

# Making Memory Sites:

Extending opportunities for people with profound and multiple learning disabilities to participate in life story work.

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# ABSTRACT

People with profound and multiple learning disabilities (PMLD) experience considerable difficulties communicating and develop idiosyncratic repertoires of communication that are understood and interpreted only by those closest to them. It is difficult to access their stories or to find out how they are living their lives via orthodox life story research practices and consequently their experiences remain hidden from history. This practice-led research was driven by the need to address a lack of methodological tools that enable the inclusion of people with PMLD as participants in life story work. The research sought to contribute to:

1. An understanding of the barriers, challenges and benefits of doing participatory life story work with people with PMLD.
2. The development of a range of methods that invite people with PMLD to participate in life story work, with specific, but not exclusive reference to rich media and digital tools.
3. A broader understanding of the every day social and cultural lives of three adults with PMLD.

Researching alongside three adults with PMLD and their circles of support for an extended period of time using a qualitative mix of life history and ethnographic methods - including the shared examination of personal archive materials, participation in every day activities and interviews with close family and friends - revealed opportunities for them to engage in their pasts. Barriers of access and communication were identified and addressed. The deconstruction of narrative norms together with framing participatory life story work within a cultural, as opposed to an individual, context invited a reinterpretation of what it means to participate in life story work. Thematic analysis of the rich body of material generated by the project identified that opportunities to participate in life story work were dependent on particular qualities of people, time and environment. Participation in life story work was found to be beneficial to the participants with PMLD because it challenged perceptions, demonstrated their value as people living socially and culturally rich lives, provided a platform for shared remembering and was a catalyst for new narratives. The findings indicate possibilities for including people with PMLD as participants in other research areas including mental health and wellbeing.

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# Chapter 1

## Introduction

### 1.1 Personal context

For the most part in my role as a life story practitioner I have worked with people with mild to moderate learning disabilities who, with some support, have been in a position to tell their own stories. My particular interest in life story work has developed through practice based research and stems not so much from a drive to make their stories public, but because I've seen the transformative power of personal storytelling - the sense of pride, increased self-esteem and self-identity that results from sharing and recording personal experiences. But in recent years I have come into contact with more people with greater support needs. Some have had a dual diagnosis of learning disability and dementia and others have had life long conditions that result in complex needs and who require very high levels of care.

This research was generated in response to the Arts and Humanities Research Council funded and Open University led project to develop a living archive of learning disability history. When I read the specification for the development of the archive my first thought was that it would be dominated by the stories of people with mild learning disabilities, in other words by those who were able to tell their stories. Many years experience facilitating life story work with people with learning disabilities has highlighted the challenges of engaging those who require more communication support in this endeavour. Scenarios that come to mind from my experience include, for example, sitting at a table happily looking at photographs together, perhaps making a few observations about the approximate age of the person, but without any anecdotal or accurate knowledge; inviting in a relative to find out about the person's story while they sit passively looking on; or accessing case files that contain detailed medical and educational records, but lack any contextual meaning.

However, it is important that the stories from people in this marginalised group are included in attempts to make public the personal histories of disabled

people to ensure their stories are captured as part of wider historical narratives (Brownlee-Chapman et al, forthcoming), and that practical and ethical methods are developed to encourage and promote participation and representation. This research is my response to this complex problem. It is shaped by my experience in life history research, and is a focussed examination of the ways to extend opportunities for people with very complex needs to participate in life story work.

## 1.2 Labels are for jars

While I have found 'high support needs' to be a useful term in that it describes what is required of others in order to meet the every day needs of an individual, I decided to apply the descriptive label of profound and multiple learning disabilities (PMLD) in both the title and the body of this research. I chose to do this for two reasons. First because of the difficulties I had experienced in finding relevant literature on the subject. It transpired that the term 'PMLD' served as a useful signpost. And second because it is the term used (although not always favourably) by the families I worked with. However I am aware of the negative assumptions associated with using the label PMLD<sup>1</sup>. In research literature people with PMLD are frequently described by the 'extent of their impairments and functioning' (Simmons and Watson, 2014b:19). As John Vorhaus (2016) points out, while all our capabilities vary 'there is more to what is valuable as a person, including what they can offer to other people, than is likely to be revealed in an audit of their capabilities and functionings' (p.39). There is therefore a danger that in viewing people with PMLD as the most disabled people in society, and compounding these views through the terminology we adopt, our expectations of their capabilities is reduced (Grace, 2015:42).

According to Grace (2015) the term PMLD is 'inconsistently applied' and its use is 'innately flawed' (p.42). However it can have value if applied with the understanding that 'within the denoted group there will be a great deal of variation' (p.42). Therefore, as labelling has the potential to 'prevent us from

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<sup>1</sup> For a thorough review of the on-going debate about the usefulness of the description PMLD see Simmons, B. and Watson, D. *The PMLD Ambiguity* (2014b:1-19) and Vorhaus J. (2016:6-8).

relating to people with PMLD as people' (Klotz, 2004:101), it is imperative that the description is seen in context in this research project. It is important to remember that a label given to an individual does not define them, but rather indicates a person who experiences 'substantial barriers to learning and participation' (Sheehy and Nind, 2005:34). As this research aims to examine the challenges that relate specifically to people who are described as having PMLD it is useful to establish what that means. Finding that a 'literature review provided different definitions and meanings' to the term, the Joint Learning Disability Service in Sheffield arrived at the following shared understanding:

"People with profound and multiple learning disability (PMLD):

- Have extremely delayed intellectual and social functioning
- May have limited ability to engage verbally, but respond to cues within their environment (e.g. familiar voice, touch and gestures)
- Often require those who are familiar with them to interpret their communication intent
- Frequently have an associated medical condition, which may include neurological problems, and physical or sensory impairments.

They have the chance to engage and to achieve their optimum potential in a highly structured environment with constant support and an individualised relationship with a carer." (Bellamy et al, 2010:233)

This definition was chosen for a number of reasons. As Bellamy et al (2010) discuss, there are many debates about the usefulness of any such term, but their final decision came about as a result of the review of descriptions drawn from respected experts in the fields of education and health, including Lacey, Ware, Samuel and Pritchard, and Hogg (Bellamy et al, 2010:226). It is not confined to children or educational settings, it emphasises the potential for growth and development given the right conditions and it is arrived at with the cautionary note 'that such labels are used gratuitously or to indicate lesser value' (2010:222). I have met and worked with many people with PMLD and - although they have all been unique individuals - I find the description offered by Bellamy et al accurate.

At the time of writing 'Raising Our Sights: services for adults with profound intellectual and multiple disabilities' Professor Jim Mansell (2010) reported a

population of 16,000 adults with profound intellectual and multiple disabilities living in Britain:

The number of adults with profound intellectual and multiple disabilities is estimated to increase by on average 1.8% each year to 2026, when the total number would be just over 22,000 people. (Mansell, 2010:3)

The anticipated population growth is due to a range of factors including increased life expectancy, growing numbers of young children surviving into adulthood, a sharp rise in Autistic Spectrum Disorders, and a greater prevalence in the BME population (Department of Health, 2001:23).

It is also understood that members of this minority group are vulnerable to discrimination that begins at birth with 'extremely negative, not to say bleak, prognoses' (Mansell, 2010:5) and continues throughout their lives with 'poor quality care' provision and the 'unthinking application of standard rules or procedures' (2010:6). Discrimination is also evident in access to technology, which although widely used in schools is 'almost unheard of in adult social care services' (2010:7). Understanding people with PMLD to be 'neither producers nor active participants' in society, can lead to the conclusion that they are 'a drain on resources' - a perception that has, according to Vorhaus (2016:45), resulted in complex political debate.

### 1.3 Gaps in the research

My literature review focused on two key areas of research; first, how participatory methods have been developed in response to the nature of life story work (see Chapter 3), and second, how people with learning disabilities are living and narrating their lives (see Chapter 2). These two areas of focus have led to the identification of significant gaps with respect to participatory life story work with people with PMLD, which I outline below. This informed the development and review of my research design.

### 1.3.1 How to conduct participatory research with people with PMLD

A lack of expertise in how to include people with PMLD in finding out about how they are living their lives and engaging socially and culturally is highlighted in the literature. Simmons and Watson (2014b:148) are of the opinion that in general there is a 'genuine gap in our methodological "toolbox"' for doing participatory research with people with PMLD in 'respectful, ethical and authentic ways'. This is a position supported by Hodge (2008) and Nind and Vinha (2013:7) who warn that the 'desire to conduct research inclusively is not matched by the practical knowledge of how this can be achieved'. Boxall and Ralph (2010:173) consider this lack of 'user involvement' a consequence of a skills deficit on the part of staff at all levels, including policymakers, about 'how to ascertain the views and perspectives of people with PMLD'. In addition, the limited papers that do research the lives of people with PMLD reveal little of their methodology and lack transparency thus making it virtually impossible for that work to be 'judged, replicated and learnt from' (Nind and Vinha, 2013:7).

### 1.3.2 How people with PMLD are living their lives

It would appear that the life stories of people with PMLD are 'largely ignored' in the research literature (Hewitt, 2006:95). Without representation, according to Mencap (2015), there is little to challenge people's attitudes and help them to understand what it means to have profound and multiple learning disability. What few stories there are have a tendency to focus on the success or otherwise of interventions whose intention it is to ameliorate deficit and adapt behaviours, which results in a 'distinct lack of detailed description of the everyday routines and lived experiences of children with PMLD' (Simmons and Watson, 2014b:138). The same is true of adults for whom there is scant evidence of storytelling (Grove, 2007). Simmons and Watson (2014b:16) argue that 'a repositioning of profoundly disabled people needs to occur that reveals their social and cultural engagement in the world and allows for their personhood to emerge'.

### 1.3.3 Research Questions

The gaps identified in the research literature led to the framing of the following research questions:

1. What are the barriers to participatory life story work that people with PMLD face?
2. How can opportunities for people with PMLD to participate in life story work be extended?
3. In what ways do people with PMLD benefit from participatory life story work?
4. How are people with PMLD living their every day lives?

### 1.3.4 Contribution

Through the examination of these questions the research aims to make an original contribution to:

1. An understanding of the barriers, challenges and benefits of doing participatory life story work with people with PMLD.
2. The development of a range of methods that invite people with PMLD to participate in life story work, with specific, but not exclusive reference to rich media and digital tools.
3. A broader understanding of the every day social and cultural lives of three adults with PMLD.

