-structured interviews which would have limited the engagement of people with severe and profound intellectual disabilities. Additionally, not including participants with severe and profound intellectual disabilities limits the generalisability of the findings around identity from these studies.

A trend across most of the studies in this review was the use of social constructionist perspectives of identity; emphasising the fluidity and co-construction of identities within society. Four of the studies (Jahoda et al., 2010; Leite & Monterio, 2008; Midjo & Aune, 2008; Tideman & Svensson, 2008) utilised longitudinal designs ranging from 6 months to 10 years. Adopting this length of study complements a social constructionist perspective since it enables the fluidity of identity to be explored through gathering more in-depth understandings of identity. Additionally, four studies (Craig et al., 2002; Dickinson & Hutchinson, 2018; Midjo & Aune, 2018; Moya, 2009) included a range of perspectives from people around the person further adding to their understanding of perceived identities. When conducting research with people with intellectual disabilities, including the views of people around the person can be valuable, particularly if they are unable to provide verbal accounts themselves (Ware, 2004; Cluley, 2016).

There were a good range of studies completed across the UK, Europe and Australia. However, all these studies favour conceptualisations of identity and the experiences of Western cultures and societies. This limits the generalisability of findings to these populations and is exclusive of Black Asian and ethnic minorities (BME). Understanding the experiences and conceptualisations of identity amongst BME populations would be important since it may

offer insight into similar or different experiences and how these correspond with perceptions held within society and how services and policies are influenced. Furthermore, only two studies (Dickinson & Hutchinson, 2018; Monteleone & Forrester-Jones, 2016) provided a reflexive account of their relationship to the topic and insight into their own positions. This provided an additional layer of understanding when reviewing the findings and outcome of the studies.

#### **1.7.6 Rationale for Current Project**

As illustrated in this chapter whilst there is a good body of literature surrounding identity amongst people with intellectual disabilities a limited number of these studies have included people with severe and profound intellectual disabilities. Arguably it is people with severe and profound intellectual disabilities whose identities are more at risk of being misrepresented, constructed by negative associations or stigma due to their difficulties communicating verbally. Whilst there are challenges to including people with severe and profound intellectual disabilities in research, creative methodologies such as photovoice have been shown to offer inclusivity. Therefore, the present study aims to discover whether photovoice can explore identity expression amongst people with limited or no verbal language. It is specifically interested in the following research questions:

1. How do people with intellectual disabilities and limited or no verbal communication express their identities?
2. Can photovoice be used as a research methodology to engage people with intellectual disabilities and limited or no verbal language?
  - i. Can we learn anything new about the person's identity through participation in the photovoice activity?
  - ii. Can we learn more about the person's identity through integrating ethnographic ideas, photovoice and dyadic interview components?

## **2. Methodology**

*'Well begun, is half done'.*

*(Quote from Aristotle)*

The aim of this chapter is to provide an overview of the methodology developed to explore the research question. It will begin by providing a rationale for the use of qualitative methods and a detailed explanation of the development and implementation of the methodology. Within this, it will outline how the method has been developed from previous research completed in the field, the recruitment procedure, participant information and ethical considerations. It will then detail how the methodology was implemented and the type of analysis used.

### **2.1 Design**

#### **2.1.1 Qualitative vs. Quantitative**

It is now common practice for researchers to equally consider not just quantitative approaches to understanding a research query, but qualitative approaches as well. Centring on descriptive rather than causal explanations qualitative approaches are interested in understanding the processes of meaning making that underlie people's understandings and interactions with the world (Pathak, Jena, & Kalra, 2013). Deciding on which approach to take, whether it be qualitative or quantitative, came down to considering the different epistemological, theoretical and methodological underpinnings for both approaches (Yilmaz, 2013). Unlike quantitative approaches that typically *'assume a common objective reality'*, qualitative approaches accept there are multiple realities and the best way to explore and interpret these is using naturalistic methodologies (Newman, Benz, & Ridenour, 1998, p.2). With this in mind, it was felt a qualitative multiple case study approach would be most appropriate, since it aligns with the project's epistemological position, the exploratory nature of the research questions and the phenomenological position that people can hold multiple perspectives of reality that are equally valid (Dempster, 2011).

As noted by Corbin and Strauss (2007, cited in Ellis 2014, p.44) conducting qualitative research provides researchers with opportunities to get to know people, understand things from their perspective and *'connect with them [participants] on a human level'*. Often taking place in a person's natural context (such as day to day environments) qualitative research is interested

in understanding the processes interaction and to *'make sense of or interpret phenomena in terms of the meanings people bring to them'* (Denzin & Lincoln, 2005, p.3). This complements an important aim of this research, since it sets out to connect with individuals who have a diagnosis of intellectual disability with limited or no verbal language and explore how they express their identity (Ellis, 2014) and tell their stories (Baxter & Jack, 2008) in their own contexts.

In line with a qualitative methodology, the social constructionist position I take for this research, will consist of viewing an individual's identity expression as a fluid and dynamic process that is responsive to the individual's interpretation and knowledge of what they deem to be 'identity'. Therefore, like previous research (see Robinson & Eagle, 2018), the project does not aim to find one 'truthful identity' but assumes there are multiple identities that are fluid in relation to context and interaction. Adopting this position assumes what we come to know about a person's identity is not fixed but shaped by the person's interactions with the world around them (Gergen, 2015; Karavella, 2013; Robinson & Eagle, 2018).

Qualitative research methodology *'recognises that the subjectivity of the researcher is intimately involved in [the] scientific research'* (Ratner, 2002 p.1). As a researcher completing this project, it is important to consider my own position in relation to the research questions, the research context and the participants. As Duncan (2013, cited in Robinson & Eagle, 2018) highlights, the researcher is thoroughly intertwined in the research process. Therefore, holding this in mind I must consider my own identity; my position as a trainee clinical psychologist and sister to a brother who has a diagnosis of ASD. Incorporated into the design of this project will be space to reflect on these issues and consider their relationship to the whole process. This will be completed through keeping a reflective journal throughout the whole process; from the study's conceptualisation, right through to dissemination (see Appendix C for extracts from the reflective journal).

**2.1.1.1 Assessing for quality in qualitative research.** The question of academic rigour in qualitative research is well known (Davies & Dodd, 2002; Gelo, Braakmann, & Benetka, 2008). This has led to a longstanding debate around the need to assess the quality of qualitative research (Mays & Pope, 2000). It is now generally considered an important step in the completion of any qualitative research project (Mays & Pope, 2000; Gómez, 2009). There have been multiple tools developed to assess quality with the aim of trying to provide choice

so that the criteria being used can depend upon the topic and purpose of the research (Mays & Pope, 2000; Probyn, Howarth, & Maz, 2016). For this research project, it was important to consider the theoretical underpinnings and quality of methodology. A quality appraisal tool introduced during clinical training that focuses their criteria on these areas is Mays and Pope (2000). Mays and Pope (2000) outline questions that can be asked of any piece of qualitative research during any point of its life with the aim of improving its quality. These have been considered throughout this research project (see Appendix D).

### **2.1.2 Adopting a Qualitative Multiple Case Study Approach**

It was important to identify a qualitative methodology, which supported creative and flexible methods of data collection, whilst remaining academically rigorous. Therefore, drawing on the study's aims, research questions and previous research (Baxter & Jack, 2008; Coons & Watson, 2013; Ellis, 2014; Gustafsson, 2017; Llewelyn, 1995; McDonald, Kidney, & Patka, 2012; Thompson, 2018), the decision was made to adopt a multiple case study approach. Defined by Baxter and Jack (2008, p.544) as *'research that facilitates exploration of a phenomenon within its context using a variety of data sources... this ensures the issue is not explored through one lens, but rather a variety of lenses'*.

This definition illustrates how a case study approach suits the epistemological position adopted for this research project as it was important to consider identity from multiple lenses across different contexts. Furthermore, it speaks to adopting naturalistic observations in context and utilising multiple sources of data collection. As noted by Yin (2012, p.13) one of the benefits of this is that it allows for the data to be triangulated *'to establish converging lines of evidence to make findings as robust as possible'*. Combining multiple sources of data and naturalistic observations allows the researcher to explore a phenomenon *'in-depth'* and *'within its real-life context'* (Yin, 2006, p.111).

The benefits of adopting a case study approach, namely, multiple sources of data and naturalistic observations, met with the aims of the research project, i.e. involving people with intellectual disabilities in research and exploring the notion of identity. As noted by Stake (1995, cited in Thompson, 2018) observing people with intellectual disabilities in their own contexts helps the researcher connect with people and get to know them within their real-life contexts. Additionally, existing research, completed with people with intellectual

disabilities, has suggested that integrating multiple methods of data collection and adapting these to the persons needs can be beneficial to involving them in research (Coons & Watson, 2013; McDonald et al., 2012; Nind, 2008). The decision to use multiple cases meant that not only could the data be triangulated within each case, but similarities and differences could be established across cases (Baxter & Jack, 2008; Gustafsson, 2017; Yin, 2012). Therefore, a multiple case study approach, would not only strengthen findings and reliability (Baxter & Jack, 2008) but it would also offer the opportunity to explore the similarities and differences across different experiences (Gustafsson, 2017). Lastly, according to Yin (2012) a case study methodology is useful to projects that involve either ‘*descriptive questions*’ (i.e. what is happening) or ‘*explanatory questions*’ (i.e. how or why it is happening). This suited the study’s aim of exploring how photovoice could involve people with severe and profound intellectual disabilities in research but also whether it could explore identity expression amongst this population.

### 2.1.3 Layers of Data Collection

Collecting data from multiple sources supports a flexible research methodology that is responsive to the needs of participants and appreciates the complexity of exploring identities (Ellis, 2014). The different layers of data collection methods incorporated into this project’s design are outlined below (see also Figure 1 below).

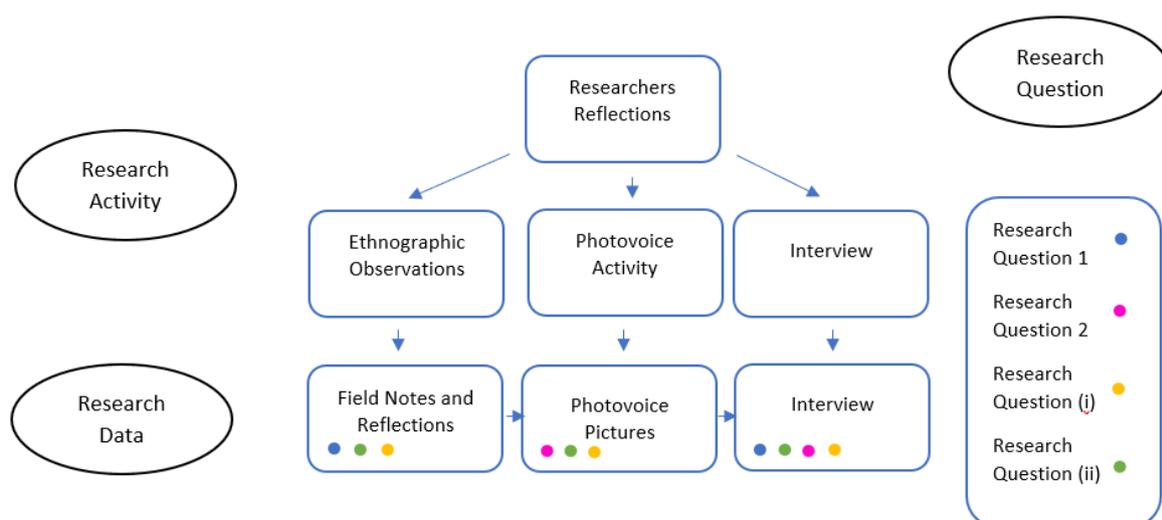


Figure 1: Visual Model of the Research Design (Adapted from Thompson, 2018)

**2.1.3.1 Ethnographic observations.** Based on previous research, one aspect of this project adopted an ethnographic approach to collecting data (Bagatell, 2007; Finlay, Walton, & Antaki, 2008; Hubert & Hollins, 2010; Ellis, 2014). Ethnography *'is the study of people in naturally occurring settings or 'fields' by methods of data collection which capture their social meanings and ordinary activities'* (Brewer, 2000, p.6). It is the researchers aim to immerse themselves within the group, observing and interpreting everyday behaviour (Holloway, Brown, & Shipway, 2010; Ellis, 2014; Fusch, Fusch, & Ness, 2017). Whilst traditional ethnographic research is longitudinal, this project will adopt a mini-ethnographic approach, only lasting several months (Ellis 2014; Fusch et al., 2017). More suited to the time constraints of doctoral students, mini-ethnography can offer a more focused method of inquiry that allows the researcher to explore the interconnectedness of culture, values and relationships (White, 2009, cited in Fusch et al., 2017). This approach is particularly suited to the aims of the project since it allows naturalistic observation of how individuals with intellectual disabilities express their identity in their own contexts allowing for the opportunity to gather richer data. As highlighted by previous research (Finlay et al., 2008; Hubert & Hollins, 2010), ethnographic approaches are considered valuable when conducting research with individuals who have intellectual disabilities since the eclectic methods are flexible and responsive to the needs of the individual, allowing for their *'voice to be heard'* (Ellis, 2014).

**2.1.3.2 Photovoice.** Photovoice involves providing participants with a camera so they can *'allow others to see the world through [their] eyes'* (Glaw, Inder, Kable, & Hazelton, 2017, p. 2). Described as the *'daughter of many mothers'*, Wang and Burris (1994, p.172) state the ambition and theoretical underpinnings, of photovoice, as something that emerged from multiple sources, including practical and theoretical approaches to empowerment, feminist theories and non-traditional documentary photography. Photovoice empowers people to identify shared issues, that mirror *'everyday social and political realities'* and the need to inform policymakers (Wang & Burris, 1994, p.174). The influence of feminist theories and methods has emphasised the importance of participants not only constructing their own knowledge about themselves but becoming empowered through the act of this knowledge making (Wang & Burris, 1994). This stresses the idea that participants are actively involved in research, not passive recipients and that knowledge not only comes from the findings but also in the act of knowledge making itself. Finally, influenced by researchers within documentary

photography, photovoice places a “camera directly in the hands of people who otherwise would not have access and allows them to be recorders and potential catalysts in their own communities” (Wang & Burris, 1994, p.175).

Photovoice involves a series of nine procedural steps; (i) select and recruit target audience, (ii) recruit participants, (iii) introduce photovoice methodology to participants, (iv) obtain informed consent, (v) identify an initial theme, (vi) distribute cameras, (vii) provide time to take pictures, (viii) meet to discuss photographs, (ix) plan a format to share photographs and stories with policy makers or community leaders (Wang, 1999; Cluley, 2016). Whilst there is a prescriptive element to these steps, Wang and Burris (1997) emphasise that there are many ways in which photovoice can be applied, across different contexts, with different groups and communities and for different purposes. This adaptability within the photovoice methodology has led to variability in its application across a wide range of contexts including, public health, education, disability studies and with refugees (see Sutton-Brown, 2014). Like previous research involving people with intellectual disabilities, (see Catalani & Linkler, 2010; Sutton-Brown, 2014), these steps were used as a guideline and not rigidly kept to so to meet the needs of participants.

**2.1.3.3 Interviews.** Typically, participants who participate in photovoice are invited to reflect on their pictures and tell their story. The participants invited to take part in this project were unable to provide verbal descriptions of their photographs. Rather than just excluding participants, interview strategies were integrated into the method to try and keep the participants as central as possible.

Firstly, the interview drew on the procedure outlined in Annabel Head’s (2017) research which explored the experiences of people with intellectual disabilities, during transition through the Transforming care programme. Head (2017) built on the work of Caldwell (2013) and utilised a Dyadic Interviewing technique. The process involves interviewing people in pairs rather than individually. The method emphasises interdependence and ‘*recognises the value of interconnected relationships*’ (Caldwell, 2013, p.492). In this project, participants were interviewed alongside their family and carers, but emphasis was placed on providing opportunities for them to communicate their preferences where possible, this was then reflected on with family and carers.

Secondly, Head (2017) also combines this method with a systemically informed interview approach called the 'internalised other' by Karl Tomm (1999 cited in Mudry et al., 2017; Haydon-Laurelut, 2013). As Head (2017) notes, this family therapy technique, invites members of the family to step into another's shoes and explore issues from multiple perspectives. For this project, family members were asked to do this throughout the interview. Due to the nature of the participants' needs, participants were unable to confirm or deny whether the carers/families' presumptions/ interpretations align with their own views. Therefore, in line with Cluley (2016) this study adopted Boxhall's (2010) approach to including carers' voices. This involves critically probing the carer's responses to the pictures such as '*what makes you think that?*' to help get a better understanding of the carer's response and where it comes from.

**2.1.3.4 Researcher's reflections.** In line with the positioning of the researcher in this project, an important aspect of the design is the researcher's reflexivity. As defined by Ellis (2014, p. 64) reflexivity is used to study the interactions between researcher and participants at a deeper level by moving the observational lens from '*focusing on the others' social and cultural experiences; to looking inwards exposing the vulnerable self*'. The aim was not to remove all bias, since this would be impossible (Amerson, 2011, cited in Fusch et al., 2017). It was more about encouraging conscious awareness of the researchers' values and make visible the '*constructed nature of research outcomes*' (Ortlipp, 2008, p.695).

#### **2.1.4 Triangulation**

As noted above, one of the benefits of utilising multiple methods of data collection, is that the data can be triangulated to identify converging lines of evidence. Triangulation can be described as combining methods (or theories or observers), in a research study, to answer a particular research question(s). Triangulation is a systematic process that involves the researcher identifying patterns, across and between data, to validate the analytic process (Mays & Pope, 2000). Through combining methods, it can help avoid biases that may arise out of just one method, help explore and explain complex issues and increase credibility and validity of research findings (Heale & Forbes, 2013; Noble & Heale, 2019; Yin, 2004). It has also been identified as a useful method when conducting research with people with intellectual disabilities, (Llewellyn, 1995) since it offers flexibility and allows for participants' preferences to be met through different methods of data collection. This study combines

ethnographic field notes, photovoice and interview data. I will explain the process of triangulation in more depth in the data analysis section below.

### **2.1.5 Reflexive Thematic Analysis**

There are no prescribed 'formulas' when it comes to analysing data collected from case study research (Yin, 2004) and many studies adopt a range of analytic procedures (most commonly content analysis, narrative analysis and thematic analysis). Taking into consideration the research aims, research questions and methods of data collection, the decision was made to utilise a Thematic Analysis approach.

Braun and Clarke (2006; 2012; 2018; 2019) define TA as '*...a method for systematically identifying, organising, and offering insight into patterns of meaning (themes) across a data set*' (Braun & Clarke, 2012, p.57). TA involves the iterative process of systematically reading and coding the data until themes are generated. It offers a way of analysing data, that doesn't necessarily rely on the researcher having a detailed theoretical understanding, in contrast to the need to understand language in narrative or discourse analysis for example (Braun & Clarke, 2012). Braun and Clarke's (2006; 2012; 2018; 2019) approach is just one of many different approaches to TA yet, the flexibility of their approach and emphasis on reflexivity and transparency (Braun & Clarke, 2019) are the reasons why it was chosen over other approaches. In addition to this Braun and Clarke (2006; 2012; 2018; 2019) argue that if implemented well it can be considered a rigorous approach to analysis. These ideas also met with the aims of this project as well as what has been recommended when conducting research with people with intellectual disabilities (Nind, 2008; Mietola et al., 2016). I explain the process of applying TA during the data analysis section below.

### **2.1.6 Application of Other Methodologies**

Whilst there has been a welcome shift to include people with intellectual disabilities in research, only a small proportion of such studies have included people with more severe and profound difficulties (Ware, 2004). Therefore, when considering methodologies for this study, it was important to review previous research. Other than photovoice, other visual methodologies such as videography and drawings had been utilised (Robinson & Eagle, 2018; Kaley, Hatton, & Milligan, 2019). Visual methodologies, including both drawings and videography were considered as they allow flexibility and the opportunity for the person to

express themselves independently. However, due to the limited research in both areas, involving people with more severe and profound difficulties, it was felt photovoice offered more of an evidence-based approach.

In terms of analysis, content analysis is another popular method of data analysis in both case study approaches and photovoice (Aldridge, 2007; Kohlbacher, 2006; Warne, Snyder, & Gadin, 2013). Like TA, whilst there are many different forms of content analysis (Hsieh & Shannon, 2005), it can be defined as *'the systematic reading of a body of texts, images, and symbolic matter not necessarily from an author's or user's perspective'* (Krippendorff, 2004, p.3). In practice it involves, a process of defining a set of units of meaning that the data will be coded in relation to (e.g. frequency of individual words and phrases) and then create categories in relation to the units identified to identify patterns of meaning. There were two main reasons for using TA over Content Analysis. Firstly, content analysis adopts more of a 'descriptive' approach to coding and interpretation of the data, rather than a more detailed and nuanced approach (Braun & Clarke, 2006), that goes beyond the descriptive. Secondly, the quantitative element of the approach did not sit well with the epistemological position of the study, nor in the idea that identity was something unique to the person.

Narrative analysis is interested in exploring *the 'human stories of experience'* (Webster & Mertova, 2007, p.1) and how these stories express different versions of the self, constructed using language (Burck, 2005). This method would have provided some interesting insight into the lives of people with intellectual disabilities. However, for the participants invited to take part in the project, communication with others and the world around them, is predominantly done through other means; such as gestures and behaviours, not speech. Therefore, the rich descriptions necessary for narrative analysis would have had to have come from those around the person, i.e. via friends, family and carers. The very act of doing this decentres the person and loses their voice. Therefore, the decision was made to continue with qualitative case studies integrating ethnographic approaches and photovoice as this allowed for the person with intellectual disabilities to be involved directly in the project thereby keeping them and their 'voice' at the centre.

### 2.1.7 Methodological Considerations and Adaptations

Important steps were taken, when designing the research methodology, to make it as accessible to people with intellectual disabilities as possible (Nind, 2008; Head, 2017). In the following section I will summarise some of the methodological considerations made as well as the steps taken to alleviate any challenges.

**2.1.7.1 Issues relating to interpretation and ascertaining views.** Visual methodologies (such as photovoice) can provide a means of including people in research and asking questions about topics, that would normally be limited by traditional methods (Glaw et al., 2017). In their paper, Glaw et al. (2017) highlight the important role visual based methods have in relation to adding layers of meaning to data and tackling issues of power between participant and researcher. Photographs enable participants to express themselves using non-verbal methods which can then be explored in more detail through discussion and reflection. However, for people with intellectual disabilities, specifically those with limited or no verbal language, it is not possible to provide those rich descriptive accounts. Whilst Pink (2007, cited in Cluley, 2016) acknowledges that talking about pictures can provide an extra layer of meaning, she also states that images can stand alone and provide insight into a person's life. Aldridge (2007) argues against interpreting pictures without having heard the story of the photographer due to issues of misinterpreting or misrepresenting their experiences.

However, concerns have been raised about whether it is possible to obtain the views of people with severe and profound intellectual disabilities as well as whether they have views about complex conceptual issues at all (Ware, 2004). In her paper Jean Ware (2004) acknowledges the importance of involving people with severe and profound intellectual disabilities in research rather than excluding them. Yet she also stresses the need to be realistic about the type of research questions asked, the capabilities of participants, the interpretative nature of analysis and the need for advocates (also termed proxies) to help provide a view on abstract issues. Therefore, to account for the issues raised by Ware (2004) and Aldridge (2007), family members and carers were invited to take the role as advocates in the research. They were specifically asked to reflect on the process of involving the participant in the photovoice activity and provide explanations of the photographs, rather than the photos being interpreted by the researcher. As Cummins (2002 cited in Ware, 2004) notes those closest to the individual are the most reliable advocate. Yet, those closest to the person

may struggle to separate their own views from those they believe to be held by the participant. Therefore, following advice from Clegg (2003 cited in Ware, 2004) family and carers were asked to position themselves in the shoes of the participant during the interview and were also provided with the opportunity to express their own views.

**2.1.7.2 Research ‘with’ vs. ‘on’: Issues relating to power.** People with severe and profound intellectual disabilities remain ‘*virtually missing*’ from the field of disability research, despite the ‘*drive towards their empowerment*’ through emancipatory and participatory practices (Mietola et al., 2017, p.264). There remain significant barriers to their inclusion in research due to the methodological and theoretical traditions of the field as well as the ableist ideologies that exist in the world (Mietola et al., 2017). In light of this, there is a political nature to qualitative research with people with intellectual disabilities that must be acknowledged. In her paper, Melanie Nind (2008) uses a quote from Kiernan (1999, p.43) to emphasise the power of the researcher and the less powerful researched:

*The goal of qualitative research is quite explicitly to ‘ground’ studies in the experience and views of respondents. Nonetheless, even in qualitative studies, it is the researcher (or, in externally funded research, the funding body) who determines the overall research questions, and the researcher who gathers, analyses and interprets the data and draws conclusions.*

As noted by Walmsley (2004) non-disabled researchers have an important moral and ethical role in empowering people with intellectual disabilities in research. This can be enacted through taking seriously the ongoing support role they hold in the research and the relationship they have with services, participants and families. Nind (2008) also notes it is important for researchers to consider the questions they ask in relation to their methodological approach. She uses Tuffrey-Wijne et al. (2008) as an example of good practice in research since rather than asking ‘if’ people with intellectual disabilities should be included in research, they centre their questions on ‘*how*’; how to include, how to support and how to understand.

In line with these ideas, this project aimed to include a flexible methodology to accommodate the needs of participants. For example, including the use of an iPad alongside a camera meant participants could use technology they were familiar with. Whilst a strict emancipatory and

participatory approach was not possible, due to the scope and scale of the project, the methodology chosen attempted to centre the person with intellectual disabilities through using ethnographic approaches, the application of photovoice and its interviewing techniques. Being aware that '*power imbalances are often camouflaged by a rhetoric of participation*' (Johnson and Walmsley, 2003, p. 191), as lead researcher I kept a reflexive journal to ensure I monitored my own biases and reflected on the process of completing the project. In doing so I aimed to be as transparent as possible throughout the project so its process and challenges could be shared with others.

## **2.2 Participants**

### **2.2.1 Inclusion and Exclusion Criteria**

Participants recruited for this project were people with a diagnosis of intellectual disabilities, a member of their family and a carer, who knew the person well. The participants in this study were people who had a diagnosis of intellectual disabilities as identified by the DSM-V (see Introduction for description of criteria). Comorbid diagnoses such as Autism Spectrum Conditions were considered on a case by case basis. As recommended by previous research, when selecting participants, consideration was made with regards to the person's ability and familiarity with using a camera (Aldridge, 2007; Povee et al., 2014; Overmars et al., 2018)

### **2.2.2 Participant Recruitment**

Recruitment of participants involved contacting private health care providers across three counties in the Midlands. These health care providers offered a range of services, including, residential services, day centre support, respite and supported living accommodation for adults with intellectual disabilities. Initial contact with services was made via telephone and email. This provided the opportunity to talk to managers about the project, answer questions and offer the provision of further information. Services that agreed to support the project were provided with a consent form that outlined their role in the recruitment of participants (see Appendix E and F). In total, one educational service, was used to recruit all participants and families for this study. Although other care support services were contacted, they were unable to commit to offering their support in the recruitment of participants. To support the recruitment of participants this service was provided with a brief easy read information sheet

(see Appendix G), a project flyer (see Appendix H), a photovoice activity information sheet (see Appendix I) and a family/carer information sheet (see Appendix J).