### 1.4 A personal lens

It appears that as researchers we lack the expertise and experience to act as facilitators in the process of participatory life story work with people with PMLD.

On the whole, stories about people with PMLD focus on an examination of deficit (Simmons and Watson, 2014a). Most researchers in the field have their roots in education, communication and health. My interest stems from life story facilitation and this research provides an opportunity to explore in depth some of the practise-based questions that have been recurrent and unresolved themes of my work.

As I delved more deeply into the practicalities raised by this research enquiry I began to feel out of my depth. A bruising encounter with an experienced speech and language therapist made me question how well equipped I was, as a life story practitioner, to contribute anything original or useful to the debate, and to position the experience and perspective I was able to bring. My interest and previous training in life history research combined with many years experience working alongside and supporting people with learning disabilities and PMLD offers an alternative perspective. I do not claim expertise regarding communication development in normal infancy or how that positions the small number of people I chose to work with in the fieldwork stage of the research. What I am interested in is the way in which profoundly disabled adults would be able to contribute and participate in their specific and personal stories and how this could be explored within the context of current narrative research debate. If we frame ourselves in narrative and use stories to make sense of and give coherence to our lives, what happens when the means by which stories are related to ourselves and each other is unavailable, 'when we as tellers are unable to create, elaborate, revise, and scrutinize our own lives by telling stories? Does such a person lack an identity and a sense of self?' (Hyden, 2008:38).

Evidence clearly suggests that participatory life story work is beneficial to wellbeing and contributes to an increase in life quality (Hewitt, 2006; Atkinson, 2010; Grove, 2014). This research therefore intends to investigate how meaningful opportunities for people with PMLD to participate in life story work can be developed. My practice is situated in a rich tradition of narrative and ethnographic research inquiry. Rather than adopting a positivist approach in which the stories of individuals are broken up, simplified and reduced, I support the position held in qualitative research whereby 'people are individualised,

speak for themselves, emerge as rounded, often complex human beings' (Walmsley and Johnson, 2003:35); research that involves 'an interpretive, naturalistic approach to the world', a way to 'study things in their natural settings, attempting to make sense of, or to interpret, phenomena in terms of the meanings people bring to them' (Denzin and Lincoln, 2003:5).

From a theoretical perspective research with people with PMLD is challenging to pin down. Klotz (2004) maintains that understandings of the life worlds of people with PMLD will be limited if 'sociologically informed theories are imposed' because their focus on 'labels, constructs, structures and meanings' cannot be applied to people with PMLD. Simmons and Watson (2014) describe the difficulty thus:

[I]t became clear that there was not one epistemological commitment that could be made, as such theoretical constructions are framed within understandings of intentional, agentic and intelligible actions, behaviours and human communications, and these taken-for-granted assumptions of the social world could not be made in Sam's case. (Simmons and Watson, 2014:135)

As such, my intention is to employ a range of interpretive, qualitative practices that highlight different aspects of the research inquiry and hold theoretical positions in an 'under-labourer' role (O'Reilly, 2009:124), while recognising their influence.

### 1.5 A 'barriers' approach

This research, like all research, does not exist in a vacuum. Experience working in education, mental health and adult social care, since the 1980s, has had a major impact on my worldview. The approach adopted in this study, with its intention to seek out and extend opportunities for participatory life story work, incorporates the examination of barriers experienced by people with PMLD and owes much to the 'social model of disability' (Oliver, 1990). The social model of disability has influenced a generation of disability researchers and was developed to counter medical models that focused on individual biological or intellectual deficits. In contrast, Oliver's model distinguished between the concepts of 'disability' and 'impairment'. Impairments are identified as 'the loss



or limitation of functional ability', whereas disability refers to 'social, material and cultural barriers' (Stalker and Connors, 2010:105). This shifted how disability was perceived by claiming that the main reason disabled people were marginalised was not because of their impairment per se, but rather as a result of how society responded to it (Oliver, 2009).

The social model criticised traditional disability research that rarely sought out the experiences of disabled people, viewed them as passive recipients of care and had little if any positive impact on the lives of those being scrutinised (Walmsley, 2010:490). Although there are many common interests in achieving social and cultural equality, disability research has, in response to this new way of thinking, tended to focus on physical rather than intellectual impairments. Consequently, 'our understandings of the barriers people with learning disabilities experience is far less well developed' (Walmsley, 2010:490). Although this may be true, opportunities for participation and barriers to inclusion have been widely explored in life story and ethnographic research traditions within the learning disability field (Walmsley and Johnson, 2003; Seale et al, 2015).

## 1.6 Thesis structure and signposting

Chapter 2, The Literature Review, explores the issues addressed in this thesis from within the broad and diverse genre of narrative research. It examines the enquiry in the context of life history research and in particular specific narrative norms and their deconstruction; communication and agency; organisation of thinking; memory, remembering and identity. Chapter 3, The Development of a Methodology, justifies the qualitative approach adopted and traces the growth of participatory research from its foundation in the concept of 'normalisation' and establishes that this research enquiry has much in common with participatory action research. The chapter draws on life history research methods within an ethnographic frame, and reviews a case study approach with a small number of participants. The value of working collaboratively with stakeholders is discussed. The chapter includes how practical factors, for example the ethical approval process and model of analysis, influenced the development of the methodology. Chapter 4, The Methods in Practice,

examines and reflects on the ethical procedures of researching with people who are governed by stringent legislative procedures. The two phases of fieldwork are described in detail and the chapter closes with a series of reflections about the method. In a departure from traditional thesis formats the research findings are presented as Case Studies and each of the three individual narratives includes what I discovered when immersed in the lives of the three people with PMLD and the micro-communities they inhabit. The case studies follow a shared format, which is designed to maintain clarity for the reader and make transparent the iterative methodology employed. Having presented the case studies in their reference-free state, they are brought into conversation with each other and with the research literature in Chapter 5. The Discussion chapter is structured around the research questions, which are addressed in the following order: (1) How are people with PMLD living their lives? (2) Is participatory life story work beneficial for people with PMLD? (3) What are the barriers to participatory life story work? (4) How can barriers be dismantled/overcome to enable opportunities for participatory life story work to be extended? The limitations and implications of this project and final reflections are offered by way of conclusion in Chapter 6.

## Chapter 2

### Literature Review

Can there really be a realm of experiences that can exist independently of the telling of them? Maybe without the telling of a life, the flow of a life- 'experience' - would have no meaning, no referent. Indeed is it possible to live a life without in some way telling it? Can a life be imagined without a sense of coherence through a narrative form - as they live through it? Some sense of time, of place, of family and friends, of wider connections? So it may be that the lived life itself is bound up with versions of speaking and telling about it. (Plummer, 2001:86)

#### Introduction

This extract from Plummer (2001) effectively encapsulates many of the issues raised in my research with people with PMLD, who according to the description offered in the previous chapter (p.3) lack the abilities of speaking and telling. As such, it becomes possible to imagine that they are unable to make sense of their experiences or even that they do not have a story to tell. Sacks (1986:116) suggests that that the 'continuity' of our 'inner narrative' *is* our lives and that we are constituted through the narratives each of us construct, 'and that this narrative is us, our identities'. Believing that in order to really know someone we must understand his or her story, Sacks goes on to state that we are each:

[A] singular narrative, which is constructed, continually, unconsciously, by, through, and in us - through our perceptions, our feelings, our thoughts, our actions; and, not least, our discourse, our spoken narrations. (Sacks, 1986:117)

Here we see Sacks reference other forms of being that do not rely exclusively on speaking and telling, but where does this leave people with learning and other disabilities who find themselves challenged by difficulties in communication (Grove, 2000), coherence (Hewitt, 2006) and memory (Lacey, 2015)? Grove (2014:8) considers the implications of not being able to tell stories as having a serious impact on 'developing a sense of self, forming relationships and understanding our experiences'. If the purpose of a review of literature is to set the research context, then in the case of life story work with people with PMLD, there is little foundation to build on. Vorhaus (2016), in his

recent work reflecting on the philosophical issues that concern those with PMLD, highlights and confirms this challenge when he says:

Books on disability would fill many libraries; books on profound and multiple learning disabilities a few shelves; and books devoted to exploring the lives of profoundly disabled people, and the experience of those who care for and work with them, rather less than that. (Vorhaus, 2016:1).

This review supports the identification of the key issues within the broad area of life history research that are of particular interest when supporting people with PMLD in this area. The search for pertinent literature on life story work with people with PMLD revealed very little when limited to those keywords. However, as my research enquiry became more refined I was able to extend the search for relevant work to highlight key areas of interest within the broad area of life history research, for example in the areas of communication, coherence and memory.

## 2.1 A conceptual frame

My academic journal and data-base library searches led to papers that described challenges that are faced when narrating a story; challenges that included communication and telling in a broad sense, narrative cohesion and organisation, and issues concerning identity, memory and remembering. By identifying the barriers faced by people with PMLD with regard to life story work I was introduced to contemporary narrative research that questions the taken-for-granted-ness of 'narrative norms' (Hyden and Antelius, 2011:590) and asks if anyone, regardless of their cognitive ability, is beholden to these.

I have found it useful to clarify and frame my research enquiry using a 'barriers' approach. The social model of disability (Oliver, 1990) offers a way to initially simplify the complexity of the research enquiry in order to make sense of it and subsequently provide clear signposts towards a range of potential solutions. Much criticised for its simplicity and described as 'too crude a tool to deliver real and lasting changes for people with learning disabilities' (Walmsley, 2010:500), it is necessary to acknowledge the fluidity of the term 'intellectual impairment' - which is ameliorated and reduced as the external world develops better

communication tools, a subject explored in depth by Goodley (2001). While acknowledging the benefit of shifting 'attention from individuals and their physical or mental deficits to the ways in which society includes or excludes them', Shakespeare (2006:29) perceives the strengths of the social model – its simplicity – as its main weakness. As Shakespeare (2006:33) argues, it is not possible to easily distinguish between impairment and disability; 'impairment is not neutral, because it involves intrinsic disadvantage'. Morris (1996:14) argues that within the social model 'there was little room for anything other than an assertion that it is external barriers, society's prejudice and discrimination that disables us', but of course it is much more complex than that when 'personal experience of impairment and/or mental distress' is taken into account. Crow (1996) supports this position when she points out that personal interpretations of impairment are not fixed and change with time and personal circumstances.