In collaboration with the service, potential participants were identified using a purposive sampling method, in line with the participant criteria, outlined above. Contact was initially made with parents who provided their consent to meet with their son or daughter. A meeting (or telephone conversation) was then organised to begin the process of assessing for consent and to talk through the project in more depth (following guidelines set out by Cameron & Murphy, 2007; for consent process see ethical considerations). The discussion also allowed for any adaptations to be made to information sheets to ensure it was accessible for each person. An on-going consent procedure was then followed (see Consent and Capacity Section for more details).

Park (1993 cited in Povee et al., 2014, p. 897) emphasises the benefits to researchers knowing *'the community of interest, personally as well as scientifically'* since this can aid the researcher conduct meaningful research and immerse themselves in the system (Turnbull, Friesen, & Ramirez, 1998 cited in Povee et al., 2014). Some of the charities contacted to participate were known to members of the research supervisory team, through previous employment, participation in research and contact through clinical work. This enabled us to understand the values endorsed by the charities, an awareness of the needs of the population they supported and a familiarity with practices which would contribute to the integration within the community and in communicating with participants and their families. In addition to this, my own awareness and experience of caring for my brother with Autism provided me with additional resources and knowledge that I could draw upon when developing rapport with all participants.

### **2.3.3 Participant Information**

All participants in this project have a diagnosis of intellectual disabilities along with other co-morbid communication difficulties such as Autism Spectrum Condition. In total three people with intellectual disabilities took part, alongside their parents and three carers (two Key Workers at College and one Key Worker in Supported Living). Other carers were invited to participate although the timings of the interview and impact of COVID-19 meant they were unable to participate. Participants were aged between 20 and 22 years. The details of each

participant are outlined in the table below. The decision to include three case studies in this project was directed through reviewing the literature (Baxter & Jack, 2008; Creswell, 2013; Yin, 2004) and previous research that had adopted similar methodologies i.e. multiple sources of data (Thompson, 2018). Three cases allowed for enough data to be collected for cross-case analysis (Creswell, 2013) and meant enough time could be spent with each person during field observations (Gustafsson, 2017) within the allocated time for the project.

<b>Participant Pseudonym</b>	<b>Participant Age</b>	<b>Participants Ethnicity</b>	<b>Participants Diagnosis</b>	<b>Family and Carers Interviewed</b>
Chloe	20	White British	intellectual disabilities and Autism	Mother and Father
Buddy	21	Mixed Race	intellectual disabilities, Downs Syndrome, Autism Spectrum Disorder and severe Physical Health Difficulties	Mother
Oscar	22	White British	intellectual disabilities and Autism	Mother and Keyworker

Table 4: Participant Details

## 2.3 Ethical Considerations

### 2.3.1 Ethical Approval

As noted by (Sanjari, Bahramnezhad, Fomani, Shoghi, & Cheraghi, 2014, p. 1) researchers conducting qualitative *research 'face ethical challenges in all stages of a study, from designing to reporting'*. Therefore, previous research has been reviewed and ethical guidelines followed to support the development of this project's methodology to ensure the project is ethically appropriate (Loyd, 2013). This research project was granted ethical approval by Health, Science, Engineering & Technology Ethics Committee with Delegated Authority (ECDA) at Hertfordshire University on 25<sup>th</sup> October 2019 (Protocol no: aLMS/PGT/UH/03863(3)). See Appendix K for ethics approval notification letter. When observations or interviews were

completed in participant's homes, local Trust Lone working policies were adhered to throughout.

There are important ethical considerations to make when conducting research with people who have moderate to severe learning difficulties, such as determining capacity, assessing for consent, communication and expression of views, withdrawal from research as well as practical and methodological challenges. In the past, these have acted as barriers to engaging people with such needs in research and can go some way to explaining why there is such a lack of research involving this population. Yet as noted by Boxhall and Ralph (2009) the fact the perspectives of people with learning disabilities who lack capacity are missing from research, is an 'ethical issue in itself'.

### **2.3.2 Capacity and Consent**

For participants with intellectual disabilities, careful consideration must be taken when thinking about capacity and consent. The participants invited to take part in this project all lacked capacity to consent so specific guidelines set out by the British Psychological Society (BPS, 2008) were followed. Initially, the process involved contacting gate keepers of prospective participants i.e. care managers and family, to provide information about the project and gain their consent to meet with the young person. In line with the BPS guidelines, parents of the participants were requested to act as a 'personal consultee'. A personal consultee is a person who is interested in the prospective participants' welfare, consulted on the prospective participants' wishes and feelings about participation in the project and advises on whether the participant, if they had capacity, would agree to participate (BPS, 2008). It is important to note this consultee *'does not give consent on behalf of the participant, but rather the researcher seeks advice from the consultee'* (BPS, 2008, p.21). Following these guidelines, personal consultees were asked to complete two forms developed by the BPS; one agreeing to their role and a second indicating their opinion on whether the person would like to engage or not (see Appendix L and M). Parents and carers were also asked to provide their own consent to take part as participants in the project (see Appendix N).

In addition to the BPS guidelines, this project recognised the importance of seeing the process of consent as one which was ongoing, rather than a one-off event (Cameron & Murphy, 2007; Cluley, 2016; Head, 2017). Building on the work of Head (2017; see Appendix O), this project

received permission to utilise a Record of Assessing Consent sheet that was developed based on suggestions from a paper written by Cameron and Murphy (2007; see Appendix P). This consent sheet was used to guide every contact with participants. It assessed both verbal and non-verbal indicators of consent and non-consent. In addition to this, in line with the flexible approach to this project's methodology, gaining consent was tailored, to each participant, depending upon their preferred communication style (Loyd, 2013). This involved meeting with participants, their parents and consulting with professionals around the person to ascertain their preferred communication method i.e. Picture Exchange Communications (PECs), social stories or multimodal methods.

### **2.3.3 Building Rapport**

Previous literature (Bagatell, 2007; Loyd, 2013) highlights the importance of allowing time prior to commencing the project to get to know participants. Therefore, prior to collecting any ethnographic data collection, I met with the participants to get to know them, their family and carers. This provided the opportunity for the participant to become familiar with the researcher and build a rapport whilst also assessing for on-going consent.

### **2.3.4 Anonymity / Confidentiality**

In addition to all participants being given a pseudonym, all data collected was stored on an encrypted audio recorder and laptop, so that data could not be transferred beyond these devices. Once printed the photographs were kept in a lockable drawer. All transcripts were anonymised and saved as a password protected document. All data was used and kept confidential following the Data Protection Act (UK Government, 2018).

### **2.3.5 Dissemination**

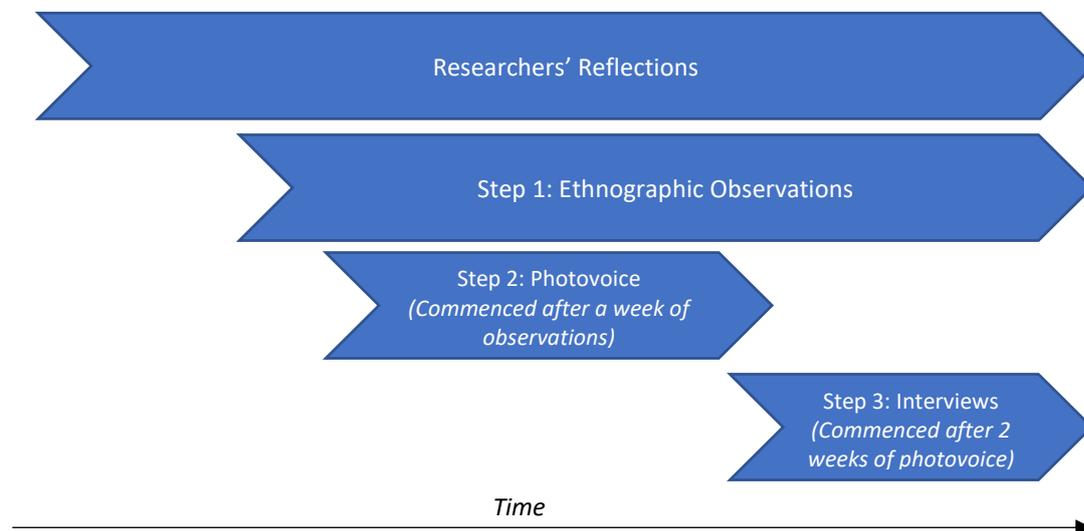
Disseminating findings from Intellectual Disability research is integral for change. Many researchers who have worked with people with intellectual disabilities emphasise the importance of dissemination, not only for ethical reasons but for the ownership of work, development of future research and for social and political commitments and implications (Iacono 2006; Boxall & Ralph, 2009; Mietola et al., 2017). All participants recruited to take part in this study, along with their families were asked whether they would be interested in coming together during the summer of 2020 to share their experiences and reflect on the

outcomes of the project. All agreed. Prior to this meeting each family will receive an easy-read report detailing the key findings and recommendations moving forward. The charity involved in the project have also expressed interest in hearing about the findings from the project so they can learn from it.

## 2.4 Procedure

### 2.4.1 A Layered Approach

A combination of data collection strategies made up this project's methodology including, ethnographic field notes, photovoice, transcribed interviews and the researcher's reflections (see *Figure 1*). The process of data collection involved stages as illustrated in figure 2. Each stage is described in more detail below.



*Figure 2: Diagram illustrating the stages of data collection*

**2.4.1.1 Stage 1: Ethnography.** Adopting an ethnographic stance, the project set out to observe participants and explore how they express their identity. Visits took place mainly at the participants' college, although one participant was also visited in their residential home. These visits occurred several times a week over the course of a month. Each participant was observed on different days, times and contexts (e.g. in college or on trips out in the community) to allow for a variation in data collection and opportunity to see the participant in different contexts. During each visit, field notes were taken describing the events that occurred throughout the observation period including how the young person presented themselves (e.g. clothes), their interactions with others, gestures and involvement in

activities (see Ellis, 2014; Fusch et al., 2017). In addition to this, conversations and statements made by those supporting the individual were also noted, with consent provided. Field notes comprised of key notes being taken during the observation and more in-depth descriptions added later (see Appendix Q). Participants were always seen with their key workers present and they were never left on their own with the researcher.

**2.4.1.2 Stage 2: Photovoice activity.** Each young person was asked to take photographs over a period of two weeks. Participants were provided with a visual information sheet. In line with the guidelines set out by Wang and Burris (1997, cited in Sutton-Brown, 2014) and designed to consider the needs of participants as advocated by Catalani and Minkler (2010) and Cluley (2016), limited instruction was given to participants around what they take pictures of. The only direction parents and carers received was to support the participant to take pictures of things that were meaningful to them. Two of the participants were provided with a camera, the third utilised their own iPad. Participants were requested to return the camera following the end of the activity. Those provided with a camera were shown how to use it. After the two weeks, cameras were collected, and photographs printed. For the participant who utilised their iPad, pictures were securely transferred to the researcher's laptop.

**2.4.1.3 Stage 3: Interviews.** Positioned within the interview with family and carers, participants were invited to share their pictures with me, their family and carers. Structured as an activity, participants were observed looking through their printed pictures. Observations were made in relation to behaviours, gestures and any use of speech. Some open and closed questions were used during this interview, such as '*what can you see?*' and '*does [participant] have a favourite picture?*'. Supported by family and carers, the participants were able to use preferred methods of communication. It also meant the parents and carers could reflect on what was observed during second part of interview that followed. Flexibility was required with this aspect of the design since participants with intellectual disabilities would have to consent to participate (see capacity and consent section). Where this was not possible, attempts were made at later times or on alternative days to complete this aspect of this interview. Due to the global outbreak of Coronavirus, two of these interviews were completed virtually using Skype and telephone (see Appendix R for an extract).

Ware (2004) talks about the importance of having advocates in the research process and holding realistic expectations about what can be achieved (independently and supported) by individuals with intellectual disabilities. In line with this, the second part of the interview involved exploring parents and carers conceptualisations of 'identity' in general as well as what their thoughts were in relation to the participants photographs and whether they captured the participants identity. As outlined above the interview process involved getting parents and carers to step into the shoes of participants though using questions influenced by Boxall (2010) and Karl Tomm (1999 cited in Mudry et al., 2017; Haydon-Laurelut, 2013). The interview also built on ideas described by Cluley (2016) and involved describing the content of photographs, how the participant was during the time of the picture and whether it was a self-directed photograph or guided (see Appendix S).

**2.4.1.4 Reflexive journal.** A reflexive journal was kept throughout the duration of the project. During the data collection stage reflections were usually completed at the end of the day, although thoughts were sometimes noted down during the day, as prompts to come back to and build on. Written through the researchers' lens, the journal contained '*thoughts, opinions, musings, discussion, and reflections on the process and the participants*' (Fusch et al., 2017, p. 930). Most of the reflections were kept separate from field notes as recommended by Fusch et al. (2017).

## 2.5 Data Analysis

The following section will describe the process of analysis for this project. It will draw on recommendations from multiple case study literature (see Baxter & Jack, 2008; Yin, 2004) and previous papers (Hubert & Hollins, 2010; Johnson, 1998; Thompson, 2018), as well as Braun and Clarke's (2006; 2012; 2018; 2019) approach to Thematic Analysis.

### 2.5.1 Analysis in Multiple Case Study Research

The analysis procedure followed recommendations from Yin (2004) and Baxter and Jack (2008). Yin (2004) describes the analysis of multiple case studies as one of the least developed areas. Therefore, it was important to draw on previous papers and literature to guide the process. The process of analysis involved triangulating the data (field notes, pictures, interview transcripts), initially within each case and then across the three cases (Yin, 2004). Literature also recommends the analytic process be presented within 'sufficient clarity' to

enable re-representation and flow charts and diagrams be used to illustrate the process (Eisenhardt & Graebner, 2007 cited in Gustafsson, 2017; see Appendix T, U and V for process of coding and generating themes). The process of presenting the within-case data was guided by previous papers, many of which included vignettes as a way of introducing the reader to the case and illustrating themes within each case pertinent to the research questions (Hubert & Hollins, 2010; Johnson, 1998; Thompson, 2018). It is important to note the photographs themselves were not analysed but incorporated into the interviews. As noted by Cluley (2016) whilst some may argue images can stand alone, *'talking about why the images were taken provided an extra layer of meaning'* which could not have been gathered from the pictures alone (p.43).

### **2.5.2 Setting up the Process of Analysis**

Once data collection was completed, the field notes were written up in Microsoft Word and the interview data was transcribed. All this information was stored securely on a password protected computer. To support the coding process across multiple data sets a manual process was chosen, rather than a computer process, to enable physical movement of codes and themes. This also meant a physical and reflexive closeness to the data was maintained rather than feeling removed by using computer software. Care was taken to ensure all the data was securely stored during this process.

*Reflection – When thinking about how to approach the analysis part of the project, I reflected back to a Thematic Analysis working group session at university. I was somewhat familiar with the process of Thematic Analysis, having previously used it, yet the session really opened my mind to how creative the approach can be. During the session we watched a video of Virginia Braun and Victoria Clarke talking about their approach to Thematic Analysis. Reflecting on this with the group, we thought about what the process meant to each of us. It was during this reflection I thought about a few points made by Braun and Clarke in their video; the reading and re-reading of transcripts and the back and forth process of coding. This toing and froing with the data made me visualise the process of analysis very much like a dance. One where you have to have familiarity with the process (or know your steps) but you need to be able to let go of what is there is at a semantic level (there needs to be fluidity) and be willing to notice when you get too immersed (start the dance again) so you can reflect on what you are bringing. I tried to hold this in mind throughout the process of analysis.*

The first step in analysis involved exploring how to organise the data. Prior to starting I met with my supervisory team and we discussed how to manage each data set in relation to the research questions. The discussions with my supervisory team helped me think about the triangulation of data and to reflect on what themes were beginning to be considered through transcription. The diagram below illustrates how each data set has been triangulated to correspond with each research question.

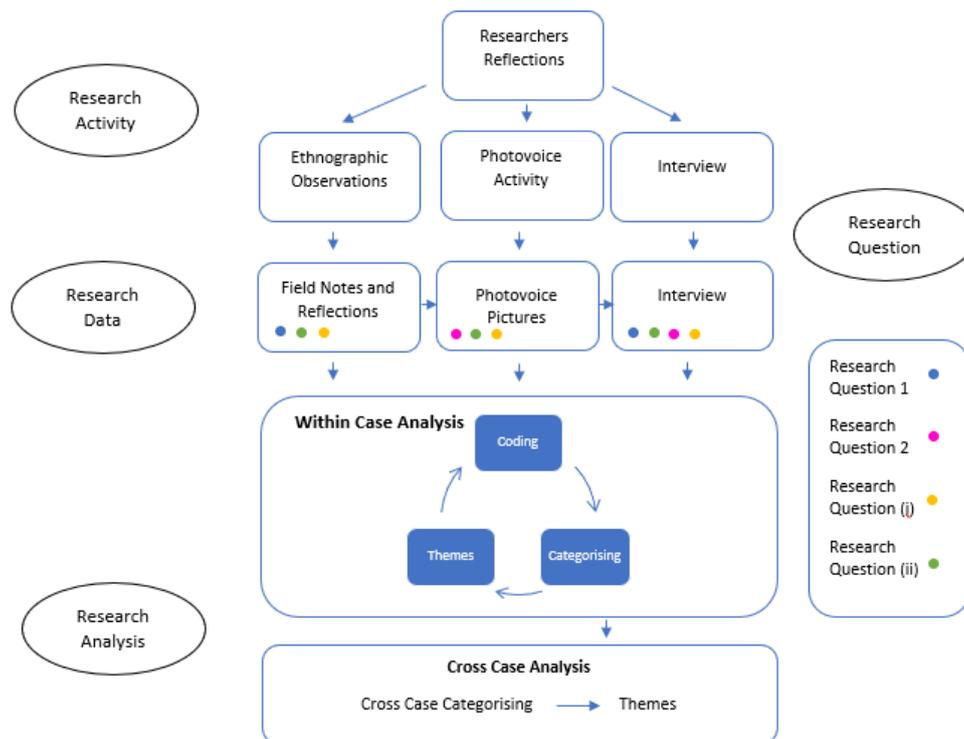


Figure 3: Diagram of triangulation of data to correspond with the research questions  
(Adapted from Thompson, 2018)

### 2.5.3 Analysis Procedure

The analysis procedure for this project took a qualitative approach, drawing on Reflexive Thematic Analysis (Braun & Clarke, 2006; 2012; 2018; 2019). The flexibility offered in Braun and Clarke's (2006;2018; 2019) approach to Thematic Analysis, meant I was able to consider the best method to identifying and analysing the patterned meanings in the data. The initial process involved immersing myself in the data as much as possible and started during the transcribing process, or arguably even before that during data collection. I made a conscious effort to note down any thoughts or reflections I had. After transcribing the data, prior to coding, I listened back to the recording and noted down any thoughts or things that stood out

to me. Following this I then commenced coding. Adopting an iterative process, data was coded line by line, with the same coding procedure followed for all stages of analysis. As recommended by Braun and Clarke (2018) I tried to code using phrases or sentences as much as possible so that the codes evoked the data and attempted to summarise patterns of meaning across data sets. Initially, the coding process took an inductive approach, exploring underlying processes, whilst also staying true to what was being expressed in the data. This allowed for the themes derived from the data to be closely linked to the content of the data (Braun & Clarke, 2012).

*Reflection – During the beginning of my dance with analysis, I noticed, I was naturally, wanting to code at a very semantic level, reporting on what was there. I also felt conscious of drawing on my memories of spending time with the person and reflecting these in things that stood out to me in the codes. It was interesting to take a step back, at various points, and just ask myself what I was possibly drawing on and whether any of the codes reflected my experience of being with the person. This helped me notice theoretical models that were being drawn in, such as Theory of Mind and other stereotypes and assumptions about the abilities of people with intellectual disabilities and Autism. It also provided the opportunity to try and go beyond the semantic level, towards a latent one, so that the patterns of meaning in the data could be explored.*

Yet as noted by Braun and Clarke (2006; 2012) it is not possible to be fully inductive, as the researcher always brings something to the data set during analysis. I noticed as I became more familiar with the data, I was more drawn to using deductive, top down, forms of coding; drawing on theoretical frameworks and ideas as a lens in which to view the data. Using reflection and discussions with my supervisory team, I tried to make the process of analysis as transparent as possible (Swain, 2018), taking into consideration what I was bringing with me to the data i.e. my own questions, biases and assumptions.

I continued to discuss, with my supervisors, the codes and themes that were being generated during the analysis to reflect on the process and explore any assumptions I was making or things I may have overlooked. I also spoke with another trainee Clinical Psychologist who was using a thematic analysis method. This helped reflect on the process and be curious of each other's ideas. To manage inter-rater reliability, I shared one of my participants transcripts, with my supervisor so she could code the data herself so we could then discuss our findings

together. Incorporating both these methods meant the coding process became more of a collaborative and reflexive process that enabled rich exploration of the data (Braun & Clarke, 2019).

**2.5.3.1 Within-case analysis.** Once each set of data (field notes, interview transcriptions) were coded, the within-case analysis began. The analysis process involved grouping all the data for each participant and identifying themes in relation to the process of enabling the participants identity to be expressed, as well as a snapshot of that person's identity presented in a vignette. Both these elements relate to the research questions for this project. This process involved attempting to identify patterns of meaning and shared ideas that cut across the data sets. I initially did this by grouping the codes in relation to a common idea (see appendix U). Once they were grouped, I then went back to the data to try and identify overall patterns of meaning. During this process of generating themes I tried to follow Braun and Clarke's (2012) recommendation of moving back and forth with the data, reflecting on my thoughts and the process.

**2.5.3.2 Cross-case analysis.** Once within-case themes were identified, a similar process was applied across all cases. The aim of this was to identify similarities and differences across the cases as well as cross case themes, in line with the research questions (Baxter & Jack, 2008; Yin, 2004). The analysis process began by going back to the codes for each data set and grouping them into cross-case categories. This formed part of an iterative process, moving between the data and the codes to identifying categories of shared meanings. This resulted in a total of 3 cross-case themes and 12 subthemes relating to each of the research questions (see Appendix V).

The following chapter will outline in detail the findings from this analysis procedure.

## **3. Results**

### *A creative dance with participants*

#### **3.1 Introduction**

This section explores the findings from the Thematic Analysis. The section begins with exploring the themes generated from the within-case analysis. Included in this section is a vignette capturing aspects of participants' identities. Lastly, the section provides a summary of the themes generated across all three cases. Throughout the section, all themes are supported by extracts from field notes, quotes from the interviews and reference to the pictures taken during the photovoice activity. The section also includes reflections captured during the process of analysis in order to illustrate the analytical process.

In line with the methodological approach to this study, it is important to note that the identities captured in this section are a snapshot of the person, at that moment in time, through the lenses of those around them, as well as my own lens as a researcher. Therefore, the aim of this section is not to present the one 'true' identity of the participants but to illustrate how data collected from different lenses (observations, pictures and interview) contribute to a collective understanding of that person's identity (Kaley, Hatton, & Milligan, 2019).

#### **3.2 Within-Case Analysis**

This section includes 3 case summaries, combining all the data (observations, photographs and interviews), for each participant. Each case summary will illustrate several themes generated from the thematic analysis. These themes will centre on the processes involved in enabling a person to express their identity. A case vignette will then capture aspects of a person's identity demonstrating the process of getting to know the person and their identities, through the different avenues of data collection. The themes and vignette will be supported by quotes, extracts from field notes and reference to pictures taken during the

photovoice activity discussed during the interview. Below is a table outlining the themes generated for each participant.

Participant	Theme 1	Theme 2	Theme 3	Theme 4
<b>Chloe</b>	<i>The richness of stories: 'A light dancing around the lawn'</i>	<i>Facilitating Independence: 'Mum have a cup of tea!'</i>	<i>Embracing Individuality: 'The sounds were like the wind'</i>	
<b>Oscar</b>	<i>Familiarity in the process: 'He's an old-fashioned chap'</i>	<i>Learning through being with: 'Comfort in the routine'</i>	<i>Creating safe environments: 'Smile and gently rock with them'</i>	<i>Inviting a position of curiosity: 'He loves his Christmas socks'</i>
<b>Buddy</b>	<i>Keeping a positive frame: 'A glass half full'</i>	<i>Blind spots: 'People think there's nothing in his head'</i>	<i>Pictures as a way of connecting: 'I like seeing him laugh'</i>	<i>Walking in their shoes: 'Buddy loves to dance'</i>

Table 5: Illustrating the themes, for enabling identity expression, generated during within-case analysis

### 3.2.1 Case Vignette: Chloe

#### 3.2.1.1 Chloe Theme 1: The richness of stories: *'a light dancing around the lawn'*.

This theme relates to the role storytelling has in supporting Chloe to express her identity as it links Chloe's actions with the knowledge that those around her hold. For example, I was told of Chloe's love for open spaces and being in outside environments, *'...anything outdoors, yeah, she just loves, say weather is no obstacle', 'she adores being by the sea' and 'she shrieks with happiness and runs, and as parents it's just a joy to see, it's like I'm free and especially if it's windy'*. Chloe's parents reflected on knowing this through observing Chloe's expressions, *'a constant smile, and seeing her body language, [pause], how to express it, you just get a sense of euphoria'*. When spending time with Chloe I often observed her opting to go outside; *'after a while Chloe got up and walked off. She returned shortly after with her coat, hat and scarf on. She then went out into the garden'*. When observing her outside, *'rather than sitting on the bench she squatted on the bench. She had moved her earmuffs off her ears and had her eyes closed'*. Her parents told me a story of a place they go to on the south coast. The

location of the cottage means that it gets extremely dark. They explained that Chloe will go out onto the lawn at night, just in her dressing gown and *'all you can see looking out the window is just blackness apart from this light dancing around on the lawn'*. Looking through Chloe's pictures, there were many taken of outside environments, open fields and green spaces.

**3.2.1.2 Chloe Theme 2: Facilitating independence: *'Mum have a cup of tea'*.** This theme relates to the need for Chloe to be supported when engaging in activities, such as photovoice, and for the environments around Chloe to be ones where she feels safe and comfortable to express herself and her identity. During the interview, her parents told me of Chloe's love for cooking *'umm, she loves to cook, but she won't listen to a word you say, [pause], 'not too much' everything with Chloe is too much'*. They spoke of her attitude towards cooking being *'you've shown me how to do it, now let me get on with it'*. This eagerness for independence was something captured further when talking with her parents.

*She'll listen if it's something new, but we only have to show her once, and then next it's that, well I know what I'm doing and go away, and she even says 'Mum, have a cup of tea' because she knows if I were to have a cup of tea, I'll go sit in the dining room area, which is off the kitchen and then sit down and have a cup of tea. So she started using that as a ploy, because she didn't want to, she didn't say, 'go away, I want to do this', it was 'Mum have a cup of tea', so I said, 'have a cup of tea and stand by the cooker', 'No!!' [says Chloe]. (Interview)*

I witnessed Chloe's eagerness for independence when spending time with her at college. She would *'navigate the computer independently', 'locate items in the shop herself'* and even request to push a stranger's buggy, *'Chloe have a go'*! When thinking with Chloe's parents about her engagement in the photovoice activity they reflected on the need to provide some instructions initially.

*'We'd say to her, hold it still and if you gave her that initial bit of supervision or instruction, it weren't supervision, I think instructions, she was more careful...there were times when she just lifted up the camera and you know clicked it and the pictures*

*didn't come out at all...but if you said to her, 'No, stop, stand still', you know, we got a few pictures that came out of nowhere'. (Interview)*

It is through having these opportunities and experiences for Chloe to exhibit her independence that she can express what is important to her and communicate aspects of her identity.

**3.2.1.3 Chloe Theme 3: Embracing individuality: 'The sounds were like the wind'.** This theme relates to the need for people to keep an open mind, not be judgemental or guided by their assumptions but accept someone for who they are and join with them as a way of getting to know them. When spending time with Chloe, I often noticed periods of time when she would interact with the environment around her. I presumed this was related to a sensory interest, which her parents later confirmed drawing on their previous experience, *'yeah, that sense of smell actually is quite a, quite a thing with Chloe'*. She would not be able to tell me what was interesting her, but it made me curious to know what was important to her.

*'When walking along the canal, Chloe was mumbling to herself. It was not clear what she was saying, much of it appeared to be sounds or noises. She would occasionally move her hand up to her mouth whilst she was doing this. Or she might stop and close her eyes whilst making a noise. Again, it wasn't clear if she was saying words or just making sounds. The sounds she was making were like the wind'. (Field Notes)*

Chloe's parents described that Chloe would often choose to spend time on her own and do things in her own way. For example they stated that Chloe *'...really for the most part, she's no desire to be around other people, she's at her happiest when she out with the two of us or people from college, just wandering out doing a walk, no pressure on her'*. When thinking about the photovoice activity, her parents reflected there would be times when *'she's taken a photograph where I thought actually, she's not, you know, taken the picture as I would have thought she'd taken it'*. Building on this example, they described occasions when Chloe would take pictures but from a different perspective from their own, *'now anybody else would have moved up to the gate to get a better view of the sheep but Chloe was quite happy to take it through the gate'*.

**3.3.1.4 Chloe case summary.** Chloe is 22 years young. She lives in the family home with her mother and father. Chloe also has an older sister who lives in supported living but returns home during certain times of the year. Chloe was introduced to me by both her parents and key worker as having *'a good sense of humour' and 'a mischievous' and 'funny'* personality. I started to see these aspects of Chloe when she interacted with her key worker saying *'3 scoops of ice-cream is too much, it will make you...'* and waiting for the response from her key worker *'sick'*. Chloe would then giggle after hearing this response and often repeat the phrase again! During the interview, her parents told me about a story of the *'musical toilet'* after she threw her sister's mini-compact disc player down the toilet and thought it was hilarious. They said this is often repeated whenever they visit Tesco's and can prove interesting listening for other people in the queue. There was also a similar story relating to a Hoover that I was told about when spending time with Chloe at college. She had asked me for the Hoover, after spilling some crumbs whilst eating her lunch. She had a big grin on her face and started giggling. When I asked about this, I was told by a carer it linked back to a previous incident involving a Hoover that Chloe had found very amusing.

There were pictures that showed Chloe's humorous side and good sense of humour, such as an ornamental frog with protruding eyes. Her parents told me of her love for frogs, *'she has a number of frogs, I mean she goes to bed every night and it's a double bed and there's barely enough room for Chloe with all her toys she's gotten on the side of the bed, three of which are frogs'*, *'she loves finding them in the garden, she'll be saying "make it hop, make it hop!"'*. There were also pictures of mud and some very muddy Wellington boots which were described as *'these two feet, these penguin feet stuck in the mud'*. When talking about this picture her parents said *'things like mud I mean, she is just like one of those youngsters, who likes, you know, if there is a dry bit of the path and a muddy bit of the path, you know where Chloe is going to be!'*. Talking with Chloe's parents about these photographs and their accompanying stories, they felt captures Chloe's mischievous identity and her *'sense of fun'*.

### **3.2.2 Oscar**

**3.2.2.1 Oscar Theme 1: Familiarity in the process: *'He's an old-fashioned chap'*.** This theme relates to the need for participants to be familiar with photography and cameras, otherwise it can act as a barrier to engagement. When talking with Oscar's mother and key worker, they reflected that they were *'disappointed he didn't take to it'*. Oscar's mother reflected *'I don't think he engaged particularly well, umm, I almost think he couldn't work out why we were doing what we were doing'*. She went on to say, *'Oscar isn't a very tech person...he's quite an old-fashioned chap'*, he *'never once asked for the camera. We had to say, but then that's not unusual'*. When talking through the process of engaging in the photovoice activity, Oscar's mother reflected on the need for the person to be interested in the process of have a familiarity with it.

*'We had to direct, I would say all the time, I don't' think Oscar was really fussed. The only thing he got excited about was the can of Tango. I can't remember, all I can remember was the Tango and it was nice, I showed him the picture that he'd taken of the Tango and he was like [imitating smiling and rocking], but whether that was because he was high on the Tango [laughs]'. (Interview)*

**3.2.2.2 Oscar Theme 2: Learning through being with: *'Comfort in the routine'*.** This theme reflects the importance of knowing Oscar, his routine, his like and dislikes in order to get to know him and his identity. When spending time with Oscar at college, I noticed the importance of knowing Oscar's routine in order to facilitate his engagement in activities. For example, whatever the activity there was a pattern or routine attached to it that couldn't be interrupted otherwise it would confuse and cause distress for Oscar. I witnessed this when Oscar was completing a puzzle. There was a very particular process for Oscar, from collecting the puzzle, emptying out the pieces even down to the 'click' the puzzle piece made when it connected with another piece. His key worker at college told me about the time she had to stay back at college, beyond the normal finishing time, after Oscar chose to do 1000 pieces and refused to leave at the end of the day (Field Notes). His key worker at his residential home also reported that Oscar refused to take pictures with her and it was only when she realised he was *'actually doing puzzles, as well, so you have to leave him, you can't interrupt him until the puzzle is finished'*. During the interview, Oscar's mother reflected *'I think part of his*

*identity is comfort in the routine'* and understanding his identity through *'what he likes doing via repetition'*. She went on to say that Oscar will then teach his routine to those around him.

*'Yeah, and Oscar can somehow manipulate us to repeat the process, umm, even Oscar, like I mean, obviously due to his Autism, repetition, routine, but he's developed his own routines and then he's taught it to us, so we know, [laughs], umm, how we have to be towards Oscar'.(Interview)*

**3.2.2.3 Oscar Theme 3: Creating safe environments: *'Smile and gently rock with them'*.** This theme relates to the importance of creating safe environments for Oscar, where he feels comfortable to be himself and has people supporting him that know him and what is important to him. During the interview Oscar's carer reflected on her relationship with Oscar and how he has an *'adamant No'* which says he doesn't want to do something.

*'I think it's all how Oscar feels comfortable with us as well...But another one of my colleagues could take him for a walk and get down the road and 'No'. So, I think there is that as well'*

The importance of Oscar's relationships with people was also evident when spending time with him. I often noticed Oscar would *'repeatedly looked over to his mother and key worker. I wondered whether this was communicating he wanted to do something or whether he was looking for reassurance'*. I observed similar behaviour with his key worker at college. During the interview his mother reflected *'it's very important to Oscar that he has people that he likes', 'Oscar likes sorts of people, they are the people he'll hold of the arms and look into their eyes and smile and gently rock with them. This means he likes you'*.

**3.2.2.4 Oscar Theme 4: Inviting a position of curiosity: *'He loves his Christmas socks'*.** This theme reflects the opportunity photovoice offers for interaction, challenging assumptions and taking different perspectives of a person when looking through the photographs together. This quote below was taken, from Oscar's mother, during the interview with Oscar, after he had identified a white car as a police car from one of the pictures.

*'I'm quite impressed he even acknowledged, I didn't even know he knew. I knew he know what a fire engine is, because one pulled up and I said, 'what's that?', 'fire engine'. It's fascinating'. (Interview)*

The quote below, was also from Oscar's mother during the interview. She became curious about some pictures Oscar had taken of his sock. She soon realised these were Oscar's 'Christmas socks', and reported 'he loves his Christmas socks', 'we buy him more each Christmas and Birthdays'. Oscar's carer reported that he would actively choose these from his drawer every day.

*'Now these ones are interesting, actually, because I asked him to take a picture of the television. But what, saying this, I wonder if he actually preferred his sock...because one of his favourite videos was on, trying to give him an idea, but he insisted on the sock...so I am actually wondering whether this is more important to him. And these ones were where he had the camera freehand'. (Interview)*

This invited Oscar's mother and carer into a discussion about whether these pictures along with the photographs Oscar had identified as his favourite illustrated his love for bold colours. They speculated whether, 'maybe Oscar likes really bold colours. It could be, and I told you he likes, well reds and pinks, [pause] and see even with this one where he chose mommy, mommy's got like a reddie colour top on'. Oscar's mother also reflected on other times he would opt for things with bold colours 'it makes sense because he's always chosen the pink cake' or if you let him choose a chocolate bar, 'it's always the boldest'.

**3.2.2.5 Oscar case summary.** Oscar is 22 years young. He lives in a residential home with several other residents. Oscar was described to me as 'happy' and 'laid back'. Although, this contrasted with what I was observing at the time, even his mother said, 'today he's a bit anxious'. I observed this through his behaviour; he was making loud vocalisations, with stern expressions on his face and rocking back and forth. I wondered whether this was because it was a change to his usual routine to which is mother agreed, as he would normally be out for a walk, something which Oscar enjoyed; 'his favourite thing is the community really, he likes

*being out and about really*'. This emphasised to me the importance of Oscar's routine. His mother stated that he *'finds comfort in his routine'* and *'expresses himself via his routine'*. His mother and carer told me of Oscar's musical interests, including Fleetwood Mac, nursery rhymes and Christmas songs. His carer added, *'if he is in a singing mood or nursery rhyme, he has to finish the nursery rhyme off and you can't interrupt him'*. When spending time with Oscar, I observed him choose a nursery rhyme book to read and he *'mumbled the nursery rhymes under his breath'*.

His mother and carer went on to talk about relationships, *'it's very important to Oscar that he has people he likes'* so that he feels comfortable and happy. They described how he would *'ask permission for everything he does, by making eye contact to check that what he is doing is okay'*. This made sense to me as I often observed Oscar make direct eye contact with those supporting him. I also noticed the importance of relationships to Oscar when he engaged in intensive interaction with those supporting him. In conversations with his key worker, at college, she informed me that intensive interaction was *'their main method of communication'* and it was clear he enjoyed it because he would be *'seen smiling'*. She told me of a story when she first did it with him and he *'smiled'* and continued to engage in it which she interpreted as being a good thing and something important to him. The more time I spent with Oscar the more he started to feel comfortable with me *'gazing over to see if I was mimicking his movements'*. On one occasion, *'he turned to me, rocked back and forth, from the waist, gradually getting closer to my face. He then smiled and giggled before returning to tapping the table'*. On our final day together Oscar *'jumped forward, swaying back and forth, then bent down and touched his nose with mine. I really got the sense he was happy'*.

### **3.2.3 Buddy**

**3.2.3.1 Buddy Theme 1: Keeping a positive frame: 'Glass half full'**. This theme reflects the family's and key worker's attitude towards supporting Buddy in the photovoice activity, supporting him to express his identity and more generally in day to day life. During the interview Buddy's mother described people as *'either glass half full or glass half empty'*. She went on to say, *'I think as a family, we're all quite like that, we kind of, see the positives and that, so.'* This was an attitude towards supporting Buddy that was not only evident in the family, but one that was also observed at college.

*It was clear to me that Buddy required a lot of support compared to his peers, yet this didn't seem to faze his support staff. Regardless of his disability, Buddy was supported to engage in activities much like any of his peers, cooking, swimming and bowling. All would be adapted to meet his needs and enable him to participate. (Field Notes)*

When discussing this with his mother in the interview, she reflected that *'we're always positive towards him because that's his identity of how he is and people around him pick up on that'*. She went on to emphasise the importance of being included and told me of a story where a man on a canal boat invited Buddy onboard despite the challenges of getting him on the boat; *'nobody had ever asked Buddy to do anything like that before'*. Buddy's mother went on to talk about engaging in the photovoice activity and other things at college and the importance of this being seen as something he does in his own way.

*'There are lots of things he does at his level...even if he's in a peer group who have disabilities, his disability is quite profound. So, he won't be doing what they're doing but he's there and he's expressing himself by what he wants to do'. (Interview)*

**3.2.3.2 Buddy Theme 2: Blind spots: 'People think there's nothing in his head'**. This theme relates to how the perception of a person's disability can get in the way of seeing other aspects of the person's identity and reduce opportunities or experiences for the person to express their identity. During the interview with Buddy's mother she described the importance of accepting people for who they are in order to see their identity.

*'I think for him to have an identity, we have to make it more acceptable to be like Buddy. So again, we have to make that happen by showing our acceptance of how her is. So he can be how he is'. (Interview)*

She went on to say how often people would be guided by their assumptions of Buddy just because of the way he looks and how this impacted on opportunities for him.

*'...for him I think it's important for people to be much more aware of him as a person than just what they can see when they first see him, because they're always gonna make assumptions about his identity, and that, they will see him as mixed race, they will see him as disabled, rather than funny, charming, you know, clever, like we see him...'. (Interview)*

*'...because he can't say, you know, he can't talk, people think there's nothing in his head, but it's just not the case'. (Interview)*

**3.2.3.3 Buddy Theme 3: Pictures as a way of connecting: 'I like seeing him laugh'.** This theme relates to how the photovoice activity offered Buddy's family a way of connecting with him, interacting with him and inviting them to take alternative perceptions through engaging with him and noticing his expressions.

*'I think it's a really good idea, because we like photos, Buddy likes photos and it's a way of him expressing himself. He's always expressed himself through photos and pictures because he's non-verbal. I think it's really positive that he can do it and he enjoys it. I like seeing him laugh when he takes pictures of himself.' (Interview)*

This last couple of quotes represent the idea that engaging with photovoice can offer a way of connecting but also questioning what is known about the person and the fluidity of a person's identity.

*'...it's strange isn't it, because that's not what I would have thought from looking at the pictures, I thought he'd definitely go for his sister. But it was definitely his cousin, so yeah, that was interesting'. (Interview)*

*'I think they [the pictures] do, up until then. But now, I'm thinking he's got a little bit of a different identity as well with all the things I'm seeing him do that I haven't done with him for a long time. So, I think they [the pictures] do. I think it's one side of Buddy, it's one half of Buddy, it's the part I saw at that time'. (Interview)*

**3.2.3.4 Buddy Theme 4: Walking in their shoes: ‘Buddy loves to dance’.** This theme relates to the importance of knowing a person, their routine, interests and providing opportunities for them to engage in safe environments, in order to see the person’s identity. During the interview I reflected with Buddy’s mother on things that would support people like Buddy to engage in photovoice.

*‘I think the thing that will help him participate more, not so much in a home with family, but in education and settings like that, is people’s understanding of what he can do, so they need to see it’. (Interview)*

The importance of knowing Buddy or providing the opportunities to get to know Buddy was also evident when observing him at college.

*She [Buddy’s Key Worker] reported that Buddy loves to dance. When I asked why she thought this, she described several occasions when Buddy was listening to music and he got up to dance. She also said he loves discos and dancing sessions. She put on the radio. After a while, Buddy got up, stood in the middle of the room and started to jig his knees. (Field Notes)*

**3.2.3.5 Buddy case summary.** Buddy is 21 years young. He lives at home with his mother, older sister and younger brother. Described by both his mother and those that support him as a ‘charmer’, the more time I spent with Buddy, the more I could see why they had described him in this way. For example, during my first morning with Buddy, he often looked over at me, despite his key worker saying, ‘now don’t you get distracted just because there is a new girl in the room’. It was during these interactions that ‘I noticed his big eyes and cheeky grin’. It also became clear when talking with his mother, she described his ability to just ‘ask with his eyes’ when wanting to get support with something. Buddy was also described to me as ‘cheeky’ and ‘funny’. Qualities which were observed when cooking with Buddy through placing the ‘whole pot of gravy granules in the saucepan’ when prompted to put more in, as well as his dancing in the kitchen whilst singing ‘relight my fire’. All these qualities were further emphasised when reviewing his pictures with his mother. There were pictures

of him taking selfies, emphasising his big eyes and grin and others using snapchat with different comical filters.

### 3.3 Cross Case Analysis

The themes described below were generated following cross-case analysis. The process involved identifying similarities and differences across the three participants and identifying themes that illustrated these, in relation to the research questions. A total of 3 themes were identified with several subthemes. The diagram below illustrates the final thematic map. Additional quotes supporting these themes can be found in Appendix W.

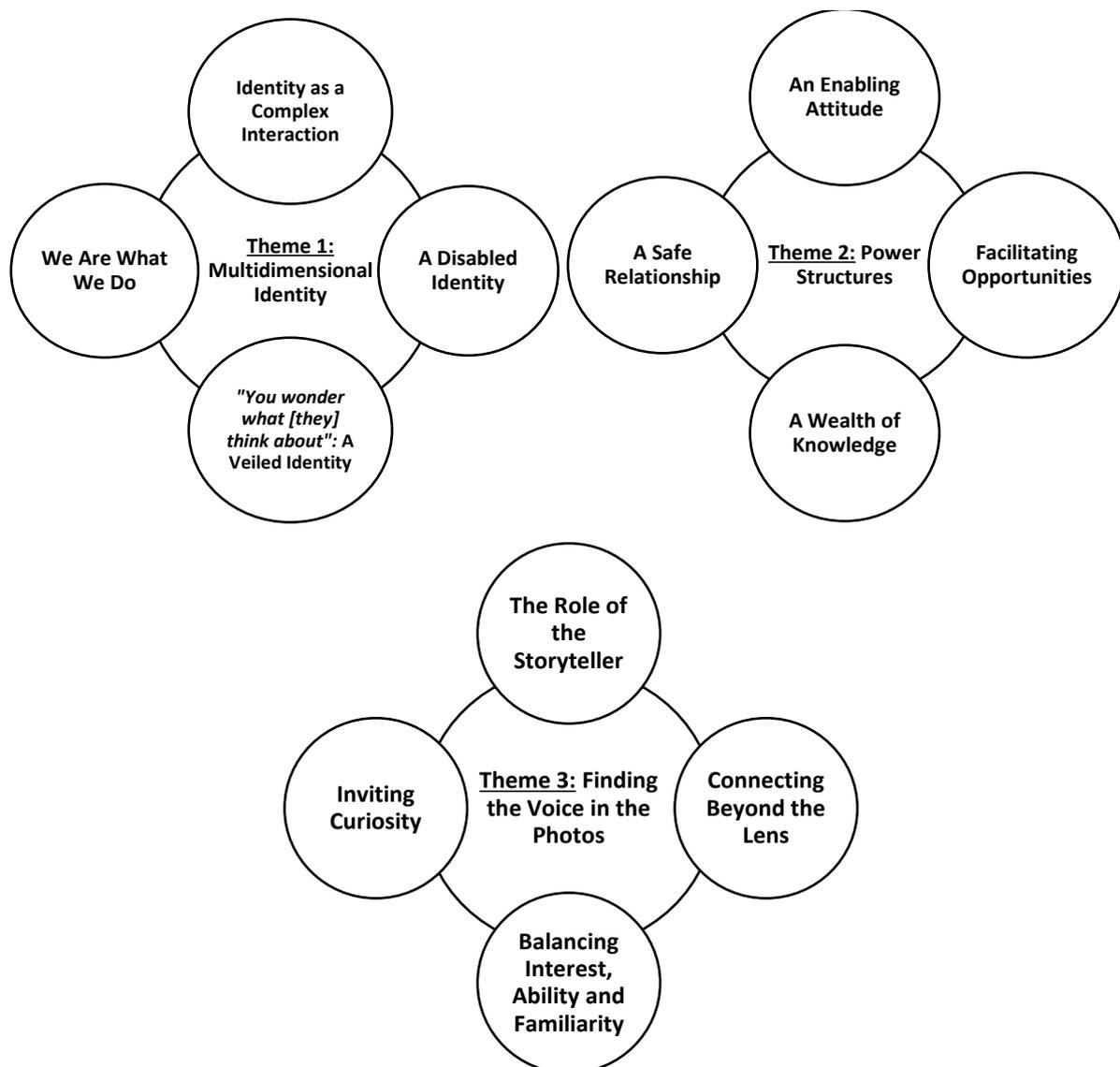


Figure 4: Final Thematic Map

### 3.3.1 Theme 1: Multidimensional Identity

This theme refers to how identity is conceptualised and expressed across participants. It involves viewing identity as 'multidimensional' and therefore fluid. It includes four subthemes, 'identity as a complex interaction', 'a disabled identity', 'we are what we do' and "*you wonder what [they] think about*": a veiled identity'.

**3.3.1.1 Subtheme 1: Identity as complex interaction.** This subtheme illustrates how participants identities were often conceptualised as a complex process which involves other people. For example, when talking with both Chloe's and Oscar's families, they spoke about identity being something that occurred between people, which could often result in different perspectives.

*'It's self-awareness, of yourself and who you think you are, and then there's other people's perception and who, or what you are, and often the two things aren't fully aligned'. (Chloe's Interview)*

*'You know, because if it was just me, what would my identity matter to me. This is me. I just do this. This only becomes an issue or a problem or a good thing, when someone else comes along into my field'. (Oscar's Interview)*

Similarly, Buddy's mother spoke about how, for people with Intellectual Disabilities, their identities are moulded and shaped by others due to the challenges in expressing and communicating themselves.

*'For people with disabilities...I think it's hard to express yourself and be yourself, I think you are moulded by other people's opinions' and approaches towards you'. (Buddy's Interview)*

In line with social constructionist ideas, this theme illustrates the interconnectedness of our identities and the importance of social processes in their development.

**3.3.1.2 Subtheme 2: We are what we do.** This subtheme relates to people perceiving and understanding the participant's identity through what they choose to do, through their behaviours, routines and in repetition of activities. For example, when talking with Oscar and Chloe's families, they both identified learning about a person's identity through repetitive behaviour.

*'Umm, by what he likes doing via repetition, so if he does something a lot and he doesn't get anxious or anxiety over it, our assumption is he quite likes it'. (Oscar's Interview)*

*'Through behaviour, you know when she is happy...and you certainly know when she's not happy, when she's insecure, I think then, you know, she'll be constantly asking, you know, coming with repeating phrases, wanting that kind of reassurance...she likes going to smell a bubble bath and body lotions and things...so yeah, yeah that sense of smell is actually quite a, quite a thing'. (Chloe's Interview)*

For Buddy's mother, she identified knowing whether something was important to Buddy through his gestures.

*'Because you can see it in his face his gestures, he will tap the screen if her enjoys it, if he is enjoying it, he will partake in it, even if it's only for a short period of time, if it's something he doesn't like he will not partake in it, he doesn't like messy play, he doesn't like touching things that are dirty, he doesn't like sticky things, so he will avoid doing those things'. (Buddy's Interview)*

This theme illustrates the dynamic process of understanding and exploring the identities of people with severe and profound intellectual disabilities through the way in which they communicate. It also illustrates the importance of joining with the person in order to get to know them.

**3.3.1.3 Subtheme 3: A disabled identity.** Families and carers spoke of how people can often take a narrow view of someone's identity just by observing their disability. For example, Buddy's mother spoke of people not looking beyond what is right in front of them.

*'I think most people see identity as what they see in front of them, rather than dig any deeper...They will see him as disabled, rather than funny, charming, you know, clever, like we see'. (Buddy's Interview)*

Similarly, Chloe's parents and Oscar's carer both spoke about how people would judge a participant, just based on their disability.

*'I used to get really upset when people made derisory comments and say things like they should have been put down at birth and some really horrendous things'. (Chloe's Interview)*

*'People judge you don't they, judge you differently'. (Oscar's Interview)*

This is an important theme to consider when exploring the identities of people with severe and profound intellectual disabilities because it can often act as a maintaining feature of stigma, marginalisation and limiting the opportunities available to those with intellectual disabilities.

**3.3.1.4 Subtheme 4: 'You wonder what [they] think about': A veiled identity.** This subtheme refers to when families and carers referenced parts of the participant's identities that are less known or familiar. For Chloe's family, they spoke about being curious of Chloe's internal world and how this related to her identities.

*'You wonder what she thinks about...she'll lay in bed and she'll just be screaming with laughter and giggling we have no idea what it's about'. (Chloe's Interview)*

*'It's difficult you know, because a lot of the time she's so, kind of, within herself, you know'. (Chloe's Interview)*

Oscar's mother also spoke about there being unknowns when it comes to understanding Oscar's preferred identities and what is important to him due to not being able to clarify their perception.

*'I don't know, may be, whether he likes strawberries or red or pinkie things. Maybe it is just something he feels comfortable with'. (Oscar's Interview)*

*'We are never quite sure if he understands them [songs]'. (Oscar's Interview)*

Much like any human being there are always parts of a person that are less familiar or less communicated. These may just be undiscovered aspects of a person's identity which may or may not be understood but are important to remain curious of.

### **3.3.2 Theme 2: Power Structures**

This theme relates to factors that impact on identity expression as well as their engagement in the photovoice activity. It comprises of four subthemes 'a safe relationship', 'a wealth of knowledge', 'facilitating opportunity' and 'an enabling attitude'. These are the things that can both support and hinder understanding someone's identity. For example, the families identified that it was important to have a good understanding of a person, their routine, likes and dislikes, without this, it may be difficult to support someone to express their identity.

*Reflection – During the initial theme generation and reviewing of the codes, I was struck by the number of things, families and carers referenced, both explicitly and implicitly, that often got in the way of people seeing the person for who they are. These often limited what someone may see of a person's identity. It also made me think about my interactions with participants and how these factors (opportunity, relationships, knowledge and attitude) could influence my own perceptions. Reflecting on this, made me think about power and the role these factors had in both supporting and inhibiting getting to know someone's identities, particularly when they are unable to verbalise them themselves. Since this process sits outside the person, it made me think about the power we hold in co-constructing a person's identity when they cannot verbally communicate themselves.*

**3.3.2.1 Subtheme 1: A safe relationship.** This first subtheme relates to the families' reflections on the importance of creating safe environments, where the participant is familiar with their routine and has a good relationship with those supporting them.

*'[participant] likes, umm, sorts of people...umm and he works better with certain people than others. So, his, I think part of his identity is I need these people for me to feel comfortable and happy, people with loud, sudden voices are not good in a way'. (Oscar's Interview)*

*'I think he's I think it depends how people relate to him, I think because he's related to well at home and here [college] now they know him, I think they see more of his identity'. (Buddy's Interview)*

*'...whether that's about having a safe and secure environment or it's about her relationship with others, I'm not entirely sure'. (Chloe's Interview)*

The interconnectedness of identities is further demonstrated in this theme and the need for people with severe and profound intellectual disabilities to have access to environments that facilitate identity expression.

**3.3.2.2 Subtheme 2: A wealth of knowledge.** This subtheme relates to the importance of knowledge when attempting to get to know someone with severe and profound intellectual disabilities. Families and carers responses suggested that knowing the person, their routine, their likes and dislikes and how they communicate would support engaging them in activities and getting to know their identity.

*'So anything that is about him is going to be expressing what he likes, and if somebody who, it doesn't have to me be facilitating but it does need to be somebody who knows [participant] and understands him, to know what is relevant to him and why he would like to do something or not do something'. (Buddy's Interview)*

*'Probably, it would, I think [pause] you probably need the input of someone who's very familiar with them, to be able to interpret, [pause], you know, some of the things they take... .They can't verbalise that, you know, I knew exactly what motivated [them], what they were drawn to now, they wouldn't be able to say...'. (Chloe's Interview)*

This theme further illustrates the importance of spending time getting to know someone with severe and profound intellectual disabilities so that patterns of behaviour, communication and experiences can supported to make sense of what is important to them.

**3.3.2.3 Subtheme 3: An enabling attitude.** This subtheme illustrates the families and carer's attitudes towards supporting the participants on a day to day basis. In doing so, it would open-up opportunities for people to express themselves and their identities.