In a paper written in response to criticisms about the limitations of the social model, Oliver (2013:2) stated that he had never claimed that it was 'an all-encompassing framework within which everything which happens to disabled people could be understood or explained'. Responding to Oliver's (2013) call for the social model to be reinvigorated, Levitt (2017:590) argues that the social model has made a valuable and insightful contribution in changing societal attitudes and relationships to disabled people, but that its 'scope does not need to be restricted to immediate practical applications'. Bearing in mind criticisms of the social model I continue to view it as beneficial if applied as a way of thinking, to inform the complex task of extending participatory life story work for people with PMLD. Using the social model provides a means to learn new information about a complex situation. The model enables a problem to be viewed from different perspectives (Finklestein, 2001), as a tool that can 'switch the focus' (Oliver, 2009:45).

By adopting a 'barriers' approach to this research inquiry, while at the same time keeping in mind the need to learn 'how an individual is impaired in order to identify their specific needs' (Crow, 1996:212), it may be possible to understand why, even in this rich tradition of narrative ethnography, the stories of people with PMLD and their participation in its production continue to be absent. As identified gaps in the research indicate, the challenges of doing participatory life

story work with people with PMLD are many and varied. In the following sections of this literature review I intend to unpick these and other challenges in greater depth. Informed and framed by the social model of disability (Oliver, 1990), the structure of this review reflects and interrogates the complexities of life story work and the specific implications this has in creating barriers to people with PMLD. This literature review begins by setting the scene of the development of life history research with people with learning disabilities and is followed by an analysis of the research about three challenges specifically faced by people with PMLD in the telling and sharing of their stories - notably communication and agency, organisation of thinking, and memory and identity. In the final section various alternative methods of accessing story are reviewed.

## 2.2 The development of life story work with people with learning disabilities

To situate the present study it is useful to understand the context of life story work generally and more specifically with people with learning disabilities. It is well accepted that life history research as we understand it today can be traced back to the sociologists Thomas and Znanieki who were working in the 1920s and based in the United States at the Chicago School. After finding initial popularity, the research method declined in use until the latter part of the twentieth century when it re-emerged through the work of, for example, Ken Plummer in the 1980s. Booth and Booth (1996) saw the potential of the method to open up opportunities for people who had previously been excluded from contributing historical evidence to tell their stories, a position supported by Atkinson (2010):

Life stories, and the opportunity to tell them, are particularly important for people with learning disabilities because they have often been silent, or silenced, while other people - families, practitioners, historians - have spoken on their behalf. Life stories begin to redress that balance as they become a means by which people with learning disabilities have a voice that is theirs. (Atkinson, 2010:7)

The growth of life history research as a way to uncover the hidden accounts of oppressed groups was particularly supported by oral history methodologies, which had begun to gain academic ground in the 1960s. In the introduction to

the 3<sup>rd</sup> Edition of the Oral History Reader, Perks and Thomson (2016) claim that,

The most distinctive contribution of oral history has been to include in the historical record the experiences and perspectives of groups of people who might otherwise be “hidden from history”, perhaps written about by social observers or in official documents, but only rarely preserved in personal papers or scraps of autobiographical writing. (Perks and Thomson, 2016:xiii)

Describing the development of oral history methodologies as ‘ground breaking’, Atkinson and Walmsley (2010:277) observe that these approaches have indeed brought ‘insights into the hidden history of intellectual disability’. However, as Atkinson<sup>2</sup> reflected, there is still ‘relatively sparse’ literature regarding life history research and oral history methodologies in the learning disability field. The limited research in this field has been expanded more recently with the adoption of creative methodologies (Ledger, 2012; Kennedy and Brewer, 2014). However, the literature continues to be limited in part due to the inherent requirements of the methods - to be both skilled in expressing yourself verbally and to have the ability to reflect on the life you have lived - skills that many people with learning disabilities are challenged by (Atkinson, 2010). As such the research that does reflect the lives and identities of people with learning disabilities more often included the accounts of people who are, with support, able to tell their stories as, for example, Cooper (1997).

There are a number of issues that inhibit researchers, who are ‘outsiders’, from embarking on work with people with more substantial learning disabilities such as PMLD. For example, there has been a call in oral history research for members of marginalised groups to ‘control the agenda’ (Rolph and Walmsley, 2016:657). However if that were the case:

[T]he voices of those with severe and profound difficulties, for example, would arguably not be heard at all, if it were not for the mediating of historians, families, or carers who are determined not to exclude their stories. (Rolph and Walmsley, 2016:663)

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<sup>2</sup> For a seminal review of the development of autobiographical accounts from people with learning disabilities see the introductory chapter of ‘Know Me As I Am: An anthology of prose, poetry and art by people with learning difficulties’ edited by Atkinson and Williams (1990)

Life story work has established as one of its core values the need for people to exchange biographical information in order to create and sustain identities (Atkinson, 2010; Hewitt, 2006). Hewitt, working in a long stay institution on the point of closure in 1990s, was particularly interested in how the life story book could support people with PMLD as they moved from a familiar institutional environment into community residences. Hewitt<sup>3</sup> (2000:90) viewed life story books as a 'resource for maintaining continuities of identities across the change of care provision'. Wishing to move away from the medicalization of people with PMLD, Hewitt (2000:94) intended to demonstrate, through the inclusion of personal biographical information and contributions by relatives and carers, a means by which the 'personality' of the person concerned could be captured and represented. Hewitt understood the value of the life story book as a 'short cut' to learning 'details about a person's past experiences, family background, likes and preferences, friendships and pastimes' (p.93).

Hewitt (2000:93) acknowledges that due to the severity of the learning disabilities of those involved in her research their 'contribution' was 'extremely limited'. Although not explicitly stated, it would appear that the stories recorded in the life story books were told exclusively by others and justifying their contribution Hewitt (2000:95) argues that 'had the books not been compiled, there would remain a huge void in the person's history which would not allow the past to be kept alive'. However, efforts were made to create opportunities for actual participation and to this end the stories were shared and the reactions of the profoundly disabled adults were monitored.

There is a sense in the writings of academics working in the field of life history research and learning disability generally, and PMLD specifically, that we need to justify our efforts and that our inhibitions create barriers. This may stem from a fear of appropriating another's story. Atkinson and Walmsley (2010:280) explore this further when they focus on the inhibiting aspects of ethical safeguarding which give rise to a 'a fear of being accused of exploiting others' and the views of activists who argue that 'history writing properly belongs to those who have experienced oppression'. However, by neglecting the subject

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<sup>3</sup> An excellent summary of the changing nature of the academic focus on identity and learning disability from the 1950s-2000 see Hewitt (2006:8)



through a concern about who has the right to tell another's story we are in danger of restricting our understanding of those people whose lives remain hidden. As Hewitt (2006) and Atkinson and Walmsley (2010) argue, in order to extend our understanding it is important to accommodate the stories of people with intellectual disabilities, paid workers, families and social researchers alongside each other, in the many and various forms in which they are created. Challenging the notion that people with PMLD are neither able to tell their stories or understand stories told to them, Grove et al (2015:305) suggest otherwise, believing that 'our expectations, our confidence, and what is prioritised in the curriculum' are frequently significant barriers.

It would appear that researcher inhibition and low expectations constitute potential barriers to doing life story work with people with PMLD. I now turn to three areas viewed as fundamental to life story work and how they manifest regards people with PMLD. In the following sections of this literature review I intend to unpick these life story norms in greater depth. The three broad areas that will be examined in turn within the context of narrative research inquiry include (i) communication and agency; (ii) organisation of thinking; (iii) memory, remembering and identity, followed by (iv) alternative ways to present a life story.

### 2.3 Communication and agency

As seen in the description of PMLD previously offered (p3), one of the main difficulties experienced by people within this population is that of communication; specifically that people with PMLD 'often require those who are familiar with them to interpret their communication intent' (Bellamy et al, 2010). It is useful to unpick the wording used in this description and to examine it within the research context. Larkin (2007) describes communication intent as communication that demonstrates an understanding that 'you can affect others by your actions'<sup>4</sup>. According to Grove (2000), communicative intent is indicated by a range of behaviours that include for example: alternating eye gaze, waiting for a response, active seeking of proximity, systematic variation in behaviour

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<sup>4</sup> A useful description of communication development in neuro-typical babies can be found in Larkin (2007).

and the persistence and intensity of behaviour. Because these behaviours are not always clearly communicated by those 'who do not have a vocabulary of words, signs or picture communication systems, but rely on facial expression, gestures, vocal sounds or other non-verbal behaviours' (Grove, 2000:3), they require interpretation. The interpreter therefore holds significant authority and the intentions of the communicator can be easily misunderstood or misinterpreted. Lacey (1996:69) describes several challenges interpreters face when the signals of communication intent are 'weak' or 'unconventional', especially in the case of nonverbal behaviours like 'biting' or 'hair pulling', when 'caregivers either do not recognise them or are reluctant to recognise them'.

It appears that the role, skill and positioning of the interpreter or caregiver is vitally important. It is particularly relevant to this inquiry to interrogate the under-researched dual nature of the caregiver/interpreter, who is both holder of life story source material and interpreter of communication intent and is a role that warrants further investigation.

### 2.3.1 Interpretation of communication

The interpreter/caregiver holds a vital role in the life of anyone who is unable to communicate using commonly recognised forms and as such can act as both a barrier to or a conduit for, participatory life story work. The emotional involvement intrinsic to this role can give rise to conflict between caregivers and professionals, as described in Goode's (1994) ethnographic study of the communication systems employed by two girls with severe disabilities. He finds that the parent of one of the girls in his study is thought of as 'uncooperative', 'unrealistic', 'delusional' or 'disturbed' when she disagrees with the 'bleak communication assessment' offered by her child's clinical team (1994:56). What becomes apparent in Goode's study is how difficult it is for those outside of the intimate home environment to appreciate the 'refined communication systems' that are operating within it. Over or underestimating the communication ability of a person with PMLD is discussed further by Grove (2000) in 'See What I Mean', a set of guidelines produced to support and validate the process of interpretation. The guidelines are designed as a strategy for the management of the 'ambiguity and anxiety' that is experienced by caregivers and professionals

alike when faced by the responsibility of ascertaining the views of those with PMLD. One way in which the uncertainty regarding interpretation can be reduced is by inviting several people to participate and to create multiple perspectives. This strategy is also built on the shared understanding that all 'communication involves interpretation and guesswork - and sometimes we do get it wrong' (Grove, 2000:4) and that there is no 'one correct meaning', but that 'meanings evolve in response to changing circumstances and will vary in relation to the differing perspectives of the individual concerned' (2000:5).