*'It's the whole thing in life isn't it, you never know something until you try'. (Chloe's Interview)*

*'...I think you can always say that people with disability can't partake or understand in lots of things. But that doesn't mean they shouldn't experience them, because if they don't experience it, they're never going to learn to be able to partake in them and lots of things you learn from continually doing...people don't ignore babies because they can't talk'. (Buddy's Interview)*

**3.3.2.4 Subtheme 4: Facilitating opportunities.** This subtheme relates to the families and carers reflections on the importance of facilitating opportunities for the participants to express themselves and their identities.

*'Yeah, she does need, part of her identity, I do think is having her own space. And this is why we do try to step back so much now, just to give some of that freedom'. (Chloe's Interview)*

*'...it's quite hard for it, for it to be facilitated so people tend not to involve people like [participant] because it's easier not to, and that's just how it is in society generally*

*speaking, it's easier not to have to do something for somebody who needs it facilitating. Which is actually quite sad'. (Buddy's Interview)*

When talking about expressing identities, Chloe's parents spoke of the importance of returning to environments that were perceived to be important to that person and how this supported the expression of their identity.

*'The sense of freedom and space I think that [participant] likes...being them, I think having the, I suppose, just the opportunity'. (Chloe's Interview)*

This theme demonstrates the co-constructed nature of identities and the responsibility that lies with those around the person to provide opportunities and not be led by assumptions or biases.

### **3.3.3 Theme 3: Finding the Voice in the Photos**

This final theme focuses on families and carers responses to the photovoice activity and what is practically needed to support a person's identity expression and what engaging in the activity can offer.

**3.3.3.1 Subtheme 1: The role of the Storyteller.** This first subtheme relates to the sharing of knowledge about the person that went in partnership with the pictures. All the families and carers told stories about the person that accompanied the pictures and contributed to a richer and more in-depth understanding of the person and possible explanations for the pictures.

*'There was nothing to say that, I didn't feel that she wasn't enjoying it...[pause]...because she was laughing, she took some at the garden centre, was it, was it a frog or something and she was laughing away taking this, but she didn't communicate verbally, because you know, she never said 'oh look at this, I'm really happy' or 'oh come and see this', she was just giggling. People were looking around, I was thinking this is marvellous, because she's always been drawn to things with protruding eyes'. (Chloe's Interview)*

*'Yeah there were ones when he was on the go kart, his cousin always, he always takes him when we go to the activity centre, he always takes him on the go kart and that, and he'll spend a good half an hour just going around the cycle track, around the playground with [participant] on the that and he absolutely lives going on that'. (Buddy's Interview)*

**3.3.3.2 Subtheme 2: Connecting beyond the lens.** This subtheme relates to the opportunity photovoice created for families and carers to explore a participant's identity through interacting with them through the pictures.

*'And we've always felt that it's been a good way to have some interaction and initiate it through pictures'. (Chloe's Interview)*

*'...so yeah, he likes, he likes to do it because he likes that interaction of the person who's doing it with because obviously we have to facilitate him doing it, he can't do it on his own. So, he likes the closeness, that interaction, that sort of doing something together'. (Buddy's Interview)*

This theme illustrates the way in which photovoice can offer more than just an activity but a way of communicating for people with severe and profound intellectual disabilities.

**3.3.3.3 Subtheme 3: Inviting curiosity.** This subtheme refers to how the pictures invited families and carers to take a curious stance when looking at them, questioning their own assumptions and encouraging them to consider alternative perspectives when it comes to exploring participant's identities. For example, Oscar's mother and carer wondered whether Oscar quite liked bold colours.

*'So, I'm just wondering if there is something about bolds, because a lot of colour going on. May be [participant] really likes bold colours'. (Oscar's Interview)*

For Chloe's parents, they became aware of the different ways in which she looked at objects and scenery since many of her pictures were taken from particular perspectives.

*'...making us look at how [participant] sees, looking at some of these pictures with the different patterns, eyeline and umm, how we don't look at a scene in the same way'.  
(Chloe's Interview)*

For Buddy's mother, not only did she realise how much Buddy liked a selfie but also when looking through the photos with him, she became aware of how much he appeared interested in his cousin.

*'I think it definitely confirms that [participant] loves a picture of himself, and he's interested if you're taking pictures...I think it was quite interesting which pictures he liked...'. (Buddy's Interview)*

*'It was, it was quite interesting which pictures he liked. He was really fascinated with his cousin, which they are very close, but I would have thought he would have chosen his sister because she can't leave him alone. Whereas his cousin is much more cool. Yeah, every picture with his cousin in he was really animated, by it, it was really interesting, and you know he's and he's verbalizing his cousin's name'. (Buddy's Interview)*

This theme illustrates the power of curiosity and attempting to position yourself in the shoes of another person. All three families became aware of something they hadn't noticed before.

**3.3.3.4 Subtheme 4: Balancing ability, interest and familiarity.** This final subtheme relates to managing a lack of understanding with familiarity and interest. Families and carers spoke of the participants lack of understanding in the concept of a camera.

*'I think if we were going to do that [photovoice], we would have to get that into a routine that she, when we went out, that I had my camera and she had hers, and a learning process'. (Chloe's Interview)*

*'...he wasn't really bothered of what was on the other side, whereas that's where I think I mentioned to you, I think a Polaroid may have been better, because it's more instant satisfaction, gratification isn't it? So, he can actually see and think, oh that's there'. (Oscar's Interview)*

Of the three participants, two, had previous experience of using a camera and were familiar with using pictures as a way of communicating. One participant was less familiar in this process which impacted his ability to engage in the process. Participants who had familiarity with pictures and cameras were more able to engage in the photovoice activity. Therefore, a couple of the families suggested there might be benefits, to using photovoice, if using a camera was integrated into their day to day routine and there were learning opportunities.

## **4. Discussion**

### **4.1 Overview of the Chapter**

This research project set out to explore whether photovoice could explore identity expression amongst people with Intellectual Disabilities who have limited or no verbal language. In order to answer this question, it was broken down into the following questions:

1. How do people with intellectual disabilities and limited or no verbal communication express their identities?
2. Can photovoice be used as a research methodology to engage people with intellectual disabilities and limited or no verbal language?
  - i. Can we learn anything new about the person's identity through participation in the photovoice activity?
  - ii. Can we learn more about the person's identity through integrating ethnographic ideas, photovoice and dyadic interview components?

The aim of this chapter is to review each of these research questions in relation to the findings from this study, as well as linking in where possible existing theory and literature. It will also discuss the implications of the project's findings on future research, the services that support people with intellectual disabilities, the practice of clinical psychology and wider policies and guidelines. Lastly, it will outline the strengths and limitations of the study, before making final recommendations towards future research.

### **4.2 Summary of Results**

The findings from this study suggest that exploring identity expression amongst people with severe and profound intellectual disabilities is a complex process. Understanding identity is not as simple as observing participants' repetitive behaviours and gestures, but one that involves interaction not only with them, but with those around them and their environment. There are important 'power structures' that families, services, professionals, researchers and wider society need to consider when attempting to understand identity and engage people with severe and profound intellectual disabilities in research. Failure to consider these power structures could lead to narrow perspectives of people's identities and the maintenance of

discriminatory practices and stigmatised views. The next section will review the findings in relation to each of the research questions.

#### **4.2.1 How do People with Intellectual Disabilities and Limited or No Verbal Language Express their Identities?**

**4.2.1.1 A social constructionist perspective of identity.** From the perspectives of families and carers, participants expressed their identities through interactions with others, their gestures and their behaviours. These ideas were captured in the first theme ‘multidimensional identity’ and illustrated in two subthemes; ‘identity as a complex interaction’ and ‘we are what we do’. These themes mirror a social constructionist perspective of identity as it places emphasis on the construction of identities in the context of social relations (Gergen, 1990 cited in Povee et al., 2014). Varying in and across contexts, Gergen (1990, cited in Povee et al., 2014, p.32) proposed there are multiple selves which ‘*can be adopted in a chameleon-like fashion to meet the demands of the changeable social world*’. Therefore, identity can be considered ‘*fluid across time and space and contextual in nature*’ (Kamlager, 2013, p.29). Like previous research conducted by Goode and Gleason, the findings from this study emphasise ‘*the centrality of interactions and relatedness*’ (cited in Koltz, 2004, p. 99). These ideas can have important implications for when it comes to thinking about identity expression amongst people with severe and profound intellectual disabilities. Adopting this perspective of identity can empower people with intellectual disabilities since it moves away from seeing the person through the lens of their diagnostic label and towards seeing them as human beings.

**4.2.1.2 Identity as a complex interaction.** In addition to how participants expressed their identities, families also referred to other factors that could shape perspectives. For example, the person’s diagnoses could overshadow other aspects of their identity and the impact of them not being able to validate their own identities. These were both captured in the themes ‘a disabled identity’ and ‘a veiled identity’. For many years now, people have acknowledged the power assimilated with the label of intellectual disabilities (McKillop, 1995). Described as a ‘*master status*’ by Hughes in 1945 its use was considered to have the power to override other aspects of a person’s identity, such as gender, ethnic origin, sexuality and religion (Beart et al., 2005; Rapley, 2004). As illustrated in the literature review, the stigma associated with the diagnostic label of intellectual disabilities can impact on a person’s

self-esteem and social interactions (Craig et al., 2002; Jahoda et al., 2010; Monteleone & Forrester-Jones, 2017). Whilst it cannot be clear what relationship participants in this study may have with their diagnostic labels, perceiving participants primarily through these labels may well limit the opportunities for the person and what is communicated about the person to others around them (BPS, 2015; Cluley, 2016; McKillop, 1995). This links to the theme 'a veiled identity'. Families and carers spoke of the challenges faced because participants were unable to offer any validation or rejection of the perceived identities. This can lead to what is often spoken about in services as well as in the literature as problem focused identities (i.e. 'they are challenging'), adopting diagnosis led perspectives of a person with severe and profound intellectual disabilities can obscure other aspects of them and directly impact their quality of life (BPS, 2015; Cluley, 2018; McKillop, 1995). The findings of this research demonstrate the importance of moving towards multidimensional perspectives of identity and not being led by diagnostic categories.

#### **4.2.2 Can Photovoice be used as a research Methodology to Engage People with Intellectual Disabilities and Limited or No Verbal Language?**

The following section explores the question above, along with question (i) and (ii).

**4.2.2.1 Photovoice: An evolving and flexible methodology.** Overall the findings from this study suggest that photovoice can be used as a research methodology to engage people with intellectual disabilities who have limited or no verbal language. Two of the participants were able to actively engage in the task and their families felt they enjoyed the experience. The third participant found it harder to engage but was still supported to use the camera which provided some opportunity to explore other aspects of his identity. Therefore, there are important considerations when attempting to engage people with severe and profound intellectual disabilities in research using this methodology.

Illustrated in the theme 'finding the voice in the photos', families and carers spoke of photovoice offering them the opportunity to interact with participants and take different perspectives when understanding aspects of their identity. It also offered families and carers the opportunity to tell stories, about the participant, which connected with the photographs they had taken. This ultimately provided a richer understanding of the person and a move away from the idea they are 'less than human' (Kamlager, 2013). For example, Chloe's mother

spoke of a time when she was taking pictures at a garden centre and she was *'laughing'* at a frog sculpture and this introduced an opportunity to engage with Chloe and interact with her. Similarly, both Buddy's mother and Oscar's mother and carer spoke about times when they too engaged with participants when taking pictures and when looking through them.

However, families and carers also emphasised the importance of needing to be familiar with a camera and the process of taking pictures. This is illustrated in the theme 'balancing ability, interest and familiarity'. For example, Oscar's engagement in the photovoice activity was impacted by his lack of familiarity with using a camera and looking at photographs. Additionally, Chloe's mother reflected on the importance of integrating the camera into Chloe's routine. These findings emphasise the importance of researchers taking time to consider the needs and abilities of participants prior to recruiting and potentially offering longer opportunities for participants to learn and familiarise themselves with a camera (Mietola et al., 2017).

Despite these challenges, participants were supported to engage in the photovoice activity. It offered a flexible approach to engaging participants (i.e. using a tablet, camera) and provided an opportunity for people to interact with participants, tell stories and be curious of their existing perceptions. The present study therefore adds to the body of research demonstrating the flexibility and inclusiveness of photovoice (Cluley, 2016; Dorozenko, et al., 2014; Shumba & Moodley, 2018). Yet it is important to consider the needs and abilities of people with intellectual disabilities and be realistic about what can be achieved (Cluley, 2016; Ware, 2004).

**4.2.2.2 Awareness of the power structures.** The findings of this study also suggest that there are important facilitating factors to consider when involving participants with severe and profound intellectual disabilities in photovoice research. For example, captured in the theme 'power structures' families and carers spoke of the importance of knowing and understanding participants, creating opportunities and empowering participants to engage in all aspects of their life. These factors have a central role in supporting participants to engage successfully in photovoice. These findings can also be thought of in the context of existing theory and research. For example, the four subthemes; 'an enabling attitude', 'facilitating opportunity', 'a wealth of knowledge' and 'a safe relationship' mirror the principles that underpin what is commonly known as Person Centred Care (PCC).

As discussed in the introduction, following the '*Valuing People*' White paper published in 2001 (DoH, 2001), the Government encouraged services to adopt person centred care as an approach to empower people with intellectual disabilities and attempt to achieve equality in areas of their life. This philosophy is often the approach adopted across services that support people with intellectual disabilities in their day to day life. The findings from this research also emphasise the importance of actively taking a PCC approach to involving people with intellectual disabilities in research. For methodologies like photovoice to be inclusive of people with severe and profound intellectual disabilities, researchers need to provide the opportunity for an individualised approach, involve those who are familiar with the person and ultimately have an enabling attitude. Adopting these principles researchers are more likely to offer environments where the person feels able to express themselves.

**4.2.2.3 Can we learn anything new about the person's identity through participation in the photovoice activity?** It remains difficult to understand the preferred identities of people with intellectual disabilities when they cannot communicate this themselves. However, the findings of this study suggest that families and carers could be invited into positions of curiosity through using photovoice and not only explore more about a person's identity but also have existing perceptions reinforced. Captured in the subtheme 'the role of the storyteller', families and carers were encouraged through the interview questions to reflect on their knowledge of the person, to step into their shoes and provide narratives in relation to the photos. Like previous research, (see Overmars et al. 2016) the pictures were therefore brought to life in the narratives provided by family and carers. Looking through the pictures in isolation limited what could be understood about the person's identities. This demonstrates the importance of accompanying the pictures with narratives rather than them standing alone (Cluley, 2016; Overmars et al., 2016).

Additionally, captured in two subthemes 'connecting beyond the lens' and 'inviting curiosity', families and carers also spoke of the opportunities photovoice offered for interacting with participants and being curious of their existing perceived identities. For example, Buddy's mother spoke of his interactions with the pictures revealing more about the strength of his relationship with his cousin. Similarly, Oscar's mother and carer spoke of the pictures possibly revealing more about his love for colour. Therefore, these findings suggest that whilst photovoice may reinforce what is already perceived of a person's identity it can also introduce

new areas to become curious of in relation to what may be important to that person. However, these additional and alternative perspectives of someone's identity rely on important facilitating factors. As discussed above there were factors that supported engagement in photovoice (illustrated in the theme power structures). In a similar fashion, these factors; 'a wealth of knowledge', 'an enabling attitude', 'a safe relationship' and 'facilitating opportunity' also play a role in gaining an understanding of a person's identity. Through implementing these ideas participants are more likely to be given opportunities to express themselves and challenge the stigma and stereotypes that may narrow perceptions of their identity.

Both these ideas emphasise the importance of directly involving people with severe and profound intellectual disabilities in research as well as those closest to them. Inviting others to act as coresearchers, as part of photovoice, was something explored by Cluley (2016). In the paper, Cluley (2016) emphasised that the narratives offered by families and carers added '*an extra layer of meaning*' that could not be gathered from the photographs themselves. Cluley (2016) highlighted this view differs from that of Pink (2007) who suggests pictures can stand alone and provide insight into peoples' lives. The results of this study support Cluley's (2016) findings and illustrate the importance of involving people around the participant as a way of getting to know them. Inviting in voices separate to those who took the pictures has been a critique of the photovoice methodology (Cluley, 2016; Ware, 2004; Wang and Burris, 1997), particularly when used with people with intellectual disabilities since it suggests talking for the person and putting words into their mouths. However, as illustrated by Cluley (2016) using specific interview questions to critically probe responses can provide a richer understanding than just relying on subjective interpretations of the pictures themselves. In this study, it was the combination of Boxalls (2010) questions and those influenced by Karl Tomm's (1999 cited in Mudry et al., 2017; Haydon-Laurelut, 2013) internalised other, that provided a richer understanding of participants and invited families and carers into those storytelling roles.

In summary, these findings suggest that exploring identity in the context of photovoice can offer an interactive and inclusive activity that invites people into positions of curiosity. The findings also emphasise the central role people familiar with the person play in providing accompanying narratives that help bring the photographs to life.

**4.2.2.4 Can we learn more about the person's identity through integrating ethnographic ideas, photovoice and dyadic interview components?** The findings from this study suggest that all three components (ethnographic observations, photovoice and interview) contributed to understanding aspects of a person's perceived identity. As illustrated in the case vignettes, the ethnographic observations often reinforced what was discussed with families and carers during the interview. For example, an aspect of Chloe's identity was described as '*mischievous*' and '*fun loving*', this was observed during interactions with her at college and captured in pictures she took of a frog and muddy wellington boots. These pictures were brought to life through the accompanying stories of her family. As discussed above, these stories were facilitated through asking internalised other interview questions and those that '*critically probed responses*' (Cluley, 2016). This suggests that all three components were important to building a rich understanding of a person's identity.

In summary, the findings from this study suggest that photovoice can be used as a method to engage participants with severe and profound intellectual disabilities in research and can give some illustration of a person's identity. However, to get a rich understanding of a person's identity, families and carers must be invited to walk in the person's shoes and provide narratives that cut across both researchers' observations and participants' photographs.

### **4.3 Clinical Implications**

There are challenges to generalising the findings of qualitative research due to issues of power relations, researcher subjectivity and the nature of qualitative data (Ramos, 1989 cited in Orb, Eisenhauer, & Wynaden, 2001). However, it can be argued that ethically researchers have a responsibility to consider the wider implications of their research (Elliot, Fischer, & Rennie, 1999). Therefore, the section below will tentatively consider both the overall implications from this study as well as more specific clinical implications.

#### **4.3.1 Overall Implications**

The findings of this study illustrate the importance of involving people with severe and profound intellectual disabilities in research. It is only through their inclusion can we begin to understand more about their identities and work towards challenging the stigmatising views that exist within society. Providing these opportunities can, not only empower people with severe and profound intellectual disabilities but, lead to an improvement in their quality of

life. This study has demonstrated that when partnered with additional observations and interview techniques, photovoice, could offer an inclusive method for people with severe and profound intellectual disabilities. However, like previous recommendations (see Boxall & Ralph, 2010; Mietola, et al., 2017) it requires the facilitation of people around the person and acceptance from ethics committees and research governance for this type of research to continue.

### **4.3.2 Specific Clinical Implications**

**4.3.2.1 Implications for clinical psychologists.** The findings from the present study support previous research (e.g. Dorozenko et al., 2015) and theories (e.g. Gergen, 2015) that conceptualise identity from a social constructionist perspective. As noted above, viewing identity through this lens can empower the person, move away from aspects of identity being overshadowed by the label of intellectual disabilities and challenge the idea they are less than human (Kamlager, 2013). Therefore, it may be the role of clinical psychologists working with services to provide training to staff, both new and existing team members, to support them to think about their understandings of how identity is conceptualised. The interview techniques, such as Boxall's (2010) critically probing questions and those of Karl Tomm's (1999 cited in Mudry et al., 2017; Haydon-Laurelut, 2013) internalised other, could be integrated into training as an activity to facilitate staff to reflect on their own assumptions when it comes to thinking about identity, and encourage them to position themselves in the shoes of others. The findings also emphasise the importance of PCC in supporting people with intellectual disabilities to express their identities. It may be that clinical psychologists have a role, not only in exploring this relationship further in research, but in delivering training to services on PCC.

Therapeutically, these findings emphasise the importance of clinical psychologists allocating time into their assessments to build rapport with individuals and develop therapeutic relationships. Much of the work with people with severe and profound intellectual disabilities is completed systemically and can, due to time pressures, neglect to directly involve the person. The findings of this research support the recommendations outlined in the BPS (2018a) document titled '*Working Relationally with Adults with an Intellectual Disability – A Discussion*'. In this paper they reference the work of Strawbridge, Dryden and Wolfe (2003 cited in BPS, 2018) who encourage psychologists to adopt a position of 'being with' the person

rather than 'doing to' and stress the relevance of the therapeutic relationship. As demonstrated in this project developing an understanding of a person's multidimensional identity requires facilitating opportunities, developing relationships, an enabling attitude and wealth of knowledge. Therefore, as with any other client, the importance of developing a therapeutic relationship and spending time with the person with severe and profound intellectual disabilities is crucial to developing an understanding of the person and is likely to have implications on the therapeutic outcome (see Reisner, 2005). Not only that, but people with severe and profound intellectual disabilities should be given the opportunity to contribute to service delivery and be involved in processes where possible.

**4.3.2.2 Conducting research with people with ID.** The findings from this study emphasise that engagement in photovoice and identity expression can be facilitated through, providing opportunities, making use of existing knowledge of the person, enabling attitudes and safe relationships. These mirror the principles of PCC. Therefore, there may be a role for researchers to explore the relationship between person centred care and identity expression further when conducting research with people with intellectual disabilities. Many researchers have excluded people with severe and profound intellectual disabilities due to uncertainties of how to involve them ethically in research (Boxall & Ralph, 2009). Of the guidance that exists, these typically centre around issues of capacity and consent, reflexivity and transparency when involving people with intellectual disabilities in research (BPS, 2008; Cameron and Murphy, 2007; Durrell 2016; Walmsley, 2004). It may be that integrating ideas from PCC will offer further structure and guidance to researchers when thinking about designing projects with people with severe and profound intellectual disabilities.

This study has illustrated that photovoice, a creative methodology, can provide an inclusive approach to involving people with severe and profound intellectual disabilities in research. As discussed in earlier chapters, creative methodologies are still viewed with caution through the eyes of ethical committees and research governance (Boxall & Ralph, 2009; Mietola et al., 2017)

**4.3.2.3 Implications for services for people with ID.** Conducting this research has illustrated that people with severe and profound intellectual disabilities can be involved in research using a photovoice methodology. Building on Cluley's (2016) research, this study illustrates how ethnographic observations can be included into the photovoice methodology

to add further richness to the data collected, and gain insight into a person's identity. This illustrates the importance of services ensuring there is time for newly trained staff to observe existing staff supporting people with intellectual disabilities. Often staff do not get the opportunity to observe existing staff or those they are supporting before they start work. These findings illustrate the importance of offering that time prior to starting work so that the new member of staff begins to gain an understanding of what is important to the person and a sense of their identity. Furthermore, these training opportunities may also involve members of the service user's family so that the 'storytelling' aspect of study could be replicated through using similar interview techniques discussed above.

Typically, staff turnover in services that support people with intellectual disabilities are high. Therefore, people with intellectual disabilities are often left with periods of time where the support they receive is from someone less familiar with their needs. These can often be times when there are higher frequencies of behaviours that challenge due to the person having to manage change, transition and being around unfamiliar people who do not know how to communicate with them (BPS, 2018b). This can be even more complex for people who cannot communicate verbally. The findings of this study suggest that when the photographs taken by participants were accompanied by narratives from families and carers, alongside observations, it gave a rich understanding of a person's perceived identity. Therefore, services could introduce programmes that encourage ongoing photobook life stories, with narratives from families and carers that can be provided to new members of staff when they start. In doing so, new members of staff could get a sense of who this person is and what is important to them during their first few days. In doing so, this may also help challenge 'problem-based identities' (i.e. they 'are challenging') being maintained during periods of change and transition.

**4.3.2.4 Implications on wider policies and guidelines.** The findings from this study suggest that the principles of PCC may have important implications for facilitating opportunities and expressing identity for people with severe and profound intellectual disabilities. At present when reviewing the literature, the majority of the guidelines are written about PCC in relation to challenging behaviour (see NICE, 2015). Therefore, there is scope for additional guidelines to be developed aimed at outlining to policy makers, services, health care professionals and

families the importance of following PCC when getting to know a person with severe and profound intellectual disabilities.

As advocated by Wang and Burris (1997, p. 369) one of the mainstays of photovoice is to '*reach policymakers*'. Positioned as a participatory action research method, photovoice, aims to empower those involved and achieve social change (Liebenberg, 2018). The findings of this research further demonstrate that people with severe and profound intellectual disabilities *can* be involved in research (see Cluley, 2016; Dorozenko et al., 2016; Mietola et al., 2017; Ware, 2004). The findings also illustrate the complex interconnected processes involved in exploring multidimensional identities. As with any other human being, it is within the human rights of people with severe and profound intellectual disabilities to be provided with opportunities to be included in all aspects of life, to express themselves and their choices (House of Commons; HOC, 2008). Therefore, building on the recommendations of previous research it is important policymakers are aware of the interconnectedness of constructing identities (Mietola, et al., 2017) and that this is considered when designing policies for services and ethical bodies governing research (Boxall & Ralph, 2009; Tuffrey-Wijne, et al., 2008).

## **4.4 Methodological Implications**

### **4.4.1 Strengths of Current Study**

There were several strengths to this project. Firstly, this project included people with severe and profound intellectual disabilities in research alongside their families and carers. This population is typically excluded from direct involvement in research which mirrors aspects of their day to day life. As noted by previous research, excluding people with any degree of intellectual disability is not only dehumanising (Mietola et al., 2017) but unethical (Boxall & Ralph, 2009; Tuffrey-Wijne et al., 2008). This study illustrates how photovoice is a flexible and inclusive method of involving them in research and offers possible avenues for further exploration. Secondly, the variety of methods utilised to triangulate the data and represent each case as comprehensively as possible resulted in a rich data collection process and in-depth analysis. It also allowed for participants strengths to be considered through a variety of data collection methods. Thirdly, the study built on existing knowledge and ideas when it comes to involving people with severe and profound intellectual disabilities in research. For

example, I drew on the BPS guidance on involving people who may lack capacity to consent in research, it also adopted Cameron and Murphy's (2007) and Head's (2017) approaches to assessing for ongoing consent. Next, the study attempted to balance some of the subjectivity of the research through using a reflexive journal. This was completed throughout the process of conducting the study which meant that there was an awareness of what was guiding thinking and allowed for discussion of assumptions and biases. Yet there are limits to our reflexivity and awareness of these assumptions and biases meaning there will always be an element of subjectivity. Lastly, utilising Boxall's (2010) questions and internalised other approaches to interviewing meant that efforts were maintained throughout to centre participants in the sharing of their narrative.

#### **4.4.2 Limitations of Current Study**

There were several limitations to this study. Firstly, it is important to consider the subjectivity of the research when reviewing the findings of this project. The findings are illustrative of the three participants' experiences in this project, the views of their family members and my own subjectivity as a researcher. It is important to consider the power of the researcher and the power of any person exploring identities of people with severe and profound intellectual disabilities as they are unable to validate any of the experiences themselves. Yet this does not mean we should exclude people with severe and profound intellectual disabilities from research but be mindful of how it is completed and what processes are put in place to illustrate transparency, whilst being mindful of what findings the research generates. Given the limitations of objectivity in qualitative research, I am aware that my own assumptions and biases may have influenced findings. As participants were not able to verbalise their experiences and identity directly, the use of families' responses – limited number of carers involved in study – at times felt like participants were being decentred.

Secondly, there were a limited number of cases in the analysis. Whilst this allowed for an in-depth rich description and analysis, as well as fitting with the projects epistemological position, it did mean that the variances across experiences of using photovoice may not have been fully captured. For example, involving more participants may have illustrated more challenges to utilising photovoice as a methodological approach as demonstrated in Oscar's experience. Thirdly, whilst the study adopted a mini-ethnographic approach, it was quite short in contrast to most ethnographic studies, therefore limiting the opportunity to join with

participants and explore a wider variety of contexts. Next, the participants invited to take part in this study were limited in terms of diversity and ethnicity, meaning the ideas captured around identity do not capture wider cultural and religious aspects that form a part of an individual's identity. Lastly, the vignettes written representing a snapshot of participants identities were not all cross calibrated as only one of the transcripts was cross coded by another member of the research team. Therefore, the vignettes remain an interpretative account of participants identities guided by families and carers accounts as well as my own observations and reflections.

#### **4.4.3 Validating the Methodology**

One aim of this study was to trial an innovative methodology to include and capture the voices of people with severe and profound intellectual disabilities. This method was built on the learnings from previous research (see Cluley, 2016; Dorozenko et al., 2015) yet it neglected to include a process for formally assessing the quality of the method. Although the study did incorporate May's and Pope's quality assessment tool it did not validate the methodology itself. As noted by Noble and Smith (2015, p. 34) *'qualitative research is frequently criticised for lacking scientific rigour with poor justification of the methods adopted'* and it is therefore important to identify a process for formally assessing the quality of the method itself. Consequently, it would be important for future research to consider ways of assessing the quality of the method. This may include using several researchers so that the analysis process could be cross validated, or family members and carers could be offered the opportunity to comment on the vignettes produced. Alternatively, researchers could collect pre/post statements from family and carers to explore similarities and differences in the data collected following ethnographic observations and application of photovoice.

#### **4.5 Ethical Implications**

Participatory research aims to work towards resolving the power imbalances that occur between people with intellectual disabilities and researchers through collaboratively involving participants in all aspects of a research project. As discussed in previous research (see Ware, 2003) there are ethical challenges to including people with all forms of intellectual disabilities in research, especially those whose language and communication abilities are limited. Therefore, alternative strategies must be explored to ensure that people with severe

and profound intellectual disabilities are included in ethical research. A strength of the current study is its consideration of recommendations made by previous research. For example, the application of the informed consent procedure developed by Cameron and Murphy (2007) and Head (2017), as well as following guidance developed by the British Psychological society (2008). It would be important that future research also follow guidelines and build on these recommendations to help inform future research.

Similar to previous research (see Ware, 2003), another important aspect to involving people with severe and profound intellectual disabilities is the use of advocates in the research process. Family members and carers can provide invaluable insight to involving their relatives in research. Additionally, the process of interviewing family members and carers from an internalised other position opened the opportunity to explore alternative perspectives whilst centring the participants. In the context of conducting qualitative research it was also important to consider the researcher's position throughout the project. Therefore keeping a reflective journal throughout a project involving participants with severe and profound intellectual disabilities can help keep participants centred, bring forth any researchers biases and assumptions and provide helpful learning points to help advise future researchers and reduce uncertainties held by researchers (Boxall and Ralph, 2009).

## **4.6 Recommendations for Future Research**

Building on the ideas discussed in this chapter, below are some recommendations for areas of future research.

### **4.6.1 Longitudinal Study**

This study was completed over a total of 3 months (first meeting with participants to last). It could be that future research adopts a longitudinal approach to capturing the identities of people with severe and profound intellectual disabilities. Through implementing a longitudinal study, researchers would have the opportunity to include a larger group of participants, as there would be more time. Furthermore, researchers could explore multiple contexts and gain wider perspectives from additional carers and family members. This may offer the opportunity to capture more aspects of a person's identity.

#### **4.6.2 Videography**

Photographs are just one method of involving participants with severe and profound intellectual disabilities in research. However, the photographs themselves are limited by only capturing a fixed moment and it can be difficult for families and carers to remember exactly what was going on beyond this picture when providing narrative accounts. One way of building on this method would be to utilise videography. There are some studies that have started to involve participants with intellectual disabilities in video ethnographic studies (Kaley et al., 2019). Although, like other studies they have mainly involved participants with less severe forms of intellectual disabilities since they have been able to participate in interviews whilst watching the videos. Depending on the approach taken, videography may offer the opportunity to walk in the shoes of participants and would not rely on them having to learn to use a camera. Despite this, the challenges remain when it comes to eliciting the participants views and perspectives since they cannot provide the narratives themselves (Kaley et al., 2019). Whilst it may not solve all the challenges of including people with severe and profound intellectual disabilities in research it may offer another medium of inclusive research.

#### **4.6.3 Additional Research Exploring Identity of People with Severe and Profound Intellectual Disabilities**

This study illustrates that understanding the identities of people with severe and profound intellectual disabilities is a complex process. Adopting a social constructionist perspective can offer opportunities to see beyond the label of someone with severe and profound intellectual disabilities and as previous research suggests this can have important implications on the person's self-esteem and confidence. However, there remains a limited amount of research exploring the identities of people with severe and profound intellectual disabilities. Therefore, this research suggests that more needs to be done when it comes to exploring identities of people with severe and profound intellectual disabilities. It would be important that research, not only continue to explore different methodologies that involve a more diverse participant group, but to continue to build on making sense of understanding the notion of identity amongst this often-forgotten population group.

As discussed above, it would be worthwhile for future research to explore ways of validating the methodology during the process of completing the study. This could be completed using one of the methods described above. For example, researchers could get feedback on the vignettes produced and explore whether it met with their own conceptualisations of a person's identity. Alternatively, researchers could ask those closest to the person to provide a narrative about a person's identity prior to completing the rest of the method (ethnographic observations, photovoice and interviews). This would allow for a comparison to be made during the interview of what the families conceptualisations of their identity were and whether there were similarities or differences in what was observed in the field work and photographs.

#### **4.6.4 Other Avenues for Future Research:**

Building on the methodologies employed by previous research (Cluley, 2016; Dorozenko et al., 2015) this study has illustrated one way researchers can include people with severe and profound intellectual disabilities in research. In line with Dorozenko et al's (2015) paper, it has also illustrated how photovoice can be used as a method to explore identity expression. Future research could explore other areas where this method could be applied. For example, researchers could utilise the method to explore the experiences of gender amongst people with severe and profound intellectual disabilities. Alternatively, the method could be used to explore peer or familial relationships amongst people with severe and profound intellectual disabilities. However, as advocated by Ware (2003) it is important researcher consider the type of research questions they ask and whether this can be achieved. In addition to exploring other areas of enquiry it may also be beneficial for future research to focus on validating the methodology itself. This could involve systematically reviewing how people with severe and profound intellectual disabilities have been included in research and what methods have been deemed successful and those less so.

## **4.7 Conclusions**

The aim of this project was to learn whether photovoice could explore identity expression amongst people with severe and profound intellectual disabilities. Following the review of 3 cases studies, findings suggest that understanding the notion of identity amongst people with severe and profound intellectual disabilities is a complex process, but one that can benefit

from a social constructionist perspective. Photovoice can offer insights into the identities of people with severe and profound intellectual disabilities, when accompanied by the narratives of people closest to them and when person-centred philosophies are adopted. Overall, involving people with severe and profound intellectual disabilities in research can have important implications on challenging assumptions and biases that often overshadow the many other aspects of their identity.

## References

Aldridge, J. (2007). Picture this: the use of participatory photographic research methods with people with learning disabilities. *Disability and Society*, 22(1), 1-17.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: Author.

Anderson, S., & Bigby, C. (2017). Self-advocacy as a means to positive identities for people with intellectual disability: 'we just help them, be them really'. *Journal of Applied Research in Intellectual Disabilities*, 30(1), 109-120.

Bagatell, N. (2007). Orchestrating voices: autism, identity and the power of discourse. *Disability & Society*, 22(4), 413-426. Retrieved 13.06.2019 from <https://doi/pdf/10.1080/09687590701337967>

Baxter, P., & Jack, S. (2008). Qualitative case study methodology: Study design and implementation for novice researchers. *The Qualitative Report*, 13(4), 544-559.

Beart, S., Hardy, G., & Buchan, L. (2005). How people with intellectual disabilities view their social identity: a review of the literature. *Journal of Applied Research in Intellectual Disabilities*, 18(1), 47-56.

Booth, T., & Booth, W. (2003). In the frame: photovoice and mothers with learning difficulties. *Disability & Society*, 18(4), 431-442.

Boxall, K., & Ralph, S. (2009). Research ethics and the use of visual images in research with people with intellectual disability. *Journal of Intellectual and Developmental Disability*, 34(1), 45-54.

Boxall, K. (2010). Involving people with profound and multiple learning difficulties in research: barriers and possibilities. In *Disability Studies Conference*. Retrieved 08.06.2019 from [https://www.lancaster.ac.uk/fass/events/disabilityconference\\_archive/2010/Papers/Boxall2010.pdf](https://www.lancaster.ac.uk/fass/events/disabilityconference_archive/2010/Papers/Boxall2010.pdf)

Boxall, K., & Ralph, S. (2010). Research ethics committees and the benefits of involving people with profound and multiple learning disabilities in research. *British Journal of Learning Disabilities*, 39(3), 173-180.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101.

Braun, V., & Clarke, V. (2012). Thematic analysis. In H. Cooper, P. M. Camic, D. L. Long, A. T. Panter, D. Rindskopf, & K. J. Sher (Eds.), *APA handbook of research methods in psychology, Vol. 2. Research designs: Quantitative, qualitative, neuropsychological, and biological* (p. 57–71). American Psychological Association.

Braun, V., & Clarke, V. (2018, June 25). *Thematic analysis – an introduction*. [Video file]. Retrieved from <https://www.youtube.com/watch?v=5zFcC10vOVY>

Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, 11(4), 589-597.

Brewer, J. D. (2000). *Ethnography*. Buckingham, UK: Open University Press.

Brewster, S. J. (2004). Putting words into their mouths? Interviewing people with learning disabilities and little/no speech. *British Journal of Learning Disabilities*, 32, 166–169.

British Institute of Learning Disabilities (2019). *Information about learning disabilities*. Retrieved from <http://www.bild.org.uk/resources/faqs/#What-is-the-difference-between-the-terms-learning-disabilities-learning-difficulties-and-intellectual-disabilities>

British Psychological Society. (2008). *Conducting research with people not having the capacity to consent to their participation: A practical guide for researchers*. Leicester: BPS. Retrieved 11.12.2019 from [https://www.ed.ac.uk/files/atoms/files/bps\\_guidelines\\_for\\_conducting\\_research\\_with\\_people\\_not\\_having\\_capacity\\_to\\_consent.pdf](https://www.ed.ac.uk/files/atoms/files/bps_guidelines_for_conducting_research_with_people_not_having_capacity_to_consent.pdf)

British Psychological Society. (2010). *Learning disability definitions and contexts*. Leicester: BPS. Retrieved 11.12.2019 from <https://www.bps.org.uk/sites/bps.org.uk/files/Member%20Networks/Faculties/Intellectual%20Disabilities/Learning%20Disability%20Definitions%20and%20Contexts%20%282000%29.pdf>

British Psychological Society. (2015). *Guidance on the assessment and diagnosis of intellectual disabilities in adulthood*. Leicester: BPS. Retrieved from <https://www.bps.org.uk/sites/bps.org.uk/files/Member%20Networks/Faculties/Intellectual%20Disabilities/Guidance%20on%20the%20Assessment%20and%20Diagnosis%20of%20Intellectual%20Disabilities%20in%20Adulthood.pdf>

British Psychological Society. (2018a). *Working relationally with adults with an intellectual disability – a discussion*. Leicester: BPS. Retrieved 08.06.2020 from <https://www.bps.org.uk/sites/www.bps.org.uk/files/Member%20Networks/Divisions/DCoP/INF311%20WEB.pdf>

British Psychological Society. (2018b). *Positive Behaviour Support (PBS)*. Leicester: BPS. Retrieved 09.06.2020 from British Psychological Society (BPS) (2018a). *Working relationally with adults with an intellectual disability – a discussion*. Leicester: BPS. Retrieved 08.06.2020 from <https://www.bps.org.uk/sites/www.bps.org.uk/files/Member%20Networks/Divisions/DCoP/INF311%20WEB.pdf>

Burck, C. (2005). Comparing qualitative research methodologies for systemic research: The use of grounded theory, discourse analysis and narrative analysis. *Journal of family therapy*, 27(3), 237-262.

Burkitt, I. (2008). *Social selves: Theories of self and society*. Retrieved from <https://sk-sagepub-com.ezproxy.herts.ac.uk/books/social-selves-2e/n1.xml>

[Caldwell, K. \(2013\). Dyadic interviewing: a technique valuing interdependence in interviews with individuals with intellectual disabilities. \*Qualitative Research\*, 14\(4\), 488-507.](#)

Cambridge Dictionary (2019). Identity. Retrieved from <https://dictionary.cambridge.org/dictionary/english/identity>

Cameron, L., & Murphy, J. (2007). Obtaining consent to participate in research: the issues involved in including people with a range of learning and communication disabilities. *British Journal of Learning Disabilities*, 35(2), 113-120.

Carter, M. J., & Fuller, C. (2015). Symbolic interactionism. *Sociopedia. isa*, 1(1), 1-17.

Catalani, C., & Minkler, M. (2010). Photovoice: A review of the literature in health and public health. *Health Education & Behaviour, 37*(3), 424-451.

Clegg, J. A. (1993). Putting people first: A social constructionist approach to learning disability. *British Journal of Clinical Psychology, 32*(4), 389-406.

Cluley, V. (2016). Using photovoice to include people with profound and multiple learning disabilities in inclusive research. *British Journal of Learning Disabilities, 45*(1), 39-46.

Cluley, V. (2018). From 'learning disability to intellectual disability' – Perceptions of the increasing use of the term 'intellectual disability' in learning disability policy, research and practice. *British Journal of Learning Disabilities, 46*, 24-32.

Coons, K. D., & Watson, S. L. (2013). Conducting research with individuals who have intellectual disabilities: ethical and practical implications for qualitative research. *Journal of Developmental Disabilities, 19*(2), 14-24.

Craig, J., Craig, F., Withers, P., Hatton, C., & Limb, K. (2002). Identity conflict in people with intellectual disabilities: what role do service-providers play in mediating stigma? *Journal of Applied Research in Intellectual Disabilities, 15*(1), 61-72.

Davies, D., & Dodd, J. (2002). Qualitative research and the question of rigour. *Qualitative Health Research, 2*(2), 279-289.

Davies, C. A., & Jenkins, R. (1997). 'She has different fits to me': how people with learning difficulties see themselves. *Disability and Society, 12*, 95-109.

Dempster, M. (2011). A research guide for health and clinical psychology. Macmillan International Higher Education. Accessed on 29.05.2020  
<https://books.google.co.uk/books?id=fqccBQAAQBAJ&printsec=frontcover&dq=dempster+a+research+guide&hl=en&sa=X&ved=0ahUKEwjH04nEttjpAhWkqHEKHMYMjCbUQ6AEIKDAA#v=onepage&q&f=false>

Denzin, N.K., & Lincoln, Y. S. (2005). *The Sage handbook of qualitative research*. London: Sage

Department of Health. (2001). *Valuing People: A new strategy for learning disability for the 21<sup>st</sup> century*. (CM4683). London. UK: HMSO.

Dickinson, D., & Hutchinson, N. (2019). Changes in understandings and perceptions of individuals, significant others and community supporters involved in a theatre company for adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 32(3), 691-705.

Dorozenko, K. P., Roberts, L. D., & Bishop, B. (2015). The identities and social roles of people with an intellectual disability: Challenging dominant cultural worldviews, values and mythologies. *Disability & Society*, 30(9), 1345-1364.

Dorozenko, K. P., Roberts, L. D., & Bishop, B. J. (2016). Fumblings and faux pas: Reflections on attempting to engage in participatory research with people with an intellectual disability. *Journal of Intellectual & Developmental Disability*, 41(3), 197-208.

Dudley-Marling, C. (2004). The social construction of learning disabilities. *Journal of learning disabilities*, 37(6), 482-489.

Dunn, D.S., and Burcaw, S. (2013). Disability identity: exploring narrative accounts of disability. *Rehabilitation Psychology*, 58(2), 148-157.

Durell, S. (2016). Research with and by people with learning disabilities. *Nursing times*, 112(6-7), 15-18.

Elliott, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving Guidelines for Publication of Qualitative Research Studies in Psychology and Related Fields. *British Journal of Clinical Psychology*, 38, 215-229.

Ellis, S. J. (2014). Perspectives of the autistic 'voice': An ethnography examining information education learning experiences. (Doctoral dissertation). Sheffield Hallam University, UK.

Erikson, E. H. (1968). *Identity youth and crisis*. New York: W.W. Norton & Co. Retrieved 12.01.2020 from <https://llk.media.mit.edu/courses/readings/Erikson-Identity-Ch2.pdf>

Fearon, J. (1999). What is identity (As we now use the word)? Retrieved from <https://web.stanford.edu/group/fearon-research/cgi-bin/wordpress/wp-content/uploads/2013/10/What-is-Identity-as-we-now-use-the-word-.pdf>

Finley, W. M. L., Antaki, C. Walton, C. (2007). On not being noticed: intellectual disabilities and the non-vocal register. *Intellectual and Developmental Disabilities*, 45(4), 227-245.

Fusch, P. I., Fusch, G. E., & Lawrence, R. N. (2017). How to conduct a mini-ethnographic case study: a guide for novice researchers. *The Qualitative Report*, 22(3), 923-941.

Gelo, O. C. G., Braakmann, D., & Benetka, G. (2008). Quantitative and Qualitative Research: Beyond the debate. *Integrative Physiological and Behavioural Science*, 42(3), <https://doi/pdf/10.1007/s12124-009-9107-x>

Gergen, K. J. (2011). The self as social construction. *Psychological Studies*, 56(1), 108-116.

Gergen, K. J. (2015). *An invitation to social construction*. (3<sup>rd</sup> Edition.). London. Sage.

Glaw, X., Inder, K., Kable, A., & Hazelton, M. (2017). Visual methodologies in qualitative research: autophotography and photo elicitation applied to mental health research. *International Journal of Qualitative Methods*, 16, 1-8.

Gómez, C. C. (2009). Assessing the quality of qualitative health research: Criteria, process and writing. *Forum: Qualitative Social Research*, 10(2), Retrieved 20.08.2019 from <http://dx.doi.org/10.17169/fqs-10.2.1294>

Goodley, D. (2000). *Self-advocacy in the lives of people with learning difficulties: The politics of resilience*. Buckingham: Open University Press.

Goodley, D. (2005). Empowerment, self-advocacy and resilience. *Journal of Intellectual Disabilities*, 9(4), 333-343.

Guba, E. G. & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. K. Denzin and Y. S. Lincoln (Eds.), *Handbook of qualitative research* (p.105 -117). Sage Publications, Inc.

Gustafsson, J. (2017). Single case studies vs. multiple case studies: a comparative study. Retrieved 01.05.2020 from <https://www.semanticscholar.org/paper/Single-case-studies-vs.-multiple-case-studies%3A-A-Gustafsson/ae1f06652379a8cd56654096815dae801a59cba3>

Harper, D. (2011). Choosing a qualitative research method. In D. Harper and A. R. Thompson (Eds.), *Qualitative research methods in mental health and psychotherapy* (p. 83-98). Wiley-Blackwell.

Haydon-Laurelut, M. (2013). Internalised-other interviewing, inclusion and the avowal of psychological reality: An anti-disablement action method. *Context*, 26, 7-10.

Head, A. (2017). *How people with intellectual disabilities experience transition through the transforming care programme: A grounded theory study*. (Unpublished doctoral dissertation). University of Hertfordshire, Hatfield, United Kingdom.

Heale, R., & Forbes, D. (2013). Understanding triangulation in research. *Evidenced Based Nursing*, 16(4), 98.

Holloway, I., Brown, L., & Shipway, R. (2010). Meaning not measurement: using ethnography to bring a deeper understanding to the participant experience of festivals and events. *International Journal of Event and Festival Management*, 1(1), 74-85. Retrieved 14.12.2019 <https://doi.org/10.1108/17852951011029315>

Hong, Q. N., Pluye, P., Fabregues, S., Bartlett, G., Boardman, F., Cargo, M., Dagenais, P., Gagnon, M. P., Griffiths, F., Nicolau, B., O’Cathain, A., Rousseau, M. C., & Vedel, I. (2018). *Mixed Methods Appraisal Tool (MMAT), version 2018*. Registration of Copyright (#1148552), Canadian Intellectual Property Office, Industry Canada.

House of Commons. (2008). A life like any other? Human rights of adults with learning disabilities. Retrieved 09.06.2020 from <https://publications.parliament.uk/pa/it200708/jtselect/jtrights/40/40i.pdf>

Hsieh, H. F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, 15(9), 1277-1288.

Hubert, J., & Hollins, S. (2010). A study of post-institutionalised men with severe intellectual disabilities and challenging behaviour. *Journal of Policy and Practice*, 7(3), 189-195.

Iacono, T. (2006). Ethical challenges and complexities of including people with intellectual disability as participants in research. *Journal of Intellectual and Developmental Disability*, 31(3), 180-191.

Jahoda, A., Wilson, A., Stalker, K., & Cairney, A. (2010). Living with stigma and the self-perceptions of people with mild intellectual disabilities. *Journal of Social Issues*, 66(3), 521-534.

Johnson, K. (1998). Deinstitutionalisation: the management of rights. *Disability and Society*, 13(3), 375-387.

Johnson, K., & Walmsley, J. (2003). *Inclusive research with people with learning disabilities: past, present and futures*. London, UK: Jessica Kingsley Publishers.

Jurkowski, J. M. (2008). Photovoice as participatory action research tool for engaging people with intellectual disabilities in research and program development. *Intellectual and Developmental Disabilities, 46*(1), 1-11.

Kaley, A., Hatton, C., & Milligan, C. (2019). More than words: the use of video in ethnographic research with people with intellectual disabilities. *Qualitative Health Research, 29*(7), 931-943.

Kamlager, C. (2013). Identity Making Process of Individuals with Mild Intellectual Disabilities. (Unpublished dissertation). University of Kentucky, Kentucky, USA.

Karavella, Margarita (2013). The impact of moving home to the identity of people with learning disabilities. (Unpublished doctoral dissertation). City University, London.

Khokhar, S., Memon, S., & Siddique, K. (2016). Exploring role of language in constructing identities: A case study of Sindh, Pakistan. *International Journal of Humanities and Social Science, 6*(3), 234 -241.

Kiernan C. (1999) Participation in research by people with learning disability: origins and issues. *British Journal of Learning Disabilities, 27* (2), 43–7.

Kliewer, C., Biklen, D., & Kasa-Hendrickson, C. (2006). Who may be literate? Disability and resistance to cultural denial of competence. *American Educational Research Journal, 43* (2), <https://doi/pdf/10.3102/00028312043002163>

Kohlbacher, F. (2006). The use of qualitative content analysis in case study research. *Forum: Qualitative Social Research, 7*(1), 1-30.

Koltz, (2004). Sociocultural study of intellectual disability: moving beyond labelling and social constructionist perspectives. *British Journal of Learning Disability, 32*, 93-104.

Krippendorff, K. (2004). *Content Analysis: An Introduction to Its Methodology* (2nd Ed.). Thousand Oaks, CA: Sage Publications.

Leite, G.A., & Monteriro, M.I.B. (2008). Identity formation of disabled individuals within a speech therapy group. *Revista Brasileira de Educacao Especial, 14*(2), 189-200.

Liebenberg, L. (2018). Thinking critically about photovoice: achieving empowerment and social change. *International Journal of Qualitative Methods*, 17, 1-9.

Llewellyn, G. (1995). Qualitative research with people with intellectual disability. *Occupational Therapy International*, 2, 108-127.

Lloyd, D. (2013). Obtaining consent from young people with autism to participate in research. *British Journal of Learning Disabilities*, 41(2), 133-140.

Luman (n.d.). Sociological Paradigm #3: Symbolic Interactionist Theory. Retrieved from <https://courses.lumenlearning.com/alamo-sociology/chapter/reading-symbolic-interactionist-theory/>

Malik, K.L., Unwin, G., Larkin, M., Kroese, B.S., and Rose, J. (2017). The complex role of social care services in supporting the development of sustainable identities: Insights from the experiences of British South Asian women with Intellectual Disabilities. *Research in Developmental Disabilities*, 63, 74-84.

Mansell, J., & Beadle-Brown, J. (2004). Person-centred planning or person-centred action? Policy and practice in intellectual disability services. *Journal of Applied Research in Intellectual Disabilities*, 17, 1-9.

Mays, N., & Pope, C. (2000). Qualitative research in health care: Assessing quality in qualitative research. *British Medical Journal*, 320, 50-52.

McClimens, A. (2008). This is my truth, tell me yours: exploring the internal tensions within collaborative learning disability research. *British Journal of Learning Disabilities*, 36(4), 271-276.

McDonald, K., Kidney, C., & Patka, M. (2012). 'You need to let your voice be heard': research participants views on research. *Journal of Intellectual Disability Research*, 57(3). Retrieved 28.05.2020 from <https://doi.org/10.1111/j.1365-2788.2011.01527.x>

McKenzie, (2012). Models of intellectual disability: towards a perspective of possibility. *Journal of Intellectual Disability Research*, 57(4). Retrieved 03.01.2020 from <https://doi.org/10.1111/j.1365-2788.2012.01547.x>

McKillop, D. R. (1995). *Influence of the label 'intellectual disability' on trainee disability service providers' impressions*. (Unpublished Dissertation). Edith Cowan University, Australia.

McLeod, S. A. (2018). *Erik Erikson's Stages of Psychosocial Development*. Retrieved 31.12.2019 from <https://www.simplypsychology.org/Erik-Erikson.html>

Midjo, T., & Aune, K. E. (2018). Identity constructions and transition to adulthood for young people with mild intellectual disabilities. *Journal of Intellectual Disabilities, 22*(1), 33-48.

Mietola, R., Miettinen, S., & Vehmas, S. (2017). Voiceless subjects? Research ethics and persons with profound intellectual disabilities. *International Journal of Social Research Methodology, 20*(3), 263-274.

Mineur, T., Tideman, M., & Mallander, O. (2017). Self-advocacy in Sweden—an analysis of impact on daily life and identity of self-advocates with intellectual disability. *Cogent Social Sciences, 3*(1), <https://doi/pdf/10.1080/23311886.2017.1304513>

Monteleone, R., & Forrester-Jones, R. (2017). 'Disability means, um, dysfunctioning people': A qualitative analysis of the meaning and experience of disability among adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 30*(2), 301-315.

Moya, H. (2009). Identities on paper: Constructing lives for people with intellectual disabilities in life story books. *Narrative Inquiry, 19*(1), 135-153.

Mudry, T. E., Strong, T., Sametband, I., Rogers-de Jong, M., Gaete, J., Merritt, S. & Ross, K. H. (2016). Internalized other interviewing in relational therapy: Three discursive approaches to understanding its use and outcomes. *Journal of marital and family therapy, 42*(1), 168.

Newman, I., Benz, C. R., & Ridenour, C. S. (1998). *Qualitative-quantitative research methodology: Exploring the interactive continuum*. Southern Illinois, University Press.