Ware (2004) asks if people with PMLD are capable of having 'views' and explains that there is an important distinction to be made; a view is not the same as a choice or a preference. Ware calls for transparency in relation to this issue of interpretation of another's 'view' and to the additional complication that those people who will likely be most skilful at interpreting responses are intimately involved in the care of the person whose 'views' are being interpreted. As with Grove, Ware encourages multiple perspectives from different people to share the responsibility of the caregiver's interpretations and subsequent inference. Brewster (2004) in her paper about the use of 'Talking Mats' to support the communication of people with learning disabilities, further supports the idea that multiple perspectives of interpretation, in this case using video analysis can be effective in reducing the authority otherwise held by the interpreter or 'communication worker'. Equally, Brewster supports the position held by Grove (2000) that the challenges of accessing the views of people with limited communication are ameliorated if understood 'not as a one off event, but as an on going process' (Brewster, 2004:166).

Consistency in response over time is one way in which interpretations of communication can be verified, as for example in the case of a 'very passive child', whose preferences were difficult to read:

I played these [8] tracks in class, over and over, for a term. And by the end of that term he started vocalising and flaring his nostrils in what looked like an angry response to the classical music! Within another half term the corners of his mouth would turn up to Take That. We were just thrilled because it became consistent. (Vorhaus, 2016:25)

To check the consistency of their interpretations about this child's preference for Take That over classical music the teacher swapped the order of the tracks around on the eight-track CD. In this way the child's teacher was adopting the philosophy to 'treat behaviour as if it is intentional with the aim of making it so' (Vorhaus, 2016:25). This concept is further explored as one of the key principals in Intensive Interaction (II)<sup>5</sup>, as explained here:

We now take the view that whatever a person does is likely to be meaningful to that person; it may simply be that sometimes we are not able to share that meaning and understand it. Often these feelings we have are more about our own irrational expectations that people with limited understandings will behave rationally than about realistic expectations of what they might achieve. (Nind and Hewett, 2005:78).

This concept is developed within the practice of II as 'imputing intentionality', which is explained as 'the process of behaving towards students/clients as if their behaviour is meaningful and communicative, even before it is' (2005:200). An example offered in support of this concept is that a clap is assumed to mean 'yes'. In this way nonverbal behaviour in the form of a physical expression is interpreted as an expression of preference and translated into language.

Throughout this introduction to the subject of interpretation and the complexities it encompasses we have seen that the weight of responsibility born by the caregiver/interpreter is reduced in a number of ways. Shared understanding and interpretation of behaviour via multiple perspectives and over a period of time are beneficial, but communication as a dialogical process is impacted by how it is responded to. As such, it is valuable to trust that all communication is meaningful and to understand that although it is not always possible to accurately read the intentions of the communicator, it is important to respond. The communication of those with descriptions of PMLD is mainly nonverbal and it is with this in mind that I now turn to how broader areas of narrative research inform the subject of reading the body.

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<sup>5</sup> Intensive Interaction is described as an approach 'that makes use of the range of interactive games that have been shown to occur in interactions between infants and their primary caregivers' (Nind and Hewett, 2005:8).

### 2.3.2 Interpreting the body

The ability to 'read the body' is, according to Lindemann (2014:15), something that we have to learn how to do, we 'learn that there is something to be recognised and that recognition requires a response'. The body can indicate information, however that indication is still open to interpretation.

It's people's bodies that express whether they are excited, puzzled, or interested; whether they are amused, fearful or determined. So, in reading their bodies - their postures, gestures, and expressions - we are simultaneously reading what's "in" their minds. (Lindemann, 2014:14)

However, this 'simultaneous reading', can be problematic as people with PMLD frequently experience difficulties with bodily expression as a consequence of sensory impairments (Grace, 2015). The disruption in both the vestibular and proprioceptive senses can result in physical expression that is unrelated to communication intent. This is also apparent in people who exhibit 'stereotypy' behaviours, understood by Nind and Hewett (2005:163) as 'organised self-involvement', and further explained as 'we saw the students as stimulating and interacting with themselves in a way that was repetitive and familiar'. Behavioural expression therefore cannot always or reliably be read as a form of communication between a person with PMLD and someone else. However, as communication intent is understood through a range of nonverbal behaviours, it is important to learn to understand and distinguish the differences.

Goode (1994:99) describes his finding that intentionality could be communicated through gesture, facial expression and movement as the 'cornerstone' of understanding how the adults and children in his study were able to converse through their bodies: 'It is the lexicon for the conversation with our bodies'. In this case the relationships under investigation were intimate and the behaviour repertoires were presumably familiar and understood. The range of communicative behaviours may need to be learnt, an understanding born through attention to looking, combined with a shared context when a smile, for example, can be interpreted in many ways and when 'we can usually tell when someone is feeling triumphant, or gets the joke, or resents the intrusion' (Lindemann, 2014:15).

Hyden (2013) examines the problems that arise when the body is neglected in narrative research, particularly when the disruption of the physical wellbeing of the narrator is integral to his or her story. Adopting the term 'embodiment' as a concept to describe the ways that 'the bodies in the storytelling event are involved and engaged in the telling of and listening to stories' (2013:127), Hyden draws on conversational stories about personal experiences to examine the role of the body:

Embodied storytelling has to do with the fact that telling and listening to stories is an activity that is accomplished through *the use of bodies*. Both telling and listening to stories involve bodily processes: the body and its parts are used as communicative instruments and as resources for structuring and interpreting stories. (Hyden, 2013:139)

In this section about interpretation the idea that 'telling' a story is intrinsically linked to the capacity for another to 'listen' is introduced. With this in mind, I now turn to the dialogical nature of the life story and how the present study can be understood within that context.

### 2.3.3 Dialogical selves and multiplicities of voices

By drawing on culturally oriented approaches to narrative it is possible to understand the communication challenges experienced by people with PMLD in new ways. Rather than seeing the storyteller as 'a singular, unified subject who is an agentic storyteller and hearer' (Loots et al, 2013:108) this alternative approach invites us to view the life story as *embedded* in the *socio-cultural context* (Riessman, 2008). This alternative way of looking and understanding removes the onus from the teller of stories and reconfigures the position of the narrative researcher as a joint participant in the storytelling event. Consequently the place of the storyteller moves away from a central, pivotal role and moves towards a dialogue with both the researcher and different aspects or versions of themselves (Loots et al, 2013:110). By inviting this alternative perspective it is possible to view life story work as a joint venture, understand and value the role of the interpreter in this context and thus extend opportunities that people with PMLD are able to participate in.

It is in this context that the relationship between the disabled person and those whose role is to act as interpreter can be understood as jointly telling stories that are 'co-constructed' in a 'storytelling event' (Hyden and Antelius, 2011:558). Hyden and Antelius (2011:595) suggest that when conducting narrative research with people who have communication difficulties it is therefore essential to 'analyse the relationship between the story and storytelling event, and the relationship between what could be called the primary storyteller and the vicarious storyteller', a position supported by Grove (2000:4) who suggests communication is like 'a picture constructed by two or more people'. It is therefore essential, according to Grove to 'identify how that meaning has built up, and who has contributed in what way'. From the perspective of narrative research it is then possible to view 'meaning and interpretation as dynamic, rather than static'.

This position is further supported using the model of the rhizome. Using the ideas developed by Loots et al (2013) from the concept introduced by Deleuze and Guattari, we can play and experiment with the personal narrative through its adoption of the characteristics of the rhizome, a specific type of organic root system. A rhizome is described as being like a map,

[T]he rhizome pertains to a map that must be produced, constructed, a map that is always detachable, connectable, reversible, modifiable, and has multiple entryways and exits and its own lines of flight. (Deleuze and Guattari, 1987/2013: 22)

Although cited by Loots et al (2013) to illustrate the multiple representations of one woman's story, I am interested in whether the metaphor can be stretched to incorporate the multiple representations or versions offered by significant others to collaboratively co-construct the stories of someone who is unable to tell their own. In that context can the idea that storytelling is a singular act be understood as a culturally imposed barrier?

#### 2.3.4 Supported communication

As we have seen in previous paragraphs, how people with PMLD are supported to participate in life story work is dependent on the way in which communication

is understood in a narrative context. Over ten years ago MENCAP commissioned a report to review the research about the lives of people with PMLD. One of the main themes that emerged in Carnaby's (2004) review concerned the 'wealth of academic literature' regarding the complexities of communication. Drawing on the work of Mirenda et al (1990), Carnaby (2004:9) summarises a 'significant shift' in how communication between people with PMLD and their supporters is viewed and understood. This shift is summarised by the 'inclusive principle that improved communication is possible for everybody', that intervention should be 'integrated, functionally relevant' and increasingly that communication is understood as 'multimodal'. It is with these shifts in mind that we will now turn to the multiple ways in which to support the communication of people with PMLD and how this is relevant to the research inquiry.

### 2.3.5 Communication environment

As already discussed, Goode (1994:87) found that the complex communication repertoires of those with PMLD and their significant others are vulnerable when transferred to environments outside the home and that 'they may not exist or may be undetectable in other contexts'. In Carnaby's (2004) review it was also apparent that augmentative and alternative communication (AAC)<sup>6</sup> devices used successfully in the school environment were not always equally effective in the home. It is understood that there is an inconsistency in responsiveness to communication not only in different environments, but also during the course of the day (Simmons and Watson, 2014b:79). What is described as 'an often unresponsive and unsupportive environment', leads, according to Sheehy and Nind (2005:34), to 'substantial barriers to learning and participation in community life'. It is important therefore to understand what a responsive environment looks like and how it acts to dismantle barriers to communication.

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<sup>6</sup> Because people with PMLD experience immense difficulty communicating, a variety of different approaches have been developed. Augmentative and alternative communication (AAC) is the term used to describe the different types of approach from 'sensory cues and objects of reference, to visual symbols and signing' (Anderson et al, 2015:286).



If the information processing of people with PMLD is understood to be different from those 'whose sensory, physical and perceptual systems are intact' (Lacey, 1996:65) then it follows that interaction with and feedback from the environment can be problematic. In coining the term 'responsive environment', Ware (2003) is describing a 'particular type of interactive environment'. Interaction can take a number of forms and takes place in an environment 'in which people get responses to their actions, get the opportunity to give responses to the actions of others, and have an opportunity to take the lead in interaction' (Ware, 2003:1).

The 'responsive environment' has become increasingly emphasised, according to Nind and Hewett (2005:36), because with it comes an increase in opportunities for people with PMLD to 'be active and interactive'. In this context the word environment is used to describe the opportunities for initiating and responding, rather than the narrow confines of the physical or geographical space in which interactions are invited. To be active and interactive in a responsive environment can be understood in many ways, but is generated and found in inclusive ways of working and dependent on a willingness to participate in the first place. According to Larkin (2007:16), 'in order to learn someone's language you must be able to motivate them to communicate'. Equally communication must be freely given and for that reason it is essential to distinguish between participation and compliance:

Participation is different from, and better than, compliance. Many practitioners obtain compliance and call it participation. It is not. Participation is an active, voluntary, constructive step on the part of the learner; compliance is doing what you are told to do. (Nind and Hewett, 2005:72).

A responsive environment is a place where people with PMLD, who possess very limited control over their lives, are viewed as communicators. Understanding and ameliorating the dominance of one communication partner over another is one of the ways in which it successfully facilitates communication partnerships, thus creating opportunities for people with PMLD to experience the 'joy of human interaction' (Nind and Hewett, 2005:1). To enter in to a dialogue with someone, be it verbal or nonverbal, it is essential to create the social and emotional environment that fosters communication. It was in

addressing the difficulties in behaviour resulting from communication challenges and how this impeded the learning environment that led to the development of II (referenced in Nind and Hewett, 2005:5).

We felt that if we could begin to establish a relationship with the students, and if we could establish a basis for communication, then all other spheres of teaching and learning would become easier and more meaningful. (Nind and Hewett, 2005:6)

Drawing on the ideas developed by Gary Ephraim (1979) (Nind and Hewett, 2005:6) about how communication and social skills develop as a natural process between caregiver and baby, interactive play was introduced to the classroom with positive results. With the introduction of playfulness, communication and social interaction became part of a process, rather than being directed towards an end product or task. As such interaction was 'concerned with negotiation and participation as opposed to dominance and compliance' (2005:14). The conditions represented here in the development of key approaches to support responsive learning environments are echoed within the ethical position of life history researchers who, drawing on the work of Portelli (2010) understand that 'narrative research does not 'give voice' to the oppressed, let alone excluded people. It is more that people give their voice to the research, not always with the consequences they want' (cited in Squire et al, 2014:20). Between life history researchers and learning-disabled narrators there can be sensitivity to power and authority that is both necessary and inhibiting (Atkinson and Walmsley, 2010).

The ideas developed in II<sup>7</sup> and drawn from caregiver and infant communication place emphasis on 'sharing control, responding to signals, establishing bonding, mutual enjoyment and reciprocity, synchronising movements and applying intentionality' (Nind and Hewett, 2005:41). It is important to understand the core principles that underpin this effective practice in the context of the research inquiry, because in adopting this approach practitioners are invited to develop communication and social relationships with those who might otherwise be

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<sup>7</sup> See Chapter 2 Theoretical background in Access to Communication 2<sup>nd</sup> Edition (Nind and Hewett, 2005: 16-41) for a thorough explanation of the theoretical frame in which Intensive Interaction was developed.

difficult to reach. One key concept within Intensive Interaction is 'tasklessness'. The difference between task and tasklessness is defined as follows:

A task includes formal notions about things such as defining what will be achieved and communicating this to the learner. Tasklessness includes also more subtle things such as taking care in interactions that your own emotional needs for the person to do this or that are not communicated to the learner. (Nind and Hewett, 2005:171)

With experience of working within this approach it is possible for practitioners to bring attention to specific tasks with an enhanced sensitivity to yourself as a 'powerful social interactor' (2005:172).

The sensitivity to power dynamics is particularly relevant to this research enquiry as it seeks to extend opportunities for people with PMLD to participate in life story work. McKim (2015) draws on the concept of the Zone of Proximal Development (Vygotsky, 1978) to illustrate Active Support, which is 'providing just the right amount of support to assist someone without deskilling them, scaffolding their abilities to ensure failure-free experiences at the peak of their competence' (McKim, 2015:24). This concept is employed in drama performances with mixed ability groups by Grove (2014:111) who describes scaffolding as 'a term used to explain how adults and teachers will guide a child by supporting and extending their contribution. The narratives are in this way scaffolded and 'co-narrated using a range of techniques that can include objects of reference, sensory props, communication aids, iPads, signing, repetition and sentence prompts' (Grove et al, 2015:311). According to Grove (2014:20) there is a range of participatory opportunity in life story work, not just in the 'telling' but in the feeling it excites, in the listening and the response. Adapting the principles introduced by Intensive Interaction, Grove suggests that story sharing with people with profound impairments should be pursued for the following two reasons:

One is that we simply have no idea what is happening in the internal world of these children - and including them in the story of their lives is surely better than giving up. The second reason is that although you may not see much change in the children themselves, you may find the group changes their response to them. (Grove, 2014:63)

In these paragraphs I have touched on the way in which an environment can be adapted to support communication and agency. This environment invites action and interaction and is structured in such a way as to be playful, respectful and sensitive to the often complex and fleeting communication intentions of people with PMLD. The communication environment is a place occupied by people who are prepared to step back from their ability to control interactions and who are able to tune in to the nuances and subtleties of pace and flow. It remains to be investigated whether the research approaches outlined here can be effectively applied to the participatory life story work posed by this enquiry.

## 2.4 Organisation of thinking

Coherence in narrative is understood to be one of the main contemporary issues in narrative research (Squire et al, 2014:26). Coherence in narrative is in this context understood through temporal flow, or the linear story, that has a beginning, middle and end. Ricoeur (1984) understood human experience to be 'arranged and bounded in time', a position examined by Plummer who wonders:

Can a life be imagined without a sense of the person accumulating traces of their experiences into some form of coherence through a narrative form - as they live through it? (Plummer, 2001:86)

However, referencing the work of Stanley (1992), Plummer (2001:89) calls into question the conventions of biographical story in which linear narratives are but one of many forms. Riessman (2013) references for example the 'lack of closure' found in illness narratives reported by Frank (1995), and suggests that coherence is not necessarily bound up with 'temporal ordering' (2013:201).

Taking for granted that we think about things by locating them in time is, according to Clandinin and Connelly (2000:30), one of the central concepts within narrative that creates tension. This tension is created by 'seeing things in time versus seeing things as they are'. Understanding that there is no such thing as narrative certainty because 'interpretations of events can always be otherwise', Clandinin and Connelly (2000:32) go on to explain the key importance of context: 'Context is ever present. It includes such notions as temporal context, spatial context and the context of other people'. The taken-

for-granted temporally coherent narrative is, according to Hyden and Antelius (2011), partly the result of 'the narratological conception of narrative', in other words, the written word, being transferred to the way in which we understand the spoken word. In Hyden's narrative work with people with brain disorders such as Alzheimer's disease he identifies our need for coherence as created by these narrative norms as problematic. When we think that people with Alzheimer's lack coherence and repeat fragmented stories, we are in danger of silencing them by privileging the stories of their relatives. If this idea were transferred to personal narrative work with people with PMLD, it may be necessary to let go of temporal coherence if it is not meaningful to them, and consider alternative models for story construction.

One alternative conceptual model could be the rhizome, as referred to earlier. In narrative work with parents of profoundly disabled children, Fisher and Goodley (2007) suggest the parents created counter-narratives in order to resist the 'linear life narratives', which in their situations were not helpful. By developing alternatives to the dominance of the 'linear life narrative', parents were able to 'enjoy their children as they are':

If life is perceived as an open book rather than a concluding chapter, parents are able to develop stories that are neither linear nor heroic but present and becoming. (Fisher and Goodley, 2007:66)

The rhizome as illustrated in this case allows the story to have multiple entry points and provides a different way of seeing and a different way of telling. In abandoning the person-centred narrative approach that makes 'sequential ordering' a 'fundamental criterion' of narrative and presents the person as a 'coherent and organised essential self' (Loots et al 2013:109), the alternative culturally oriented story gives up the 'illusion of the one true self'. Sermijn, Devlieger and Loots (2008) experimenting with form and inspired by Deleuze and Guattari (1976), expanded on this idea:

There is no right entryway that will lead the researcher to the truth/reality about an individual. The illusion that there is such a thing as one entryway that leads to the real self is completely given up. The rhizomatic self has many possible entryways and every entry will lead to other connections, and different versions of selfhood in which one is no more 'true' than the other. (Loots et al 2013: 111)

The parents in Fisher and Goodley's (2007) study found this alternative way of perceiving their disabled children's lives as useful and supportive. In so doing they were able to reject the unattainable age-related milestone narratives traditionally offered. The letting go of temporal ordering as an essential narrative component is a liberating, if daunting prospect, and is a useful reminder that many of the barriers to participatory life story work are socially constructed and as such can be looked at in this context. However, even if coherence and sequence are understood as literary constructions, they remain 'organising axis' for making sense of life narratives (Tamboukou, 2010:6). As such, temporal sequencing can be viewed as a resource in storytelling as opposed to 'inherent' in story (Squire et al 2014:27). Given that people with learning disabilities frequently experience difficulty with narrative coherence (Hewitt, 2006:8), how do these ideas and challenges translate regarding the present research enquiry? Should temporal coherence be abandoned in favour of the book that can be opened at any page, or are there other possibilities for supporting this process? Hyden and Antelius (2011) found that people with cognitive disabilities resulting from Alzheimer's Disease were frequently inventive when telling stories in spite of their difficulties. This was achieved through a combination of physical animation and vocalising on the part of the 'primary' narrator and was supported by collaborative partners or 'vicarious storytellers'. Here we see the story itself as co-constructed performance, which reflects the ideas discussed earlier regarding 'scaffolded' learning.