NICE (2015). Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. Retrieved 21.05.2020 from <https://www.nice.org.uk/guidance/ng11/resources/challenging-behaviour-and-learning-disabilities-prevention-and-interventions-for-people-with-learning-disabilities-whose-behaviour-challenges-pdf-1837266392005>

Nind, M. (2008). Conducting qualitative research with people with learning, communication and other disabilities: Methodological challenges. Retrieved from <http://eprints.ncrm.ac.uk/491/1/MethodsReviewPaperNCRM-012.pdf>

Nobel, H., & Heale, R. (2019). Triangulation in research, with examples. *Evidenced Based Nursing*, 22(3), 67-68.

Nobel, H., & Smith, J. (2015). Issues of validity and reliability in qualitative research. *Evidence-Based Nursing*, 18(2), p.34-35.

Orb, A., Eisenhauer L., & Wynaden, D. (2001). Ethics in qualitative research. *Journal of Nursing Scholarship*, 33(1), 93-96.

Ortlipp, M. (2008). Keeping and using reflective journals in qualitative research process. *The Qualitative Report Volume*, 13(4), 695-705.

Overmars-Marx, T., Thomése, F., & Moonen, X. (2018). Photovoice in research involving people with intellectual disabilities: A guided photovoice approach as an alternative. *Journal of Applied Research in Intellectual Disabilities*, 31(1), 92-104.

Pathak, V., Jena, B., & Kalra, S. (2013). Qualitative research. *Perspectives in Clinical Research*, 4(3), 192.

Pink, S. (2007). *Doing visual ethnography: Images, media and representation in research*. London, UK: SAGE Publications Ltd.

Porter, J., Ouvry, C., Morgan, M., & Downs, C. (2001). Interpreting the communication of people with profound and multiple learning difficulties. *British Journal of Learning Disabilities*, 29(1), 12-16.

Povee, K. (2014). The identities and social roles of people with intellectual disabilities: Challenging dominant cultural worldviews, values and mythologies. (Unpublished doctoral dissertation). Curtin University, Perth, Australia.

Povee, K., Bishop, B. J., & Roberts, L. D. (2014). The use of photovoice with people with intellectual disabilities: Reflections, challenges and opportunities. *Disability & Society*, 29(6), 893-907.

- Probyn, J. E., Howarth, M. L., & Maz, J. (2016). The 'middle bit': how to appraise qualitative research. Retrieved from <http://usir.salford.ac.uk/id/eprint/38119/>
- Rapley, M., Kiernan, P., & Antaki, C. (1998). Invisible to themselves or negotiating identity? The interactional management of 'being intellectually disabled'. *Disability & Society*, 13(5), 807-827.
- Rapley, M. (2004). *The social construction of intellectual disability*. Cambridge University Press. Retrieved 09.05.2020 from [https://books.google.co.uk/books?id=KdQS5Z\\_mGbQC&pg=PA1&source=gbs\\_toc\\_r&cad=4#v=onepage&q&f=false](https://books.google.co.uk/books?id=KdQS5Z_mGbQC&pg=PA1&source=gbs_toc_r&cad=4#v=onepage&q&f=false)
- Ratner, C. (2002). Subjectivity and objectivity in qualitative methodology. *Forum: Qualitative Social Research*, 3(3). Retrieved 25.05.2020 from <http://dx.doi.org/10.17169/fqs-3.3.829>
- Rattansi, A., & Phoenix, A. (2005). Rethinking youth identities: Modernist and postmodernist frameworks. *An International Journal of Theory and Research*, 5(2), 97-123.
- Reisner, A. D. (2005). The common factors, empirically validated treatments, and recovery models of therapeutic change. *The Psychological Record*, 55, 377-399.
- Rękosiewicz, M. (2018). Identity development in people with mild intellectual disability: A short-term longitudinal study. *Current Psychology*, 1-10.
- Rioux, M. H. (1997). Disability: the place of judgement in a world of fact. *Journal of Intellectual Disability*, 41(2), 3-30. Retrieved 29.11.2019 from <https://doi.org/10.1111/j/1365-2788.1997.tb00686.x>
- Rix, J. (2006). Does it matter what we call them? Labelling people on the basis of notions of intellect. *Ethical Space: The International Journal of Communication Ethics* 3(4), 22 -28.
- Robinson, J., & Eagle, S. (2018). An exploration of drawing as a method for understanding identity in adults with a learning disability. (Unpublished masters dissertation). University of Bristol, United Kingdom.
- Rojas, S., & Sanahuja, J.M. (2011). The image as a relate: video as a resource for listening to and giving voice to persons with learning disabilities. *British Journal of Learning Disabilities*, 40, 31-36.

Salt, E., Melville, C., & Jahoda, A. (2019). Transitioning to adulthood with a mild intellectual disability—Young people's experiences, expectations and aspirations. *Journal of Applied Research in Intellectual Disabilities*, 32(4), 901-912.

Sanjari, M., Bahramnezhad, F., Fomani, F. K., Shoghi, M., & Cheraghi, M. A. (2014). Ethical challenges of researchers in qualitative studies: the necessity to develop a specific guideline. *Journal of Medical Ethics and History of Medicine*, 7, 14.

Shumba, T. W., & Moodley, I. (2018). Part 1: A review of using photovoice as a disability research method: Implications for eliciting the experiences of persons with disabilities on the Community Based Rehabilitation programme in Namibia. *African Journal of Disability (Online)*, 7, 1-11.

Spassiani, N.A., Meisner, B.A., Abou Chacra, M.S., Heller, T., & Hammel, J. (2019). What is and isn't working: Factors involved in sustaining community based health participation initiatives for people ageing with intellectual and developmental disabilities. *Journal of Applied Research in Intellectual Disabilities*, 32(6), 1465-1477.

Strack, R. W., Magill, C., & McDonagh, K. (2004). Engaging youth through photovoice. *Health Promotion Practice*, 5(1), 49-58.

Sutton-Brown, C. A. (2014). Photovoice: A methodological guide. *Photography and Culture*, 7(2), 169-185.

Swain, J. (2018). *A hybrid approach to thematic analysis in qualitative research: Using a practical example*. London, UK: SAGE Publications Ltd.

Thompson, T. G. (2018). *Thriving with Down Syndrome: A Qualitative Multiple Case Study*. (Unpublished doctoral dissertation). University of Denver, Canada.

Tideman, M., & Svensson, O. (2015). Young people with intellectual disability—The role of self-advocacy in a transformed Swedish welfare system. *International Journal of Qualitative Studies on Health and Well-Being*, 10(1), 25-100.

Tomar, N., & Stoffel, V. (2014). Examining the lived experience and factors influencing education of two student veterans using photovoice methodology. *American Journal of Occupational Therapy*, 68(4), 430-438.

Tuffrey-Wijne, I., Bernal, J., & Hollins, S. (2008). Doing research on people with learning disabilities, cancer and dying: ethics, possibilities and pitfalls. *British Journal of Learning Disabilities*, 36(3), 185-190.

Vignoles, V. L. (2017). Identity: Personal AND Social Identity. In K. Deaux and M. Snyder (Eds.), *The Oxford Handbook of Personality and Social Psychology* (p.289 - 309). USA: Oxford University Press.

UK Government (2018). Data Protection Act. London, UK: HMSO

Walmsley, J. (2001). Normalisation, emancipatory research and inclusive research in learning disability. *Disability & Society*, 16(2), 187-205.

Walmsley, J. (2004). Inclusive learning disability research: the (nondisabled) researcher's role. *British Journal of Learning Disabilities*, 32(2), 65-71.

Wang, C., & Burris, M. A. (1994). Empowerment through photo novella: portraits of participation. *Health Education Quarterly*, 21(2), 171-186.

Wang, C., & Burris, M. A. (1997). Photovoice: Concept, methodology, and use for participatory needs assessment. *Health Education & Behaviour*, 24(3), 369-387.

Wang C. (1999) Photovoice: a participatory action research strategy applied to women's health. *Journal of Women's Health*, 8 (2), 185 -192.

Ware, J. (2004). Ascertaining the views of people with profound and multiple learning disabilities. *British Journal of Learning Disabilities*, 32(4), 175-179.

Warne, M., Snyder, K., & Gadin, K. G. (2013). Photovoice: An opportunity and challenge for students' genuine participation. *Health Promotion International*, 28(3), 299-310.

Webster, L., & Mertova, P. (2007). *Using narrative inquiry as a research method: an introduction to using critical event narrative analysis in research on learning and teaching*. London: Routledge.

World Health Organization. (1992). The ICD-10 classification of mental and behavioural disorders: clinical descriptions and diagnostic guidelines. World Health Organization. <https://apps.who.int/iris/handle/10665/37958>

World Health Organization. (2018). International classification of diseases for mortality and morbidity statistics (11th Revision). Retrieved from <https://icd.who.int/browse11/l-m/en> on 10.12.2019

Yilmaz, K. (2013). Comparison of quantitative and qualitative research traditions: epistemological, theoretical, and methodological differences. *European Journal of Education*, 48(2), 311-325.

Yin, R. K. (2004). Case study methods. Retrieved 20.04.2020 from <https://www.scribd.com/doc/37102046/Robert-Yin-Case-Study-Research>

Yin, R. K. (2006). *Case Study Methods*. In J. L. Green, G. Camilli, & P. B. Elmore (Eds.), *Handbook of complementary methods in education research* (p. 111–122). Retrieved from <https://psycnet.apa.org/record/2006-05382-006> on 01.05.2020

Yin, R. K. (2012). *Applications of case study research*. London: Sage. Retrieved 28.04.2020 from [https://books.google.co.uk/books/about/Applications\\_of\\_Case\\_Study\\_Research.html?id=PL\\_epxoGHM4C&printsec=frontcover&source=kp\\_read\\_button&redir\\_esc=y#v=onepage&q&f=false](https://books.google.co.uk/books/about/Applications_of_Case_Study_Research.html?id=PL_epxoGHM4C&printsec=frontcover&source=kp_read_button&redir_esc=y#v=onepage&q&f=false)

## Appendices

### **Appendix A: Systematic Literature Search**

#### Systematic Literature Review Process:

During the early phases of this project an initial scoping of literature was completed using Google Scholar. Conducted between June 2018 – September 2018 the search was based on the question of ‘identity expression amongst individuals with intellectual disabilities and no or limited verbal language’. This provided the opportunity to get a rough idea of what literature existed, whether a systematic review had been completed and where the potential gaps were in the literature.

As the project became more refined (e.g. integrating in photovoice as a methodology) it was then broken down into concepts to create search terms. This process enabled the operationalising of the research question and conducting a search which would return as many relevant papers as possible. This process included identifying as many alternative terms and concepts that address the same question (e.g. Intellectual disabilities, Learning Disabilities and Developmental disabilities). This was completed for all search concepts, i.e. identity and photovoice.

During initial searches on PubMed, Scopus Google Scholar and PsycNet, only one paper was identified that incorporated the three research themes; ‘photovoice’, ‘identity’ and ‘Intellectual Disabilities’ (Dorozenko et al., 2015). Therefore, the decision was made to broaden out the systematic review to focus on how identity has been explored and what methods have been utilised to explore identity amongst people with intellectual disabilities. Therefore, the search criteria were changed to ‘Intellectual Disabilities’ (alternatives: ‘learning disabilities’, ‘learning disability’, ‘neurodevelopmental disability’, ‘neurodevelopmental disabilities’) and ‘Identity’ (alternatives: ‘identities’). By doing this, it allowed for a more in-depth review of how identity has been explored amongst people with Intellectual Disabilities.

Database	Date	Search Stream	No. Titles
<b>PubMED Search 1</b>	June 2019	Intellectual Disability OR Intellectual Disabilities OR Developmental Disability OR Developmental Disabilities OR Learning Disability OR Learning Disabilities  AND  Identity OR Identities  AND  Photovoice  <i>Search completed in Title, Abstract and Key Words</i>	1
<b>PubMED Search 2</b>	July 2019	Intellectual Disability OR Intellectual Disabilities OR Developmental Disability OR Developmental Disabilities OR Learning Disability OR Learning Disabilities  AND  Identity OR Identities  <i>Search completed in Title, Abstract and Key Words</i>	148
<b>Scopus Search 1</b>	July 2019	Intellectual Disability OR Intellectual Disabilities OR Developmental Disability OR Developmental Disabilities OR Learning Disability OR Learning Disabilities  AND  Identity OR Identities  AND  Photovoice  <i>Search completed in Title, Abstract and Key Words</i>	3
<b>Scopus Search 2</b>	July 2019	Intellectual Disability OR Intellectual Disabilities OR Developmental Disability OR Developmental Disabilities OR Learning Disability OR Learning Disabilities  AND	350

		Identity OR Identities  <i>Search completed in Title, Abstract and Key Words</i>	
<b>APA PsycNET Search 1</b>	Aug 2019	Intellectual Disability OR Intellectual Disabilities OR Developmental Disability OR Developmental Disabilities OR Learning Disability OR Learning Disabilities  AND  Identity OR Identities	24

*Table 6: Initial Searches of Databases*

Inclusion and exclusion criteria were then developed based on the research question, knowledge of the literature and discussions with the supervisory team (see table 1 in Introduction).

The main systematic review was completed in PUBMED between June 2019 and September 2019 (see table 6). Various searches were conducted, using different terms, to try and identify the most suitable arrangement of terms. Boolean search operators were used to broaden and narrow the search criteria. This identified 148 articles.

Additional searches were also completed in Scopus between June 2019 and September 2019. A Similar process was applied to the Scopus searches including multiple trial searches. Outcomes were then compared with the previous PUBMED search and any duplicates deleted. A final search in Scopus was completed on 08.08.19 and this identified 350 articles (13 of which were duplicates from the PUBMED search). An additional search was completed on PsycNET to explore a further database. All papers did not meet the inclusion and exclusion criteria.

The final part of the search involved reviewing the reference lists of all relevant papers to identify if any additional papers could be added to the search. In addition to this, Google Scholar was used to look for any more recent papers. This search identified one other paper not included in the existing searches.

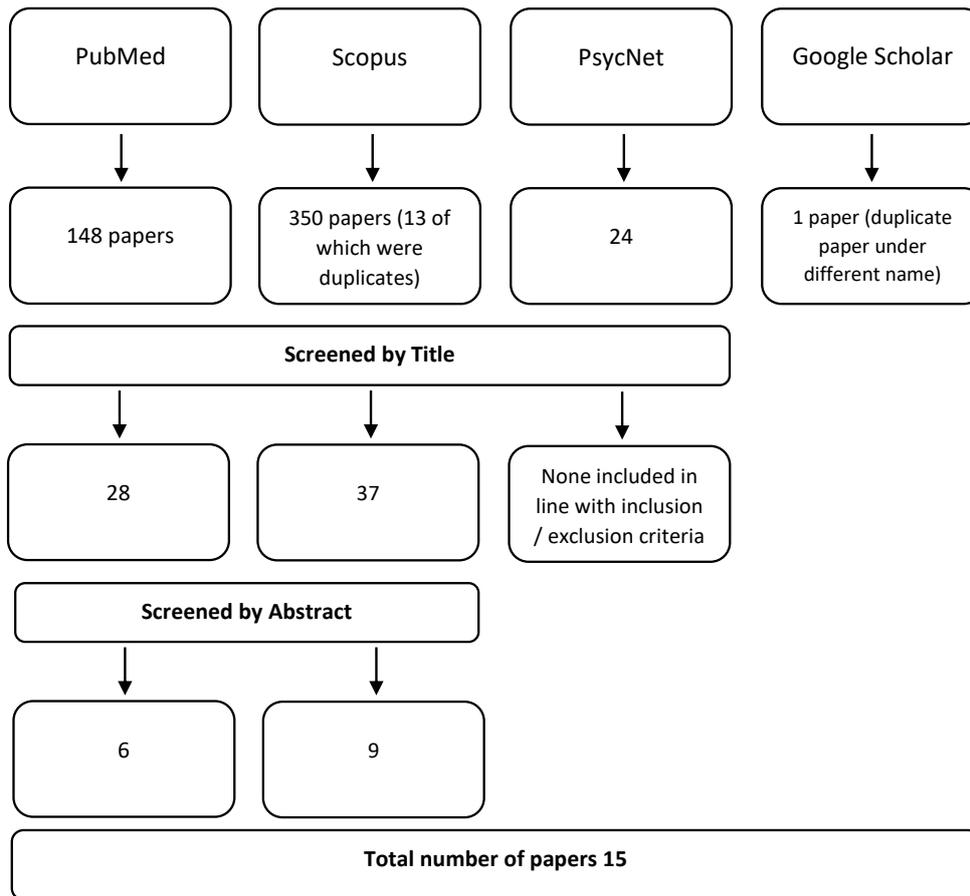


Figure 5: Systematic Review Process

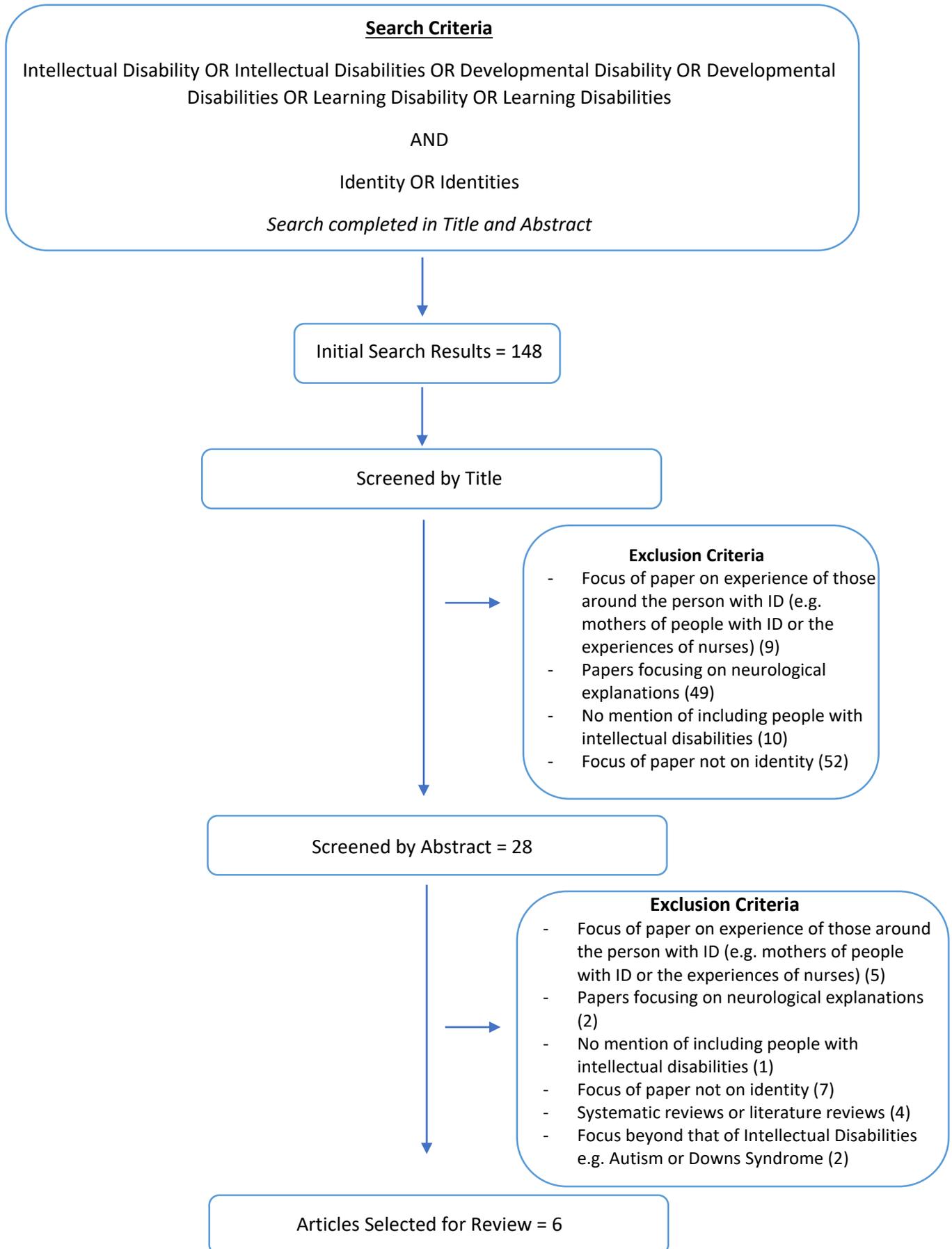


Figure 6: Systematic Literature Search: PubMed

## Systematic Literature Search: SCOPUS 1

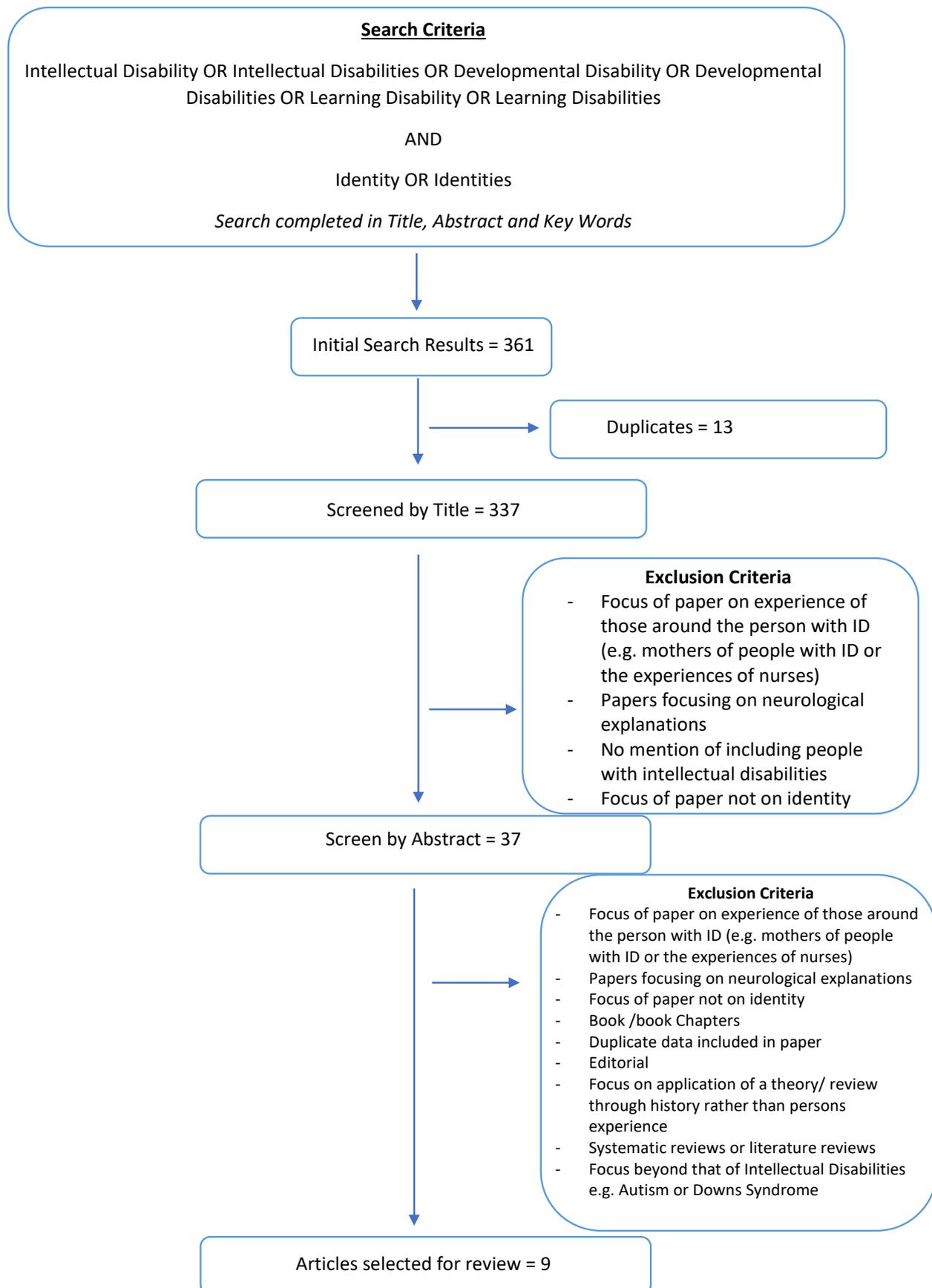


Figure 7: Literature Review Scopus

## Appendix B: Summary of Papers Included in Systematic Review

Title, Year and Location	Research Methodology	Participants	Summary of Study	Strengths and Limitations
<p>Anderson &amp; Bigby (2017).</p> <p>Self-Advocacy as a means to positive identities for people with Intellectual Disability: 'We just help them, be them really'.</p> <p>Australia and UK.</p>	<p>A qualitative research study. Participants were interviewed using semi-structured interviews. The analysis utilised a constructivist grounded theory approach</p>	<p>25 participants were invited to take part across 6 self-advocacy groups. From both Australia and UK.</p>	<p>The study aimed to explore the experiences of participation in self-advocacy groups and whether involvement had an impact the social identity of people with intellectual disabilities (p. 110). Despite differences in participant groups there were similarities across experiences. Participants reported a sense of control, a shared sense of ownership and group cohesiveness. The authors conclude of the importance of self-advocacy groups in the lives of people with intellectual disabilities.</p>	<p>Good range of participants, from multiple self-advocacy groups and across two different countries.</p> <p>However, there wasn't much reflexivity on the similarities or differences that maybe experienced by participants in the two countries. There was also limited information given about the nature of the self-advocacy groups. Nor did the researchers themselves provide much information about themselves.</p>
<p>Craig, Craig, Withers, Hatton &amp; Limb (2002)</p> <p>Identity conflict in people with Intellectual Disabilities: What role do service providers play in mediating stigma?</p>	<p>Mixed approach utilising three methods; audit of referrals, focus group and survey of attitudes of service providers. The analysis utilised involved identifying themes from the focus group (paper doesn't</p>	<p>Audit involved reviewing 92 people across caseload and waiting list. The single session focus group included 6 participants (5 males and 1 female). Survey of attitudes included 31 professionals across</p>	<p>The study was interested in the relation people with intellectual disabilities had with their disabled identity and whether services influenced this (p.63). Drawing on multiple methods of data collection; audit, focus group and</p>	<p>As noted by the study, the sample sizes are small and therefore findings should be viewed cautiously (p.71). Despite this, it may be important for services to consider training in how to support people with intellectual disabilities in</p>

England, UK.	specify what process this involved).	psychology, social services and health workers.	questionnaire. The audit revealed that support was not being sought for difficulties with identity. People with intellectual disabilities were aware of the stigma associated with the label and found it uncomfortable to talk about it. They found services were able to acknowledge the importance of asking people with intellectual disabilities about their experiences but found it difficult to support them when they struggled to express their experiences. The studies' findings supported previous research and suggested that more support for professionals would be an important step forward.	conversations about their diagnosis. Further limitations of this study include the disproportionate number of service-users in the focus group compared with the service providers. Additionally, using focus groups may limit the inclusion of some people with intellectual disabilities due to the difficulties conversing in a social environment.
Dickinson & Hutchinson (2018)  Changes in understanding and perceptions, significant others and community supporters involved in a theatre company for adults with Intellectual Disabilities.	The study involved a qualitative approach. Conducting interviews with people with intellectual disabilities who were members of the theatre company group and focus groups with significant people in their lives and	A total of 14 members with intellectual disabilities were interviewed, with an additional 11 significant people and 10 community supporters.	This study was interested in gathering multiple perspectives (people with intellectual disabilities, families, carers and community members) of intellectual disabilities within the context of a theatre group. It was specifically interested in	This study offers a unique way of exploring identity amongst people with intellectual disabilities that utilises their strengths. It identified some important implications for involving people around the person in services and discussions.