Being unable to tell their own stories, people with PMLD are highly dependent on 'the interpretations and scaffolding strategies' of others to communicate their needs (Grove, 2007:252). The parent or carer is, as discussed earlier, not only responsible for interpreting the needs of the person with PMLD, but also carries the responsibility of 'recording, memorizing, and sharing key events so that personal histories are not forgotten' (Grove, 2007:252). Grove was specifically interested in how parents and carers were able to structure and make coherent the events in the lives of the disabled person. Using structural analysis of interviews with the parents and carers of six profoundly disabled adults, Grove (2007:252) found that the accounts 'were not fully elaborated and lacked high points':

Together, the data from the interviews, the life storybook, and stories written by parents confirm the impression that parents and carers were easily able to project clear and positive pictures of the individuals in the study. However, the recall and construction of specific personal stories, as distinct from habitual events, presented more of a challenge. (Grove, 2007:257)

Grove (2007:258) found that this lack of 'climatic high point' in their storytelling could be for a number of reasons including the relentlessness of caring routines and the inability of the disabled child to initiate discussion about their life events. Grove concludes that her research highlights the need for 'fostering rich and affectively engaging experiences, recording of narratives, and the development of skills in collaborative telling for both the individuals concerned and their interactive partners'. Narrative contingency and people with PMLD is supported in a number of ways and will be discussed towards the end of this chapter.

In this review of the relevant literature on coherence in storytelling we are reminded of the fundamentals of narratives. How we tell our stories is different from how they are written. Temporal sequencing can be a useful resource in narrative, but not helpful if it acts as a benchmark for milestones of child development that are not achievable or if people have difficulties understanding or communicating notions of time. Our stories as co-constructed representations of our life experiences will not capture the 'true self' and can be constituted from highlights or from the every day mundanity, from other people's experience of us, or from a chronology of life events.

On the one hand I take a pragmatic approach to developing a participatory life story practice that creates opportunities for people with PMLD to exert maximum agency, but at the same time I ask questions about the nature of life story work and the implications that has for someone with PMLD. Sometimes described as heroes of the here and now, in that their focus appears to remain in the present moment, I shall turn next to a further complexity that people with PMLD experience in life story work - the subject of memory and identity.

## 2.5 Memory and identity in life story work

People with severe learning disabilities can find 'remembering even much repeated activities' difficult (Lacey, 2015:44). Lacey (2015) speculates that some people with PMLD may 'constantly experience, even much repeated, activities as if for the first time'. Indeed, people with PMLD are sometimes seen to be living in the here and now, 'their lives are of the moment' (Evans, in Vorhaus, 2016:27). And yet memory is a contemporary phenomenon, 'something that while concerned with the past happens in the present' (Rothberg, 2009:3).

The focus of this research enquiry is about extending opportunities for people with PMLD to participate in life story work and as such I am interested in what this broad research area can tell us about the relationship between memory, identity and life story, particularly in the case of people with PMLD. Brockmeier (2005:12) sees even the very earliest one-word sentences of children as marking 'a way to step out of the temporal flux of sensations and perceptions and hold on to them, consider and reflect on them'. And these stories we tell help us to make sense of our lives, 'our stories do not simply represent us or mirror lived events - they constitute us, shaping our lives and relationships' (Brown and Augusta-Scott, 2007:ix). If this social constructionist position is accepted it has implications for people who have both memory and communication difficulties.

If we accept that we are constituted by the stories we tell, and yet as in the case of people with PMLD, we are not able to tell, the responsibility of representation and identity falls to those who know us well. This idea has been explored by Kitwood (1997:8) who defines personhood as 'a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being'. Lindemann (2014:3) describes being held in personhood as a common practice used by families who care for a disabled relative, a practice whereby the family actively construct or maintain 'an identity for her when she cannot, or can no longer, do it for herself'. Recalling the experience of relating to her profoundly disabled younger sister, Lindemann (2014:8) comments that it was her family who 'gave her all the identity she had', because 'the narrative



tissue that constituted her personal identity' did not include any stories that she had independently told.

Understanding that people with PMLD 'do not and can never articulate' sufficiently to create their own identities, Hewitt (2000) sought to investigate how parents and carers created a 'sense' of who the disabled person was through their relationships and social interactions. The life story books compiled through interviews with parents and carers were viewed as a resource to 'allow the past to be kept alive' and were used as a way of 'describing the person's real self' (2000:94).

In terms of research, traditionally people with profound disabilities have been largely ignored in the identity literature. Using life story books takes the focus away from viewing them as 'subjects' or 'clients' and considers them as people with their own unique life. (Hewitt, 2000:95)

As previously mentioned Simmons and Watson (2014b:14) support the view that the literature regarding identity in relation to people with PMLD is limited and also remark that what literature that does exist tends to be 'impairment' and 'provision' focussed.

In Goode's (1994) ethnographic study of deaf-blind children he also recognised that identity was assigned or 'bestowed' on the children by others in relation to their impairment. Goode found that the identities ascribed differed from person to person dependent on their relationship. Wishing to 'socially reconstruct' the children in his study 'in a fashion truer to their actual human qualities and capabilities' Goode (1994:17) found that he needed to 'enter their world'. In this sense Goode understood the identities of the children to be found through his relationship to them on their own terms, defining intersubjectivity as a 'mutually recognised interiority to a same world' (p.24). In this way Goode understood identity to be fluid and relational.

Riessman (2008) calls up the work of Yuval-Davis (2006) who equates identities with narratives, the 'stories people tell themselves and others about who they are (and who they are not)' but the identity is fluid, 'always producing itself through the combined processes of being and becoming, belonging and longing

to belong' (Riessman, 2008:8). Here we find that identity is found in our narratives, but also in relationship to others, a position supported by Brockmeier (2015:188) who disputes the widely held view that identity is the 'result of repeated acts of autobiographical self-identification'.

Although language is essential in the formation, elaboration, and negotiation of self-understanding and identity, the issue of identity belongs to a picture that is more extended than that of language. It also comprises pre- and nonconceptual modes of meaning-making and identity that draw on bodily, intersubjective, and other cultural forms of life. (Brockmeier, 2015:173)

Brockmeier (2015:203) found that the 'loss of autobiographical capacities', as in the case of those who are disabled, ill or injured, did not 'automatically result in a loss of one's sense of oneself'. Finding that autobiographical practices are not the only practices that define our identities, Brockmeier (2015:218) argued that it was through taking part in 'a multitude of intersubjective practices' that identity, meaning and story were established.

The task of co-curating a selection of past experiences and making them available and accessible is partly based on the premise that this shared remembering has value with regard to identity construction. Brockmeier's (2015:315) research suggests that it may be that establishing the practice of shared remembering simply provides greater opportunity to connect to others and that the curated recollections, although fixed, contain the potential for what is referred to as 'starting points of new narratives'. This was the subject of research regarding the role of life story work for people with PMLD who were undergoing transitions in care (Middleton and Hewitt, 2000).

Concerned about the lack of attention to the identities of those being cared for by people who had no prior knowledge about their pasts, Middleton and Hewitt (2000:265) examined the creation and use of life story books as a 'social act of remembering'. They understood life story books as a vehicle for both 'making the past a topic of concern' and for raising questions about 'what it is to remember':

What it is to possess the past, what it is to have memories as a property of the conduct of a person's participation also features in social acts of remembering. (Middleton and Hewitt, 2000:265)

Middleton and Hewitt argue that life story work makes visible the agentic participatory social interactions of those with PMLD and consequently model the potential for others to interact with them and thus form and maintain relationships (Middleton and Hewitt, 2000; Hewitt, 2006). Sensory ethnographer Pink (2015:63) understands social relationships as integral to the way that we 'live, understand and communicate through our senses' believing that our identities are lived through 'our participation in social and material environments'.

In his ethnographic research Goode (1994:24) found intersubjectivity problematic because in his relationships with profoundly disabled participants he was unable to take for granted 'a mutually recognised interiority to a same world'. However, recalling the work of Schutz (1970), Goode (1994:88) was reminded that the 'knowledge we share with one another in the everyday world is partial, incomplete, and incoherent', although we assume it is not. However, when unable to share our life stories with others it is difficult to create opportunities for others to become interested in our lives (Grace, 2015:28). Thus finding expression through personal narrative, however incomplete or incoherent, is one way to connect with others, a necessity 'for such social animals as ourselves' (Grace, 2015:28).

## Conclusion

This review began by highlighting the sparse research literature that is available concerning the lives of people with PMLD. Although life history research is seen as a way to redress this (Atkinson, 2010), researchers are inhibited from embarking on this subject for a number of reasons, including those related to appropriation and authority (Rolph and Walmsley, 2016). Using the social model of disability (Oliver, 1990) as a tool to think about life story work with people with PMLD in new ways I focus on how the organic impairments associated with people who live with this label, which are viewed as barriers to participatory life story work, could be seen from an alternative perspective. By

questioning taken-for-granted narrative norms it is possible to move away from the notion of the singular telling of a coherent story that accurately recalls past events and experiences. This alternative way of understanding personal narratives can lead to increased opportunities for participation. In the literature I found that stories are co-constructed by the teller and the listener, that there is no one true version of the self and that temporal coherence is used as a resource to make sense of life events, not integral to the telling of them, and that sequential event based stories are positively unhelpful in some cases as, for example when age-related milestones remain unmet.

Research has found that responsive environments create opportunities for communication and that further opportunities arise from playfulness and tasklessness. There are identified gaps in the research regarding the skills required in collaborative storytelling. Little is known about memory and how it is linked to issues of a sense of self and how life story work can act as a catalyst for exchanging biographical information and building social cohesion. Rapid developments in areas of rich media and technology are also creating unexplored areas for participatory life story work. Much of the existing research that involves people with PMLD in personal narrative work is confined to its use post-production. However, life story work is not confined to telling, it includes the gathering of story, and the review of life story materials. The methods by which this is achieved appear to be absent entirely from the literature and will be the focus of the next chapter, which details how the methodology was developed.

## Chapter 3

# The Development of a Methodology

### Introduction

In this chapter the choices that were made in the design of the fieldwork will be explained, critiqued and justified. I will introduce how I approached the research enquiry and why this was considered appropriate. One of the gaps identified in the current research with people with PMLD is that we don't know how to do it. A lack of expertise in how to involve people with PMLD in finding out about how they are living their lives and engaging socially and culturally is also highlighted in the literature. Simmons and Watson (2014b) are of the opinion that there is a genuine lack of knowledge and expertise when doing participatory research with people with PMLD, a position supported by Hodge (2008) and Nind (2013). Boxall and Ralph (2010:173) consider this dearth of participatory research to be the result of not knowing how to establish the 'views and perspectives of people with PMLD'. However, there is a growing population of people who occupy this group and who require representation. It was in this spirit that the following methodology was developed. In this chapter the methodological approaches that created the foundation for the method design are discussed.

### 3.1 A qualitative approach

The methodological decisions made in this project were informed and shaped by the work of key researchers in the field, by the three families who agreed to participate and in response to a range of practical matters. The approaches were positioned within the framework of qualitative research. I understood that in order to find answers to my research questions I needed to immerse myself in the day-to-day lives of these families and become sensitive to the subtle, nuanced communication behaviours that were taking place. Those researchers whose work resonated with my position all advocated a move away from 'measuring to observing' (Hewitt, 2000:90).

I sought to understand how the opportunities for people with PMLD to participate in life story work could be extended and as such this was a substantive rather than theoretical enquiry, which investigated 'specific issues in a specific setting' (Bogdan and Taylor, 1975: 26). It was essential in this research project to adopt a holistic, as opposed to reductionist, methodological stance, and employ 'research procedures that produce descriptive data' in order to understand the people I was investigating as 'part of a whole' (Bogdan and Taylor, 1975: 4). Denzin and Lincoln (2003:4) describe qualitative research as 'a situated activity' consisting of 'a set of interpretive, material practices that make the world visible'. Through the use of these various practices it becomes possible to change the way we see and understand the world around us:

They turn the world in to a series of representations, including field notes, interviews, conversations, photographs, recordings, and memos to the self. At this level, qualitative research involves an interpretive, naturalistic approach to the world. This means that qualitative researchers study things in the natural settings, attempting to make sense of or interpret, phenomena in terms of the meanings people bring to them. (Denzin and Lincoln, 2003:5)

Of course every research project by its very nature requires a unique methodology, which meets the requirements of the specific research enquiry. With regards to participatory life history research with adults with PMLD, there is a sparse foundation from which to work. This methodology was adapted and developed as a result of exploring how researchers from a range of disciplines were working effectively alongside people with PMLD and by talking with supervisors and the families who had shown an interest in participating. I have found examples of replicable practice from several sources, notably Ben Simmons and Debbie Watson (2014b), Helen Hewitt (2000, 2006) and David Goode (1994), to support and develop a methodological response to this enquiry, but equally have found inspiration from trans-disciplinary sources, as will become clear throughout this chapter. Above all I sought to work within a methodology that intentionally foregrounded the capabilities of the profoundly disabled participants. The methodological design was constructed in such a way as to understand the strengths of the disabled participants rather than their deficits, how those strengths operated within the communities that the

participants occupied and how they could be used to extend the opportunities for participatory life story work.

### 3.2 Is it participatory research or research about participation?

At this point it is useful to consider why it is important that people with profound disabilities should have opportunities to participate in life story work. Why is it not acceptable for us, as researchers, to simply get on with the task of constructing their biographies? The foundations of inclusive and participatory research methodologies in the context learning disability can be traced back, according to Walmsley and Johnson (2003), to the mid twentieth century and the development of a theoretical concept termed 'normalisation':

Normalisation is a set of ideas, or a theory, with applied and practical outcomes. It originated in Denmark and Sweden in the late 1950s, but was later recast in North America during the 1970s and 1980s. This means that there are two main strands of normalisation: the original Scandinavian version and the recast North American version. (Walmsley and Johnson, 2003:45)

In essence 'normalisation'<sup>8</sup> reflects a position whereby people with learning disabilities are encouraged to 'obtain an existence as close to normal as possible' (Bank-Mikkelsen, 1969, cited in Walmsley and Johnson, 2003). This position was developed in response to an understanding that people with learning disabilities were a 'devalued group with a devalued image' and that by adopting practices that improved the external image of a person with learning disabilities it was possible to enhance their life opportunities (Mee, 2012:103). However 'normalisation' was heavily criticised as, at its core, was an expectation that 'it required change on the part of people with learning disabilities' (Walmsley and Johnson, 2003:48), rather than an acceptance and celebration of difference. As such the theory reinforced a set of ideas that valued conformity over difference (Brown and Smith 1992; cited in Culham and Nind, 2003:71). Criticisms of normalisation led to clarifications in intended meanings; Perrin and Nirge (1985) stating that the term normalisation did not

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<sup>8</sup> For a comprehensive account of the development of 'normalisation' and how it influenced participatory research approaches within the learning disability field and the self-advocacy movement see Walmsley and Johnson (2003).

mean normalcy, while Wolfensburger (1983), responsible for developing the North American strand of the theory, extended the term to include both how people with learning disabilities presented themselves in society and the roles they performed. According to Walmsley and Johnson (2003) these ideas had a vast impact on services and policy in the UK. The development and implementation of the idea that people with learning disabilities were 'deserving of ordinary patterns of living encouraged others to view them as potential contributors to research' (2003:48) and viewed participation in research as a valued social role.

According to Walmsley and Johnson (2003:54), the 'autobiography, life history and ethnographic traditions have led the field in inclusive learning disability research'. Walmsley and Johnson (2003:9) define inclusive research as research in which people with learning disabilities are active participants 'not only as subjects but also as initiators, doers, writers and disseminators of research'. Culham and Nind (2003:73) highlight the key way in which 'difference' is viewed from the standpoints of inclusion and normalisation, 'The former is celebratory and the latter more apologetic'.

It might be argued that normalisation and inclusion are guiding philosophies that have the same end in common, but that have different ideas about the means of reaching that end. (Culham and Nind, 2003:74)

The contributions of people with learning disabilities to developing inclusive life history research are well documented by members of the Social History of Learning Disability Group at the Open University<sup>9</sup>, among others.

However there remains a limited application of inclusive methods in researching with people with high support needs when the spoken word is unavailable. There are a number of issues that inhibit researchers from embarking on work in this area. There has been a call in participatory life history research for example, for members of marginalised groups to 'control the agenda'. However,

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<sup>9</sup> The Social History of Learning Disability (SHLD) Research Group is based in the [School of Health, Wellbeing and Social Care](#) at The Open University, and is committed to researching and disseminating learning disability history in ways which are inclusive of people with learning disabilities, their carers, relatives and advocates.



[T]he voices of those with severe and profound difficulties, for example, would arguably not be heard at all, if it were not for the mediating of historians, families, or carers who are determined not to exclude their stories. (Rolph and Walmsley, 2016: 663)

In the wide-ranging methodological review paper 'Practical considerations in doing research inclusively and doing it well: Lessons for inclusive researchers', Nind and Vinha's (2012) focus is on participatory research in the field of learning disability. Nind and Vinha (2012:60) usefully provide an 'aide-memoire for practice', a series of questions to be considered, 'intended to provoke reflection and stimulate considered action'. Several of these, I would argue, are extremely challenging to meet when researching alongside people with PMLD, but all provoke reflection. Alternative methods of creative participatory research that include nonverbal disabled participants have been developed and will be reviewed later in this chapter.

One of the key issues raised by this research inquiry is the initiation of ideas. The research proposal was my response to an advertised studentship that was framed within a clearly structured umbrella project – to develop a living archive of learning disability history. Therefore the idea to examine extending opportunities for participatory life story work with people with PMLD was mine. However it is not possible to imagine that the research participants would have approached me with initial ideas for the project. As such it became essential to weigh up the benefits and burdens of undertaking this research with people who were not in a position to initiate or consent to an interest in the proposal. I shall explore the ethics of the developing methodology at a later stage, however it is important to understand that without the input of researchers in the field of participatory research with people with PMLD there is a danger that they become excluded from research on these grounds. However, as Nind and Vinha (2012:13) cite in their review: 'Including those less able to communicate may well present insurmountable methodological difficulties and this exposes an ideological dilemma at the core of user involvement' (McClimens et al, 2007).

Bearing in mind the differences referred to earlier regarding normalisation and inclusion, it would be a mistake to adopt a methodology that sought to impose

unrealistic expectations on the profoundly disabled research participants, as in so doing I would in effect be pandering to an external and superficial appearance of inclusion, rather than celebrating what is achievable within a participatory framework. Drawing attention to the ethical challenges of conducting participatory research with people with PMLD, Nind and Vinha (2012:14) draw attention to the need to neither 'over-burden' nor 'over-protect' people involved in inclusive research partnerships. One way to achieve an ethically sound participatory frame is to divide up the tasks that need to be done 'according to' skills and interests and so on, thereby working 'together but separately'. The research methodology needed to incorporate a clear frame to ensure that inclusion and distributed patterns of participation remained paramount and also that the research process included clear outcomes that were intended to benefit the profoundly disabled participants.

### 3.3 Action Research –a closer fit?

As mentioned in the previous section the idea for this research project came in response to an advertised studentship. I saw that there was a large-scale project to develop a living archive of learning disability research and my immediate response was 'what about people with PMLD? Do their stories belong in this archive, and if so, how will they get there?' My reaction was the result of having tried, and in my mind failed, to develop a meaningful way to engage people with PMLD with their stories. I was frustrated at my inability to do this work. And I'd been trying to do it for over twenty years. As such, although the proposal submitted was concerned with engaging people with PMLD in participatory life story work, it is rooted in action research. The research questions came out of my practice-led experience and were inspired by the three-year studentship, which provided an opportunity to improve my practice. The research questions did not come from the disabled participants themselves, or other communities of interest, although as the methodology developed it became ever more refined in response to the conversations that took place with the prospective participants' families and their allies.