<p>England, UK.</p>	<p>community supporters. Thematic analysis was used.</p>		<p>exploring the impact of being involved in a theatre group on people with intellectual disabilities and their identities and how it affected perceptions of people with intellectual disabilities by those around them (p.692).</p> <p>They found that the theatre group had a positive impact not only for people with intellectual disabilities and their quality of life but on perceptions held by others. Specifically, the group helped <i>'develop social connections and deeper understandings of relationships'</i> (p.701).</p>	<p>However, the use of interviews may make it difficult for some people with intellectual disabilities to participate. The participants in the study were also all White British.</p>
<p>Dorozenko, Roberts and Bishop (2015).</p> <p>The identities and social roles of people with an intellectual disability: challenging dominant cultural worldviews, values and mythologies.</p> <p>Australia.</p>	<p>This qualitative study involved utilising photovoice and conversational interviewing to collect data. Analysis involved causal layered analysis to deconstruct the data.</p>	<p>18 members of an advocacy agency with intellectual disabilities. All participants were recruited from Australia.</p>	<p>This study explored the social construction of intellectual disability and was conducted within a participatory framework. It was interested in whether people with intellectual disabilities have an awareness of this label and wanted to explore other identities that are often overshadowed by the label</p>	<p>This study helps emphasise not only the importance of involving people with intellectual disabilities in research but that there are important social structures and interactions to explore when it comes to conceptualising identity amongst people with intellectual disabilities. It also offers some important</p>

			of intellectual disabilities. Involving members of a self-advocacy with intellectual disabilities, photovoice and conversational interviewing was conducted. The study revealed the complex processes involved in constructing identities for people with intellectual disabilities and that it was not prominent identity for people with intellectual disabilities. The identities for people with intellectual disabilities were instead informed by ' <i>broader social contexts</i> ' and ' <i>social relations</i> ' (p.1360).	recommendations for analysing creative methods in the form of causal layered analysis.
Jahoda, Wilson, Stalker and Cairney (2010).  Living with stigma and the self-perceptions of people with mild intellectual disabilities.  Scotland, UK.	This study adopted a qualitative design drawing on ethnographic approaches, lasting between 6 months to 1 year. Participants were also provided with a camera to take pictures or keep videos diaries with. No direction was given on themes of pictures or video diaries.. Adopted a social	The study recruited 17 people, in their late teens and early twenties, from specialist mental health services. All participants had a diagnosis of mild to moderate intellectual disabilities. They also had difficulties with anxiety or depression (p. 525).	This study explored the impact of stigma on the self-perceptions of people with mild intellectual disabilities. It utilised a range of creative methodologies that could be chosen by participants (photographs, video diaries). It also used an ethnographic approach. The study found that participants wanted to take an active role in	A strength of study was its use of multiple data collection sources. This improved the accessibility of the study and meant participants could choose the means in which they felt most comfortable expressing their views.  A limitation of this study was that participants were

	<p>constructionist perspective. Interviews were also conducted with participants and their families and carers as well as some teachers, social workers and health care professionals.</p>		<p>shaping their identities and quality of life. The study emphasised the importance of using creative methods to support the expression of identities and illustrates that researchers do not need to rely on verbal communication. The study also concludes that a lack of verbal communication should not be considered a barrier to engagement.</p>	<p>recruited from specialist mental health services which may impact the generalisability of findings.</p>
<p>Leite and Monterio (2008). Identity formation of disabled individuals within a speech therapy group. Brazil.</p>	<p>This qualitative study utilised data collected from a previous research project as well as current data from a speech and language group. It included interview transcripts and video clips of young people with intellectual disabilities receiving speech therapy in a school clinic setting over a two-year period. Analysis of the study involved micro-genetic analysis, exploring the minute details of the interviews and clips of interactive episodes.</p>	<p>The study involved 7 young adults with intellectual disabilities, aged between 16 and 27 years. All participants were attending a weekly speech and language group.</p>	<p>The study reflected on the formation of personal identity of mentally disabled young people who were receiving speech therapy in a group context. Using data collected from a previous research project, that explored the negative image groups of siblings held about their sibling with a diagnosis of intellectual disabilities. The study aimed to explore the relationship between images these participants had of themselves and those put across by the social group they belong to. They found that there were discourses present in the</p>	<p>The strengths of this study were its longitudinal approach and involving multiple voices when thinking about the construction of identity. It also reflected on the researcher positions and the influence this had over the conception, implementation and analysis of the study. The study offers some important implications such as supporting the construction of positive identities through those closest to the person.  However, it lacks in detail in relation to how long ago the</p>

			<p>verbalisations of those with intellectual disabilities. They emphasise the importance of directing action towards those closest to individuals with intellectual disabilities to support the development of positive identities.</p>	<p>previous data was collected. It also was quite limited in its recruitment process, only using one group.</p>
<p>McClimmens and Gordon (2008).</p> <p>Presentation of self in E-everyday life: How people labelled with intellectual disability manage identity as they engage in the blogosphere.</p> <p>UK.</p>	<p>Adopting a qualitative approach informed by interactionist and ethnographic perspectives. The study gathered data from observations, the blogs created and from a structured questionnaire and focus group</p>	<p>The study doesn't specify how many participants took part in the study, but all had a diagnosis of intellectual disabilities.</p>	<p>The study was interested in exploring the online habits of people with intellectual disabilities and whether this could provide an understanding of identities are shared online. Participants were signed up to a public blogging site and notes and observations were made of their interactions and blogs. The study found that whilst participants were able to access the blogs, they had limited interactions with other users. The researchers reflect on the way blogs can protect people with intellectual disabilities from discrimination they experience day to day yet there are challenges (e.g. writing skills) to supporting people with intellectual</p>	<p>This study offered a unique way of exploring the expression of identity for people with intellectual disabilities and one that is important in the way most people interact in society.</p> <p>The limitations of this study had limited success getting people with intellectual disabilities to interact with 'others' online. Additionally, the use of a public forum may have impacted the expression of the self.</p>

			disabilities engage in interactions using this forum.	
<p>Midjo and Aune (2018). Identity constructions and transition to adulthood for young people with mild intellectual disabilities.  Norway.</p>	<p>The study adopted a qualitative approach, drawing on interpretative paradigms to analyse interview data. It was completed over a two-year duration. Analysis involved an interpretative approach to analysing the data from interviews. It drew on the qualitative approach outlined by Brinkmann and Kvale (2015) which involves looking for patterns in the transcripts around constructions of the self. These were then combined into themes.</p>	<p>The study involved the perspectives of 4 young adults with mild intellectual disabilities, five parents and five professionals. These people were recruited from several services.</p>	<p>This study was interested in the self-constructions of people with intellectual disabilities. It involved exploring how people with intellectual disabilities communicate their identities with people around them in everyday life. The findings suggest that participants constructed their identities through talk about everyday life. They also found important gender related differences in how people with intellectual disabilities spoke about independence, with women developing stronger identities in context of social roles (p.44). Lastly, the study also found differences in perceptions of people with intellectual disabilities during periods of transition. Whilst participants felt they were '<i>actors in their own lives</i>' (p.33) professionals</p>	<p>This study has some important implications for services and the way professionals construct the identities of people with intellectual disabilities.  However, the sample size of this project was small and may not be generalisable to all people with intellectual disabilities due to the variances of experiences particularly when it comes to times of transition.  It also didn't provide much information of the process of analysis or the researchers position but just referenced an approach</p>

			and parents could impact on these perceptions through the opportunities provided and level of support offered.	
<p>Mineur, Tideman and Mallander (2017).</p> <p>Self-advocacy in Sweden – an analysis of impact on daily and identity of self-advocacy with intellectual disability.</p> <p>Sweden.</p>	<p>This qualitative study utilised ethnographic approaches and semi-structured interviews. An interpretative approach based on hermeneutic theory was used to analyse the data.</p>	<p>Individual interviews were conducted with 26 self-advocates from six different groups.</p>	<p>The study's aim was explore self-advocacy groups in Sweden, whether they had any impact on society perceptions and how important membership was to people with intellectual disabilities, with specific focus on the daily lives and identity (p.3). The findings suggest participants felt self-advocacy offered a range of importance and opportunities to their daily lives. It specifically supported people to feel a sense of connection, normalisation and had important effects on how they viewed themselves (p.6).</p>	<p>The study acknowledges that it is difficult to generalise the findings from the research to all people. The findings also illustrate the importance of formal positions for development of positive identities. It also explores the similarities and differences between different self-advocacy models.</p> <p>A limitation of the study is the lack of capturing the negative or critical opinions of self-advocacy and whether they can negatively impact a person's identity.</p>
<p>Monteleone and Forrester-Jones (2016).</p> <p>Disability means, um dysfunctioning people: a qualitative analysis of the meaning and experience of</p>	<p>This qualitative study utilised semi-structured interviews. Analysis was completed using Interpretive Phenomenological Analysis.</p>	<p>A total of 15 adults with intellectual disabilities took part in the study. Recruitment involved purposive sampling and all participants were recruited from a working farm.</p>	<p>This study set out to explore how people with intellectual disabilities viewed themselves and their disability. It was also interested in their own understandings of disability,</p>	<p>The findings from this study have important implications for designing services because they illustrate the views and experiences of people with intellectual</p>

<p>disability among adults with intellectual disability.</p> <p>UK.</p>			<p>their social relationships and self-esteem (p.12). The findings emphasised the importance of social relationships and how this helped guide the participants own behaviour, perceptions of identity and view towards whether they fitted in, in society. They also found the presence of stigma in their own perceptions of themselves and that when participants compared themselves to others without disabilities this was more likely to lead to lower self-esteem.</p>	<p>disabilities in social contexts.</p> <p>The study included participants covering an age range of 44 years. Whilst this allowed for a range of experiences, it may have also impacted accounts given due to changes in terminology and vast differences in experiences. They were all recruited from on service which may have influenced responses (p.40).</p> <p>The interview method also limited the participants who could participate.</p>
<p>Moya (2009).</p> <p>Constructing lives for people with intellectual disabilities in life story books.</p> <p>UK.</p>	<p>This qualitative study involves the construction of life story books. Discourse analysis was used to analyse the talk and texts in interviews and the books themselves.</p>	<p>This study involved 6 participants transitioning from long stay hospitals to community care settings. It monitored experiences across both settings.</p>	<p>The study aimed to explore the use of life story books for people with intellectual disabilities transitioning across two settings. Life story books were analysed in three ways, how they were as a resource, for getting to know the person, defining the person and for displaying personality and uniqueness. The findings illustrated that despite the</p>	<p>There are important implications of this research for services making sure things written down are not taken for granted but an invitation to ask questions and in addition to spending time with the person.</p> <p>The study involved a relatively small sample over a small amount of time which means that capturing</p>

			different uses of the life story books what is written about the person is considered a direct representation of them with particular emphasis on past experiences. The researchers also highlighted the important role of advocates when people with intellectual disabilities are unable to communicate their lives verbally. As much of what is gathered about the person would be passed on by service to service, meaning there are often aspects of the person which are lost over time (p.149).	the person's identity maybe very specific to that context and situation.
<p>Rapley, Kiernan and Antaki (1998).</p> <p>Invisible to themselves of negotiating identity? The interactional management of 'being intellectually disabled'.</p> <p>Australia.</p>	<p>A qualitative study that incorporated interviews. Themes were drawn out of the transcripts however it was not clear what process was used.</p>	<p>All participants in the study had mild to moderate intellectual disabilities and were living in a family care situation or in supported independent living. Participants were purposively recruited through service providing agencies. The study involved a larger number of participants but only</p>	<p>The study was interested in exploring the perceptions people with intellectual disabilities have of their disabled identity and the impact this has on their lives. The finding suggest that it is important that people with intellectual disabilities are not made to feel like they have to fit in. Participants were aware of their disabled identities and</p>	<p>The findings from this study were part of a larger project, however the paper was limited in the information it gave to several details such as reflexivity, analysis and context.</p> <p>It does however consider its findings in relation to other studies and compares and contrasts whether people</p>

		incorporated 8 participants in the paper.	the impact on their social experiences (p.842).	with intellectual disabilities have an understanding of their labels and the impact this may have.
<p>Rekosiewicz (2018).</p> <p>Identity development in people with mild intellectual disability: A short-term longitudinal study.</p> <p>Poland.</p>	<p>This study adopted a quantitative design. Drawing on the dual-cycle model of identity formation (Luyckx et al, 2006) and an adapted version of the Dimensions of Identity Development Scale (DIDS; Rekosiewicz, 2015). The study used single variable analysis of variance.</p>	<p>The study recruited 127 participants. They were grouped in relation to age; late adolescence 16-17 and emerging adulthood 20-21 years and also level of intellectual functioning; mild intellectual disability and within intellectual norm. Participants were asked to complete the DIDS 3 times with 6-month intervals.</p>	<p>The project was interested in monitoring identity formation across late adolescence and early adulthood and compare results across two groups ranging in intellectual functioning. It was also interested in exploring identity development over time. Unlike what might be assumed the results of the study suggested that people with intellectual disabilities did not differ in their identity development compared with people without a diagnosis. The findings suggested that participants with intellectual disabilities faced similar experiences to those developing neurotypically.</p>	<p>The study involved a good number of participants. It also did not try to generalise findings beyond the people in the study to people with more severe forms of intellectual disability but recognised there is likely to be some differences due to ability to express and communicate.</p> <p>The study also acknowledged findings that were different to the main ones. For example, people with intellectual disabilities expressed they engaged more so with decisions related to their future than those within the intellectual norm group. The study was also completed over a longitudinal framework.</p> <p>The study did not explore the meaning of experiences of participants in relation to identity development which</p>

				may have provided more in-depth understanding.
<p>Salt, Melville &amp; Jahoda (2019).</p> <p>Transitioning to adulthood with mild intellectual disability – Young people’s experiences, expectations and aspirations.</p> <p>UK.</p>	<p>This qualitative study utilised semi-structured interviews. An interpretative thematic analysis was used to analyse the data.</p>	<p>The study involved 8 participants all with mild to borderline intellectual disabilities.</p>	<p>The purpose of the study was to explore participants experiences of transitioning to adulthood. It was specifically interested in the emotional and socio-cognitive experiences of participants. They found that participants perspectives were very similar to views of a typically developing young adult. The themes from interviews emphasised normalisation, independence and being given opportunities like any other person.</p>	<p>There were several strengths to this project including the exploration of transition and identity development, a pilot study and WASI-II test. The paper also provided lots of detail around the analysis which is often neglected in other papers.</p> <p>The paper acknowledges that it was on the lower end of participants required for thematic saturation. Yet they state that it is instead best considered a snapshot of experiences and perspectives rather than an exhaustive list.</p>
<p>Tideman &amp; Svensson (2015).</p> <p>Young people with intellectual disability – The role of self-advocacy in a transformed Swedish welfare system.</p> <p>Sweden.</p>	<p>This qualitative study collected data over a period of 10 years using repeated interviews with members of two self-advocacy groups as well as participant observations. Analysis involved cooperative inquiry.</p>	<p>The study incorporated two self-advocacy groups for young adults with intellectual disabilities. It involved interviewing and observing 12 members between the years of 1996 and 2013.</p>	<p>This study set out to explore the marginalisation of young adults with intellectual disabilities in Sweden and the significance of self-advocacy in the new welfare context (p.2). The findings of the study illustrated the significance of closing the institutions and transfer of care to local governments.</p>	<p>The strengths of this project include its longitudinal approach and varied methods of data collection. It also positioned participants as co-researchers in the project.</p> <p>The limitations of this paper are reflexive aspects of themselves as well as the</p>

			<p>However, this presented new challenges for participants in managing day to day life in society. The findings illustrate the difficulty in finding the right balance between giving individual responsibility and independence at the same time providing an adequate amount of support. The self-advocacy groups provided opportunities for members to develop a collective solidarity, empowerment and the opportunity to develop identities away from their intellectual disability's diagnosis.</p>	<p>processes involved. They centred their discussion on the findings of the study rather than any design aspect of the study.</p>
--	--	--	---	---

*Table 7: Summary of Papers Included in Systematic Review*

## Appendix C: Extracts from Reflective Journal

## Appendix D: Quality Review of Current Study

As reflected in section .... of the method, the quality criteria offered by Mays and Pope (2000) was used throughout this piece of research to reflect on the quality of this thesis.

Mays and Pope (2000) Quality Criteria	Evidence for Criteria
Worth or relevance – was this piece of work worth doing at all? Has it contributed usefully to knowledge?	The literature search demonstrated that the majority of the research conducted with people who have intellectual disabilities are those with mild to moderate difficulties.
Clarity of research questions – if not all the outset of the study, by the end of the research process were the research questions clear? Was the researcher able to set aside his or her research preconceptions?	<p>The research questions were clearly stated along with a rationale at the end of the introduction chapter. The findings of the study were also outlined in relation to each research question in the results section. More summarising could have occurred in the results for each research question in the results section to clarify overall findings.</p> <p>There wasn't much reflection on the researchers' preconceptions of the questions. Although a reflexive journal was kept which helped consider the researchers position.</p>
Appropriateness of design to the question – Would a different method have been more appropriate? For example, if casual hypothesis was being tested was a qualitative approach really appropriate?	<p>Utilising multiple methods of data collection suited the study's aims because it increased its flexibility and inclusiveness for people with severe and profound intellectual disabilities. Each element (ethnography, photovoice and dyadic interview) has been used when involving people with intellectual disabilities in research. Thematic analysis also supported this flexible approach.</p> <p>On the other hand, more participants could have been included to allow for more variety of results however this may have impacted the depth of exploration for each participant.</p>
Context – Is the context or setting adequately described so that the reader could relate the findings to other settings?	There is only a small amount of information provided about the context in which participants were observed. Although there is enough detail to support the replication of the study.
Sampling – Did the sample include the full range of possible cases or settings so that conceptual rather than statistical generalisations could be made (that is, more than convenience sampling)? If appropriate, were efforts made to obtain data that might contradict or modify the analysis by extending the sample (for example, to a different type of area)?	<p>Purposive sampling was important to ensure participants included in the study met the criteria. Efforts were made to gather a range of different contexts although in the end only one context was used to recruit participants.</p> <p>Also, all the participants included in this study had comorbid diagnoses of Autism which may have influenced results.</p>
Data collection and analysis – Were the data collection and analysis procedures systematic? Was the	There is a detailed description given of the studies analysis process. Additional information is also provided in Appendix (T, U and V). The research also provided some reflections of

<p>'audit trail' such that someone else could repeat each stage including analysis? How well did the analysis succeed in incorporating all the observations? To what extent did the analysis develop concepts and categories capable of explaining key processes or respondents' accounts or observations? Was it possible to follow the iteration between data and the explanations for the data (theory)? Did the researcher search for disconfirming cases?</p>	<p>the process of analysis to support the readers understanding of what influenced the decisions at different stages of analysis.</p> <p>There is some detail of disconfirming cases, although more contrast could have been provided in the results section to develop the layers in each theme.</p>
<p>Reflexivity of the account – Did the research self consciously assess the likely impact of the methods used on the data obtained? Were sufficient data included in the reports of the study to provide sufficient evidence for readers to assess whether analytical criteria had been met?</p>	<p>The researcher made an effort to reflect throughout the process and consider their own position and the influence on the results of the study. Although more could have been done to consider the impact of the researcher's presence on what was being observed or documented.</p>

*Table 8: Quality Review of Current Study*

## Appendix E: Service Information Sheet

This is an official notification by Emma Krisson of the University of Hertfordshire in respect of a study involving human participants. This study has been approved by The University of Hertfordshire Health, Science and Engineering and Technology Ethics Committee with Delegated Authority: aLMS/PGT/UH/03863(2)



### Invitation to Participate in a Research Project

*'Can Photovoice as a methodology be used to explore identity expression amongst people with Intellectual Disabilities who have limited or no verbal language?'*

I am a Trainee Clinical Psychologist studying at Hertfordshire University. As part of my training I am carrying out a project exploring how people with Intellectual Disabilities express their identity. There is still a lack of understanding around identity expression amongst people with Intellectual Disabilities and much of what we know about the person (their likes, dislikes, their personality) still comes from those around the person. Therefore, I hope that by completing this project it will help identify creative ways of engaging with people who have Intellectual Disabilities and develop more of an understanding of identity expression amongst the population. These approaches can then be utilised by services and families.

#### What is the Project?

The project involves exploring whether Photovoice can be used as a method to explore identity expression amongst people who have Intellectual Disabilities who have limited or no verbal language. Photovoice involves providing people with cameras so that they can capture things that are important to them in their everyday life. Photovoice has previously been used with people who have Intellectual Disabilities, yet identity expression has not been explored as part of these projects.

#### Recruitment

I am writing to enquire whether you would give me permission to recruit participants from among the individuals currently residing in your care. I would need help to identify a group of participants and their families that meet the following criteria:

- Aged 18 years and above.
- Have a diagnosis of Intellectual Disabilities (Comorbid diagnoses would be considered on case by case basis).
- Have limited or no verbal communication abilities
- A member of their family agrees to participate in the project to support the person take pictures and then participate in an interview following the Photovoice exercise.

Your support in the project would include:

- Reaching out to prospective participants and their families through the distribution of information about the study.
- Placing posters around the service (optional)
- [Optional] A carer from your service can also volunteer to be involved in the project by supporting the person to take pictures and then participate in an interview following the Photovoice exercise.
- Agree to 2-3 visits so that I can get to know the person and observe how they express their identity in day to day life. Consent from the person would be ongoingly assessed and consent will be gained independently from family.
- Since observations would be occurring around other service users (not involved in the project), there would be the option of providing information to them so that they are aware of what was going on.

**Capacity and Consent**

As a service, consent to support the identification and recruitment of participants will be sought prior to contact with any participants, through signing a consent form. The form will detail your support in the project (outlined above), withdrawal and safeguarding procedures.

Participant consent will be captured via two different methods.

- Family and Carers: Provide consent to participate at the beginning of the project
- Person with Intellectual Disabilities: Due to issues of capacity, consent to take part in activities will be assessed on an on-going basis through observations and conversations with family.

If you have any comments, or questions about this project, please contact myself using the contact details below.

**Permission and Ethics**

This research has been approved by the Health, Science, Engineering & Technology Ethics Committee with Delegated Authority (ECDA; aLMS/PGT/UH/03863(2)) at Hertfordshire University.

If you are interested in taking part in this study, I would be happy to send out the necessary consent forms. Many thanks in advance for your consideration of this project. Please let me know if you require further information.

Kind Regards,

Emma Krisson

Lead Researcher of Project

Trainee Clinical Psychologist

Email: [\[email\]](#)

## Appendix F: Service Consent Form

This is an official notification by Emma Krisson of the University of Hertfordshire in respect of a study involving human participants. This study has been approved by The University of Hertfordshire Health, Science and Engineering and Technology Ethics Committee with Delegated Authority: aLMS/PGT/UH/03863(2)



### Service Provider Information Sheet and Consent Form

#### Why do this study?

I am interested in exploring whether Photovoice as a methodology supports identity expression amongst individuals with intellectual disabilities who have little or no verbal language. Previous, studies have neglected to directly involve individuals with similar needs in research and relied on those around them. This project aims to provide valuable insights into identity expression for these young people and illustrate how communication tools can support these interactions. It also aims to provide useful methodological recommendations for future projects and work to reduce marginalisation that these individuals experience.

#### What will the services' participation involve?

- Reaching out to prospective participants and their families that meet the eligibility criteria (aged 18 years and above, have a diagnosis of intellectual disabilities (not limited to) and have limited or no verbal communication ability) through the distribution of a flyer
- Placing posters around the service (if required)
- [Optional] A carer from your service can also volunteer to be involved in the project by supporting the person to take pictures and then participate in an interview following the Photovoice exercise.
- Agree to 2-3 visits so that I can get to know the person and observe how they express their identity in day to day life. Consent from the person would be ongoingly assessed and consent will be gained independently from family.
- Since observations would be occurring around other service users (not involved in the project), there would be the option of providing information to them so that they are aware of what was going on.

#### Capacity and Consent?

As a service, consent to support the identification and recruitment of participants will be sought prior to contact with any participants, through signing a consent form. The form will detail your support in the project (outlined above), withdrawal and safeguarding procedures.

#### How long will participation take?

From our first meeting through to our last will span over 2-3 months. There is the option of meeting again later in 2020, with all members of the project, to share findings from the study.

**Confidentiality / Anonymity?**

Pseudonyms will be used as a way of protecting the individuals' identity. All information will be stored anonymously and securely, which means no body will know who said what. Any data collected will kept on a secure password protected device.

As a contributor within this research study, I understand that:

1. My participation is voluntary, and I may cease to take part in this research study at any time and without giving a reason.
2. I will support the identification of potential participants
3. I will provide potential participants with copies of the information sheets
4. I will help coordinate meetings between the researcher, participant and family
5. All data will be stored anonymously once it has been collected. This means that it will be impossible to trace information back to me. As such, if I decide I want to withdraw my data from this study I will only be able to do this up until the transcript has been anonymised. If I decide to withdraw my data, I should contact Emma Krisson (Researcher).
6. I am aware that if there are any photographs of myself taken during the Photovoice activity these will be stored securely and not shared beyond the researcher and supervisory team. Consent will be re-requested for any photographs used beyond this.
7. During any observations or meetings, any concerns regarding any evidence of mistreatment, abuse or other potential problems will be raised to the relevant people within the service and local safeguarding procedures will be followed. Data collection with these participants will be stopped at this point.
8. This research has been approved by the Health, Science, Engineering & Technology Ethics Committee with Delegated Authority (ECDA; aLMS/PGT/UH/03863(2)) at Hertfordshire University.
9. All my questions about the study have been satisfactorily answered and I am aware of what my participation involves.
10. The researcher will treat my participation in this study confidentially and that anything I say in the interview will be treated confidentiality, unless it leads [researcher/carers] to believe that my safety is in danger. In this case they will be unable to keep this information confidential.
11. I am aware that data collected from this study, will be stored and used anonymously within a report for a submission as part of the Doctoral in Clinical Psychology Training programme.
12. I am also aware that information provided as part of this project (including any anonymised direct quotations) may be published in an academic journal.

Consent to use data collected for an additional future project:

The current project aims to explore identity expression using a specific methodology and analysis. There may be an opportunity to use alternative forms of analysis in future research. This would continue on from this research project. Please indicate below whether you provide consent for your data to be stored securely and contacted in relation to it being used for future research. If the data is not used it will be destroyed following the guidelines set out by the British Psychology Society.

*(Please tick the box that indicates your answer).*

- I consent to my data being stored securely and being contacted in relation to its use in future research.
  
- I do not consent to my data being used beyond this research project.

I have read and understood the above, and agree to take part:

Service Provider [manager]: \_\_\_\_\_ Date: \_\_\_\_\_

I have explained the above and answered all questions asked by the service:

Researcher's Signature: \_\_\_\_\_ Date: \_\_\_\_\_

## Appendix G: Participant Information Sheet

This is an official notification by Emma Krisson of the University of Hertfordshire in respect of a study involving human participants. This study has been approved by The University of Hertfordshire Health, Science and Engineering and Technology Ethics Committee with Delegated Authority: a.LMS/PGT/UH/03863(2)

**University of Hertfordshire UH** Ethics Committee

### Information Sheet for Participants



Hello.



My name is Emma Krisson. I am doing a research project.



I am interested in getting to know you, what you like doing...



...and what you do not like doing.



I will you a camera to use for two weeks



Your family or carer can support you to take pictures



You can take pictures of things that are important to you



You will give me back the camera after two weeks



If you would like to meet, I can come visit you at your home or [service]



If there is anything else you would like to know, you can contact me.

**Emma Krisson**

*Researcher*

*Trainee Clinical Psychologist*

*Email: xxx xx*

**Title of study:** Can Photovoice be used as a methodology to explore identity expression with individuals who have intellectual disabilities and limited or no verbal language This research project has been approved by Health, Science, Engineering & Technology Ethics Committee with Delegated Authority (ECDA; aLMS/PGT/UH/03863(2)) at Hertfordshire University. If you have any queries concerning this document, please contact me, Emma Krisson, [\[email\]](#) or Maria Qureshi, [\[email\]](#), who is supervising this project.

## Appendix F: Flyer



# Volunteers Needed!

Do you care for someone or have someone in your family that has Intellectual Disabilities and are interested in participating in a camera activity?

A study is being completed, by Hertfordshire University exploring identity expression amongst individuals with diagnoses of Intellectual Disabilities who have little or no verbal language.

## What Does Participation Involve?

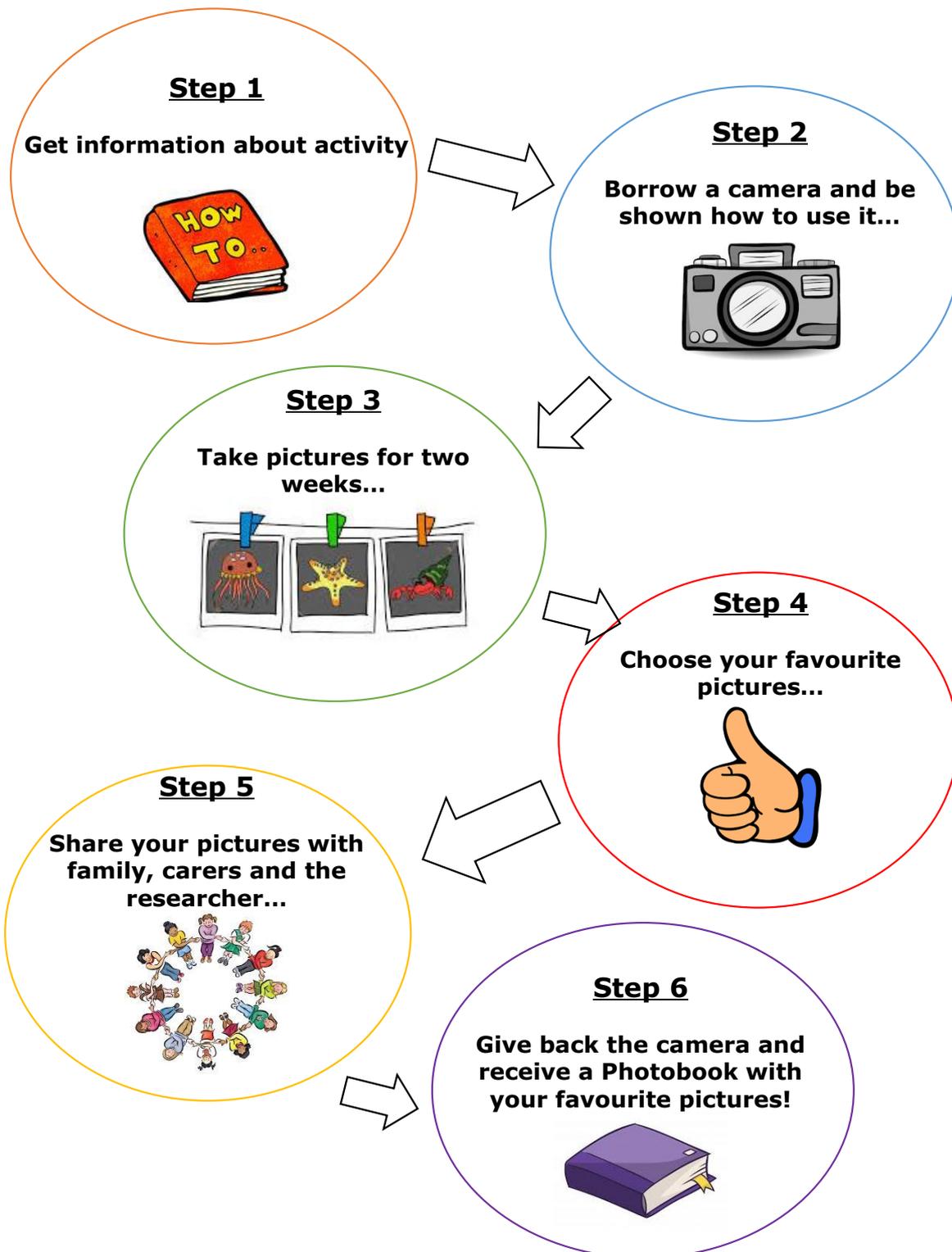
1. After completing consent procedures, time will be spent getting to know the family and person with Intellectual Disabilities. This will be done through meetings and observations.
2. The family /carer will then be asked to support their loved one or service user to complete an activity with a camera capturing everything meaningful to that person.
3. After completing the activity, we will all come together to share the pictures and talk about views of identity expression .

This study has been ethically approved by the University of Hertfordshire. For more information about this study, please contact: [Emma Krisson \(email: \[emma.krisson@herts.ac.uk\]\(mailto:emma.krisson@herts.ac.uk\)\)](mailto:emma.krisson@herts.ac.uk)

University of Hertfordshire **UH**

Appendix I: Photovoice Information Sheet

**Photovoice Activity Information Sheet**



## Appendix J: Parent/Carer Information Sheet

This is an official notification by Emma Krisson of the University of Hertfordshire in respect of a study involving human participants. This study has been approved by The University of Hertfordshire Health, Science and Engineering and Technology Ethics Committee with Delegated Authority: aLMS/PGT/UH/03863(2)



### Family and Carer Participant Information Sheet

*Project Title: Can Photovoice be used as a methodology to explore identity expression with individuals who have intellectual disabilities and limited or no verbal language?*

My name is Emma Krisson and I am inviting you to take part in a research study that I am undertaking as part of my Doctorate in Clinical Psychology at the University of Hertfordshire. Before you decide whether to do so, it is important that you understand the research that is being done and what your involvement will include. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask us anything that is not clear or for any further information you would like to help you make your decision. Please do take your time to decide, whether or not, you wish to take part. Thank you for reading this.

#### **What is the project about and what does it involve?**

I am interested in exploring how we can find ways of supporting people with intellectual disabilities who have little or no verbal language to express their identities. The study involves recruiting participants with intellectual disabilities, their family and or carers to take part in:

- **Observations:** These will take place with the service provider who got in touch with you (e.g. day centre) and will involve observing your family member/service user at the day centre. Observations will take note of expressions of identity e.g. clothing, activities, likes, dislikes, communication and interaction.
- **Photovoice Activity:** Photovoice is a method which involves providing participants with cameras. It offers the opportunity for individuals to capture visual representations of their everyday lives and share this with those around them. With your support, your family member/service user will take pictures over the course of two weeks. The photographs taken will represent things important to that person.
- **Feedback and Sharing Interview:** This interview will provide the opportunity for your family member to share their pictures and, if possible, identify the ones they like most. It will also include a conversation about identity expression, what it means to you as family/carers, what expressions of identity you notice in the photographs, how you understand it and any challenges faced. It will last approx. 1 -2 hours.

We are intending to recruit participants to this project who may not have capacity to consent to their participation. This means that they may not determine for themselves whether or not they want to take part.

The project has been approved by the Health, Science, Engineering & Technology Ethics Committee with Delegated Authority (ECDA; aLMS/PGT/UH/03863(2)) at Hertfordshire University. It is our responsibility to make sure the project is safe for each participant and does not cause them harm or distress. To help with this, the researchers need information from people who have known the participant for some time.

### **Why do this project?**

For individuals with neurodevelopmental difficulties such as intellectual disabilities they often experience stigma, discrimination and marginalisation. They are also often seldom involved directly in research which only further contributes to marginalisation and relies on the voices of those around them.

This research project aims to work towards tackling these challenges by directly involving people with intellectual disabilities in research. It is hoped that completing this project it will provide new insights into ways of engaging, interacting and exploring identity expression amongst individuals with intellectual disabilities who have no or limited verbal language. It is also hoped that this research will illustrate methodologies that work when exploring these areas and pave the way for future research. In doing so, fewer people with intellectual disabilities will be excluded from research which will help provide opportunities for their experiences to be heard.

### **Is it Compulsory to take part?**

Participation in this study is completely voluntary. It is up to you, whether or not, you decide to take part in this study. As participants, you are able to withdraw from the study at any time, even if you have already agreed to take part. If you decide, not to take part it will not affect you in anyway.

### **Why have I been approached?**

You have been approached for two reasons. Firstly, as a partner, friend or relative of a prospective participant in the study, you will have an interest in the person's well-being and welfare.

Researchers in the project would like to discuss with you whether you think that your partner, friend or relative would like to take part. As you have known them for some time, you may be aware of any views they have about taking part in such as project. The researchers would like to respect the person's wishes. Your involvement in the project will also help inform the researchers about any possible difficulties they may have. You may also be able to tell us how they may communicate that they want to stop being involved.

A 'personal consultee' is a partner, friend or relative of a prospective participant, who provides the researchers with advice. If you would like further information about being a personal consultee, please contact the lead researcher.

Secondly, you have also been approached because of your relationship with the prospective participant. The project would benefit from involving people close to the person for their support as well as the sharing of information about the person, their likes and dislikes.

So, your role in the project is to act as a personal consultee for your relative, friend or partner to support the project and participate in a semi-structured interview.

- Supporting your family member to take pictures over a two-week period (without too much influence on what they take pictures of).
- Taking part in a post Photovoice interview (lasting approx. 1-2 hours) to share views on identity expression.

In total this project should involve meeting on 2-3 occasions over the course of 2-3 months. This will provide time for me to get to know your family member/service user and give you the information required to support them to complete the Photovoice activity.

### **What do I have to do now?**

If you think that your partner, friend or relative would be interested in taking part, please complete the attached form (*Invitation to act as a Personal Consultee*) and return it back to the lead researcher.

If you think that your partner, friend or relative would be interested but you are not sure about whether you would like to talk about this with the researcher or get involved yourself, then please suggest who else could be approached.

If you think that your partner, friend or relative would not be interested in taking part, then it is important that you still complete the form attached indicating this in the box provided.

### **How will the information collected be used?**

I will use the data collected from observations, photographs and transcripts from the interviews to help me understand how identity is expressed and whether Photovoice as a methodology can help support identity expression. I will use a Thematic Analysis (TA; Braun and Clarke, 2006) approach to data analysis. This information will be saved on a laptop as a password protected document.

As part of my doctoral training I will write a research report from the findings of the study. This will then be submitted to Hertfordshire University examination board. My supervisors will also have access to the report to support me while I am writing it. To support the development of practices the findings from this project will be written up for publication in a peer-reviewed academic journal.

I may use direct quotations from the interview in either or both of these reports. All information that could be used to identify participants, carers or family involved will be fully

anonymised throughout, including the use of pseudonyms. I will make arrangements to come speak with all those involved in the study, about the findings, if this is something you would be interested in.

Photographs taken during the photovoice activity will be printed and provided to participants in a photobook at the end of the project.

**Will information I give be kept confidential?**

Your identity, along with your partner, relative or friend participating in the project, will always remain anonymous. The data you provide will only be accessible to the research team involved. All data including personal details will remain stored on a password protected computer. Your data will solely be used for the purposes of the study. However please be aware that if you say anything that threatens your own safety or that of others, this will need to be reported to the programme coordinator.

If during any part of the study there are any concerns or evidence regarding mistreatment, abuse or any other potential problem, this will be raised to the relevant people and safeguarding procedures will be followed. Data collection at this point will stop.

You have the right to withdraw from the study at any time. Please just use the contact details below. As the written report of this study will be submitted in the summer of 2020, beyond this time I will not be able to withdraw the data you have contributed to both the submission to University and academic journal. Prior to commencing this project, the researcher will talk with you about confidentiality.

**What will happen to the forms when I have completed them?**

The forms will be looked at by the researcher. Either the care team or Emma will be in contact with you to let you know whether or not the researcher would like to speak to you and arrange a time for a discussion.

If you do not return the form, we will presume you do not wish to be contacted about the project.

**How can I find out more about the project?**

You can contact Emma Krisson (Lead Researcher) on xxx xxx or [\[email\]](#) to discuss the project further. You can also contact Dr Maria Qureshi ([\[email\]](#)) who is supervising the project from Hertfordshire University.

You can also contact either Emma or Maria should you have any complaints or concerns about the project.

Thank you for your time.

Emma Krisson

Trainee Clinical Psychologist

## Appendix K: Ethical Approval

### HEALTH, SCIENCE, ENGINEERING AND TECHNOLOGY ECDA

## ETHICS APPROVAL NOTIFICATION

**TO** Emma Krisson  
**CC** Dr Maria Qureshi  
**FROM** Dr Simon Trainis, Health, Science, Engineering & Technology ECDA Chair  
**DATE** 25/10/2019

Protocol number: **LMS/PGT/UH/03863**

Title of study: Working Title: Can Photovoice be used as a methodology to explore identity expression with individuals who have intellectual disabilities and limited or no verbal language?

Your application for ethics approval has been accepted and approved with the following conditions by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

**Dr Louisa Rhodes**  
**Dr Annabel Head**

#### **General conditions of approval:**

Ethics approval has been granted subject to the standard conditions below:

**Permissions:** Any necessary permissions for the use of premises/location and accessing participants for your study must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

**External communications:** Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

**Invasive procedures:** If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and copies of your completed consent paperwork to this ECDA once your study is complete.

**Submission:** Students must include this Approval Notification with their submission.

#### **Validity:**

This approval is valid:

From: 25/10/2019

To: 30/04/2020

## HEALTH, SCIENCE, ENGINEERING AND TECHNOLOGY ECDA

# ETHICS APPROVAL NOTIFICATION

**TO** Emma Krisson  
**CC** Maria Qureshi  
**FROM** Dr Simon Trainis, Health, Science, Engineering & Technology ECDA Chair  
**DATE** 23/12/2019

Protocol number: **aLMS/PGT/UH/03863(1)**

Title of study: Can Photovoice be used as a methodology to explore identity expression with individuals who have intellectual disabilities and limited or no verbal language?

Your application to modify and extend the existing protocol as detailed below has been accepted and approved by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

**no additional workers named**

**Modification:** Detailed in EC2

### **General conditions of approval:**

Ethics approval has been granted subject to the standard conditions below:

**Original protocol:** Any conditions relating to the original protocol approval remain and must be complied with.

**Permissions:** Any necessary permissions for the use of premises/location and accessing participants for your study must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

**External communications:** Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

**Invasive procedures:** If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and copies of your completed consent paperwork to this ECDA once your study is complete.

**Submission:** Students must include this Approval Notification with their submission.

### **Validity:**

This approval is valid:

From: 23/12/2019

To: 30/04/2020

## HEALTH, SCIENCE, ENGINEERING AND TECHNOLOGY ECDA

# ETHICS APPROVAL NOTIFICATION

**TO** Emma Krisson  
**CC** Maria Qureshi  
**FROM** Dr Simon Trainis, Health, Science, Engineering & Technology ECDA Chair.  
**DATE** 24/01/2020

Protocol number: **aLMS/PGT/UH/03863(2)**

Title of study: Can Photovoice be used as a methodology to explore identity expression with individuals who have intellectual disabilities and limited or no verbal language?

Your application to modify and extend the existing protocol as detailed below has been accepted and approved by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

**no additional workers named**

**Modification:** Detailed in EC2

### **General conditions of approval:**

Ethics approval has been granted subject to the standard conditions below:

**Original protocol:** Any conditions relating to the original protocol approval remain and must be complied with.

**Permissions:** Any necessary permissions for the use of premises/location and accessing participants for your study must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

**External communications:** Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

**Invasive procedures:** If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and copies of your completed consent paperwork to this ECDA once your study is complete.

**Submission:** Students must include this Approval Notification with their submission.

### **Validity:**

This approval is valid:

From: 24/01/2020

To: 30/04/2020

## Appendix L: British Psychological Society Personal Consultee Forms

This is an official notification by Emma Krisson of the University of Hertfordshire in respect of a study involving human participants. This study has been approved by The University of Hertfordshire Health, Science and Engineering and Technology Ethics Committee with Delegated Authority: aLMS/PGT/UH/03863(2)



### Acting as a Personal Consultee

*Project Title: Can Photovoice be used as a methodology to explore identity expression with individuals who have intellectual disabilities and limited or no verbal language?*

Please select **one** of the following options:

*Sign below*

I think that my partner, friend or relative may **NOT** like to take part in the project.

.....

I think my partner, friend or relative may be interested in taking part and I would like to discuss this further with the researcher.

.....

*(By signing I agree to be contacted further about the project)*

I think that my partner, friend or relative may like to take part in the project but I do not wish to be consulted.

.....

*(By signing I **do not** agree to be contacted further about the project)*

Thank you for taking the time to complete this form. Please return it to the lead researcher, Emma Krisson.

## Appendix M: British Psychological Society Personal Consultee Declaration

This is an official notification by Emma Krisson of the University of Hertfordshire in respect of a study involving human participants. This study has been approved by The University of Hertfordshire Health, Science and Engineering and Technology Ethics Committee with Delegated Authority: aLMS/PGT/UH/03863(2)



Participant Code

### Personal Consultee Declaration

*Project Title: Can Photovoice be used as a methodology to explore identity expression with individuals who have intellectual disabilities and limited or no verbal language?*

1. I can confirm I have read and understood the Information for consultees in the Family and Carer Information Sheet
2. I can confirm I have had the opportunity to ask questions about the project.
3. I can confirm I have had the opportunity to ask questions about my role as a personal consultee.
4. I understand the purpose or the project, what my involvement entails and what the participants involvement entails. In my opinion, they would not object to take part in the project.
5. I understand that the project is voluntary and should my partner, relative or friend wish to withdraw, at any time, they can do without giving a reason.
6. If my partner, friend or relative wish to withdraw I understand this would not affect their care or treatment in anyway, or their legal rights.

Name

Date

Signature

Consultee:

.....

Lead Researcher:

.....

*Developed by the British Psychological Society (BPS, 2008). Guidelines for conducting research with people who may lack capacity to consent. A Practical Guide for Researchers. Leicester: BPS.*

## Appendix N: Family/Carer Consent Form

This is an official notification by Emma Krisson of the University of Hertfordshire in respect of a study involving human participants. This study has been approved by The University of Hertfordshire Health, Science and Engineering and Technology Ethics Committee with Delegated Authority: aLMS/PGT/UH/03863(2)



### Family/Carer Summary Sheet and Consent Form

*Project Title: Can Photovoice be used as a methodology to explore identity expression with individuals who have intellectual disabilities and limited or no verbal language?*

#### **Why do this study?**

This research is interested in exploring whether Photovoice as a methodology supports identity expression amongst individuals with intellectual disabilities who have little or no verbal language. Previous, studies have neglected to directly involve individuals with similar needs in research and relied on those around them. This project aims to provide valuable insights into identity expression for these young people and illustrate how communication tools can support these interactions. It also aims to provide useful methodological recommendations for future projects and work to reduce marginalisation that these individuals experience.

#### **What will my participation involve?**

- To support the participant to engage in the study and complete the Photovoice activity. Photovoice is a method which involves providing participants with cameras. It offers the opportunity for individuals to capture visual representations of their everyday lives and share this with those around them. Participants will be asked to take pictures of things meaningful to them in their everyday lives (activities, interests, hobbies, clothing, people, places etc).
- To support the person taking the pictures without influencing them or their involvement as much as possible. Where support is provided beyond this, for it to be documented and reflected back to the researcher.
- Where possible to ask, anyone, who is photographed for their consent to be included in the picture and to let them know about the project so they are aware.
- To participate in a semi-structured interview (lasting approx. 1-2 hours) that explores identity expression and to reflect on the participant sharing their photographs. These interviews will be audio-recorded.

#### **How long will participation take?**

Contact will consist of a few meetings over the span of 2 -3 months, from consent being provided and data being collected. The semi-structured interview will take place following the observations (2-3 meetings) and two-week Photovoice activity.

#### **Confidentiality / Anonymity?**

Pseudonyms will be used as a way of protecting all individuals involved in the project, which means no one will know who said what. Any data collected will kept on a secure password protected device.

Photographs taken during the photovoice activity will be printed and provided to participants in a photobook at the end of the project.

As an informed participant of this research study, I understand that:

1. My participation is voluntary, and I may cease to take part in this research study at any time and without giving a reason.
2. I agree to participate in a semi-structured interview, that will be audio-recorded, following completion of observations and Photovoice activity.
3. All data will be stored anonymously once it has been collected. This means that it will be impossible to trace information back to me. As such, if I decide I want to withdraw my data from this study I will only be able to do this up until the transcript has been anonymised. If I decide to withdraw my data I should contact the researcher directly.
4. During any part of the project concerns regarding any evidence of mistreatment, abuse or other potential problems will be raised to the relevant people within the service and local safeguarding procedures will be followed. Data collection with these participants will be stopped at this point.
5. I am aware that if there are any photographs of myself taken during the Photovoice activity these will be stored securely and not shared beyond the researcher and supervisory team. Consent will be re-requested for any photographs used beyond this.
6. I agree to the creation of a photobook, with just my family members photographs in it, following the completion of the project.
7. During the analysis and write up for the project I am happy to have quotes of what I stated in the report. Again, this will be anonymised and not directly linked to the participant, family member or carer.
8. This research has been approved by Health, Science, Engineering & Technology Ethics Committee with Delegated Authority (ECDA; aLMS/PGT/UH/03863(2)) at Hertfordshire University. This means it has been approved by a panel of professionals to make sure it meets high standards.
9. All my questions about the study have been satisfactorily answered and I am aware of what my participation involves as well as the limits of confidentiality.
10. The researcher will treat my participation in this study confidentially and that anything I say in the interview will be treated confidentiality, unless it leads [researcher/carers] to believe that my safety is in danger. In this case they will be unable to keep this information confidential.
11. I understand that information from the interviews, including direct quotations, may be used in a report for submission as part of the Doctoral in Clinical Psychology training programme.
12. I agree that the information I provide as part of this project (including anonymised direct quotations) may be published in an academic journal.

Consent to use data collected for an additional future project:

The current project aims to explore identity expression using a particular methodology and analysis. There may be an opportunity to use alternative forms of analysis in future research. This would continue on from this research project. Please indicate below whether you provide consent for your data to be stored securely and contacted in relation to it being used for future research. If the data is not used it will be destroyed following the guidelines set out by the British Psychology Society.

*(Please tick the box that indicates your answer).*

- I consent to my data being stored securely and being contacted in relation to its use in future research.
- I do not consent to my data being used beyond this research project.

**I have read and understood the above, and agree to take part:**

Family/Carer Signature: \_\_\_\_\_ Date: \_\_\_\_\_

I have explained the above and answered all questions asked by the participant:

Researcher's Signature: \_\_\_\_\_ Date: \_\_\_\_\_

## Appendix O: Permission to use Resources

### Email correspondence from Dr Annabel Head

Re: Request permission to utilise adapted checklist from thesis  
From: Annabel Head  
To: Emma Krisson

Hi Emma,

Yes of course - please go ahead

Thanks  
Annabel

### Dr Annabel Head

#### Clinical Psychologist

---

**From:** Emma Krisson  
**Sent:** 12 July 2019 14:29:10  
**To:** Head, Annabel  
**Subject:** Request permission to utilise adapted checklist from thesis

Hi Annabel,

I hope you are well.

I have just been tightening up my consent procedure and forms. After reading some papers along with your thesis, I was wondering whether it would be possible to get permission to use/adapt the checklist you developed from Cameron and Murphy (2006). I will also make contact with them to get their permission.

Let me know if you would be happy to provide permission / if you have any questions.

I look forward to hearing from you.

Best Wishes  
Emma

---

**From:** Joan  
**Sent:** 24 July 2019 11:39  
**To:** Emma  
**Subject:** Permission to use recommendations / checklist developed  
Hi Emma

Apologies for the delay in replying to you – Lois is on holiday and I am only in the office occasionally now as I am finishing my work with Talking Mats at the end of July.

I am happy for you to use a similar consent procedure that we outlined in our paper and to adapt the resources developed and that of Annabel's checklist

I wish you well in your research and am sure Lois would be very interested to read your plan and final results

Best wishes

Joan

---

**From:** Emma Krisson [\[email\]](#)  
**Sent:** 19 July 2019 11:12  
**To:** Info [email]  
**Subject:** Permission to use recommendations / checklist developed

Dear Joan and Lois,

I am a Clinical Psychology Doctorate Trainee at Hertfordshire University. I am completing my thesis on exploring whether Photovoice as a methodology can be used to explore identity expression amongst individuals with Intellectual Disabilities and Autism who have no or limited verbal language.

Dr Annabel Head is part of the supervisory team for this project. She previously contacted you (when she was completing her thesis) to request developing a checklist from the recommendations outlined in your 2006 paper titled:

'Obtaining consent to participate in research: the issues involved in including people with a range of learning and communication disabilities'.

For my thesis I would like to adopt a similar consent procedure that you outlined in your paper as well as adapting the resources you developed and that of Annabel's checklist. Would you be happy to provide permission for me to do this? If you would like to know anymore about the project or have any questions please feel free to get in touch with myself.

Thank you for your time. I look forward to hearing from you.

Kind Regards,  
Emma Krisson  
Trainee Clinical Psychologist  
University of Hertfordshire

## Appendix P: Consent Checklist

### Assessing Consent Form

What are the signs that the person has understood the information? Were any of the following evident?

<b>Signs the person is listening/has understood</b>	<b>Was this observed? (tick)</b>	<b>Describe the Evidence</b>
High level of engagement e.g. eye contact, body language.		
Positive non-verbal responses e.g. nodding		
Positive verbal responses e.g. stating 'yes'		
Any additional behaviours to note or comments from carers.		

What are the signs that the person has not understood the information?

<b>Signs the person is listening/hasn't understood</b>	<b>Was this observed? (tick)</b>	<b>Describe the Evidence</b>
Low level of engagement e.g. lack of eye contact, unimportance.		
Any negative non-verbal responses e.g. facial expressions, leaving the room?		
Concerns person is just complying with the researcher - Are they just agreeing?		
Any additional behaviours to note or comments from carers.		

*(Assessing Consent Form – Adapted from Head (2017) and Cameron and Murphy (2007))*

## Appendix Q: Extracts from Field Notes

## Appendix R: Extract from Participant part of Interview

## Appendix S: Interview Questions

## Appendix T: Example of Coding Procedure

## **Appendix U: Thematic Mapping Within Case Analysis**

## Appendix V: Thematic Mapping Cross Case Analysis

## **Appendix W: Additional Quotes to Support Themes**

### **Theme Multidimensional Identity**

#### Subtheme 2: We are what we do

*'He can somehow manipulate us to repeat the process, umm, even he like, I mean, obviously due to his Autism, repetition, routine, but he's developed his own routine and taught it to us, so we know'. (Oscar's Interview)*

#### Subtheme 3: A Disabled Identity

*'I don't think people are looking at him in the same way we are [family] looking at him because people will always see disability first'. (Buddy's Interview)*

### **Theme: Power Structures**

#### Subtheme 4: Facilitating Opportunities

*'So, if he has something that he says he wants to do then we facilitate that so he can have an identity of his own'. (Buddy's Interview)*