Nind (2014:9) describes the 'key premise' of participatory action research as 'the notion of exchanging expertise and working together in a process in which

action and research are simultaneous and inseparable'. According to Lacey (2015:37), the 'doing' of action research has been represented as part of 'a cycle or spiral', in which 'the cycle is a simple but powerful iteration and reiteration of 'plan, do, review' underpinned by reflective practice'. It is a research approach used widely by practitioners who are interested in evaluating and improving their practice (McNiff and Whitehead, 2011). This implies that action research, as a methodology, is open to different levels of participatory engagement. While acknowledging that this research inquiry was practitioner-led at the start, once the studentship was awarded the involvement of stakeholders became a priority. As Lacey suggests,

[O]ne of the best ways to inform others of what is happening is to include them in the research right from the beginning...to help the practitioner-researcher to devise the study, develop the data gathering tools, collect the data and help to understand what it means. (Lacey, 2015:38)

The description of action research fits with the way ethnography is described by O'Reilly (2009). According to O'Reilly, ethnography as a methodology is fundamentally iterative-inductive in that the design evolves as the research progresses. With that description in mind I recognised that ethnography could provide a framework within which to hold a range of approaches to this specific study.

### 3.4 Working ethnographically

I had the opportunity to attend an afternoon workshop with narrative researcher and scholar Catherine Kohler Riessman a few weeks before beginning the long fieldwork stage of this project. She described my proposed engagement with the three participants and their circles as 'deep hanging out'; a term originally coined by anthropologist Clifford Geertz. As the year went on, and friends and colleagues asked me about what I was doing and how I was doing it, I frequently called upon this phrase. It encapsulated the tone of the time I spent with the families. It would have been impossible to enter their personal, private spaces with a clipboard or to assume a position of authority. I had been invited to 'hang out', albeit within a structured and intentional frame of methodological inquiry.

There were a number of factors that led to the development of a methodology within an ethnographic frame. I was influenced by the work of David Goode (1994) who wrote 'A World Without Words', the account of his engagement with two deaf-blind children, one of whom lived in a long-stay institution, while the other lived at home with her family. As a result of his immersion in the lives of these two girls Goode was able to understand how they effectively communicated with their bodies and how a range of different structures supported those 'conversations' with the body. Having discussed Goode's research and findings more thoroughly in the Literature Review, I will not cover it a second time here, but suffice to say that in Goode's (1994:2014) opinion, for those who wish to examine the 'experience of people with disabilities, there is probably no better research method' than ethnography.

Simmons and Watsons' (2014b) book 'The PMLD Ambiguity', was also a key factor in the decision to adopt aspects of an ethnographic methodology. They suggest that there are multiple 'benefits of longitudinal research' and the development of 'methods to allow for many voices' that also capture 'small changes', (2014b:149). Ethnography as a methodology became a clear way to frame a sympathetic and thoughtful range of transparent methods to address the questions asked of the research. Understanding ethnography as a methodology through which the researcher is 'making the strange familiar' Goodley et al (2004:56) describe this as involving 'getting to know people by being there, alongside them, during ordinary days, to try to capture their experiences at first hand'.

Vorhaus (2016:129), in his recent publication, 'Giving Voice to Profound Disability', argues in favour of ethnographic studies as a way to observe 'the lives of children and adults with profound disabilities over several years'. It would appear that immersion in the lives of the research participants over a 'sustained' period is one of the most useful ways in which to gather empirical evidence and develop understanding. According to O'Reilly (2009:3) 'sustained contact' with people 'within the context of their daily lives' is at the centre of ethnographic methodology. From the authors cited here and from personal experience supporting people with PMLD, the quality and quantity of time spent

with the research participants seemed a non-negotiable element in the choice of methodological approach.

### 3.4.1 Time as an essential element in the methodology

One of the ideas explored by Goode (1994) in 'A World Without Words' is the different ways in which those who come in to contact with people who are profoundly disabled perceive them. A stranger might see someone as a 'monster or object of disgust', a doctor as 'essentially and irremediably flawed', whereas a nurse, whose relationship has developed over time was able to see 'someone capable of human interaction'. Although these are views reported from some time ago, it is clear that by spending extended periods of time with people who have limited communication ability it becomes apparent that sophisticated strategies are in operation. By allowing time for observation and interaction it becomes possible to 'build up a picture of what they can do, rather than what they are unable to do' (Vorhaus, 2016).

Sheila Evans, one of the interviewees quoted in Vorhaus's book encapsulates a view held about many people with PMLD, that 'their lives are of the moment', (2016:27). Therefore if one's research is asking questions of communication strengths and capabilities then there is a requirement to invest time in that process, as Vorhaus clearly states that:

To appreciate what someone with PMLD is capable of, and the significance of their progress and achievement, requires not only an understanding of the person gained from extensive first-hand experience, but also a preparedness to look for signs of their responsiveness and potential, and to go on (and on) looking; all of which takes us a long way beyond any initial categorisation of the capabilities as absent, limited or underdeveloped. (Vorhaus, 2016:29)

It would appear that the longer time is spent with someone with PMLD, the more skilful one might become in reading signs of 'responsiveness', and interpreting reactions. This is a skill, Hewitt (2006:32) argues, which is the 'single most important aspect of encouraging participation'. According to Klotz (2004:101) it is only through long-term anthropological engagement with people with PMLD that it is possible to develop relationships and enter the 'lifeworld of

the people in question'. Klotz warns that in order to do this it may be necessary to let go of the 'theoretical and methodological tools' used by sociocultural theorists, because they get in the way of our ability to 'relate to them as people who are already fully human and encultured beings'.

I would agree that long-term engagement as advocated in ethnography is an essential component in researching the lives of people with intellectual disability. It would seem that for this inquiry it would be necessary to spend as long as was required to become what Clandinin and Connelly (2000:77), describe as a 'sensitive reader of and questioner of situations', in the narrative weave of the everyday - a range of stories that can appear to the 'new and inexperienced eyes of the researcher as a mysterious code'. When spending time alongside people with PMLD the researcher must tune in to and read an entirely unique set of codes - a set that are not recognisable to those without an established relationship.

### 3.4.2 Working with stakeholders

People with PMLD require support in most aspects of their lives, as the description offered previously (p.3) makes clear. As such it was apparent from the outset of this research enquiry that the research methodology must be one that was inclusive of the people who are contained within the key participants' circles of support. Members of these circles were to become key stakeholders in the research and their support would be an integral element in the success or otherwise of the project. However it was vital their input was supportive rather than dominant and that the participatory opportunities of the disabled participants remained a shared primary goal.

In 'Valuing People; A New Strategy for Learning Disability for the 21<sup>st</sup> Century', (Department of Health, 2001), there are two paragraphs specifically referring to people with PMLD, one of which reinforces this position:

People with profound and complex disabilities may have difficulty communicating their needs and wishes. They may need the support of someone who knows them well such as a family member, an advocate or a supporter. Nevertheless it is important to enable people with profound

and complex needs to exercise as much control as possible over their lives. (2001:101)

Any research methodology designed to examine an aspect of the lives of people with PMLD must draw on the knowledge and expertise of people who have established relationships with them. Researching the mental health needs of people with PMLD, acknowledging that they like everyone else experience these difficulties but lack the ability to communicate their needs, it is those closest to them who are best placed to 'interpret key matters of importance' on their behalf (Sheehy and Nind, 2005:35). Sheehy and Nind (2005:36) argue that 'We need to challenge the myth that there is special knowledge that only specialists have' and that the insights that those people who know individuals with PMLD well are 'under-used and under-valued'.

Those who know people with PMLD well not only have insights and expertise, but their support in the successful implementation of new ways of working is critical (Goldbart and Marshall, 2004). In their research examining the introduction of AAC and the role parents played, Goldbart and Marshall (2004:196) effectively involved them in the 'research decision-making process'. If the success or otherwise of AAC is dependent on the active support of parents then it would seem that they and others who are involved in the day-to-day support of people with PMLD must equally perform a vital role in developing participatory life story work and be included in the design of the methodology.

Commenting on the role of allies in the development of life story work, Hewitt considers their contribution essential:

[P]eople with profound learning disabilities will require complete assistance with compiling their life story books. To make the books as comprehensive and authentic as possible it will be necessary to include the accounts of third parties, in particular the person's immediate family or other relatives and long-term relationships with friends and carers. (Hewitt, 2006:22)

In the context of life story work it would appear that as researchers we are dependent on those who know people with PMLD on several counts - firstly to support our interpretations of idiosyncratic, non-symbolic communication repertoires, and secondly to report the events and experiences of the life story

itself. This position of responsibility opens up the potential for a shift in balance - away from the disabled participant and towards the people who can speak with authority on their behalf and therefore the research methodology needed to take this in to account by triangulating interpretation.

If then the contribution to life story work made by the disabled participants themselves is as limited as Hewitt (2000:92) would suggest, and those that know them intimately 'constantly speak on behalf of them, and it is how they are represented', my research methodology necessarily had to include a method to examine how this takes place in the context of their daily lives. Rather than perceiving this as a contested and problematic issue that is possible to resolve, we can as suggested by Goodley (2001), come to an understanding and appreciation of 'distributed competence', and accept, as Nind (2013:25) points out, that the value of participatory research with people with PMLD is in 'what we can do together rather than alone'. As such, as Nind concludes, the research may not be 'inclusive', but is 'in the interests of people with PMLD'.

The idea of 'distributed competence' and working harmoniously with those who have close relationships with people with PMLD, while all the time retaining the disabled participants in a central and pivotal position within the research, leads towards a methodology that has co-construction and shared authority at its core. If the members of the circles of support are viewed as experts in interpreting the communication of the disabled participants and those interpretations are made visible in such a way that they are open to examination, it may be possible to interrogate the unfolding stories and potential for participation using a 'culturally-oriented' as opposed to an individual and linear narrative approach (Loots et al 2013). In this way the circles of support, providing the social structure for the disabled participant, would present a 'polyphony of voices' (Bakhtin, 1981), each with their unique perspective based on experience, shared events and personal relationships and aligns with the notion of the rhizome (see p. 28).

This idea chimes with the participation of 'circles of support', which invites multiple entryways - none more true than any other (Goodley, 2007). The



circular and social context for storytelling is reminiscent of one of Myerhoff's favourite quotations which originates in the traveling Jewish theatre:

Stories. Listen. Listen. Stories go round in circles, they don't go in straight lines, so it helps if you listen in circles. Because there are stories inside stories, stories between stories, and finding your way through them is as easy and as hard as finding your way home. And part of the finding is the getting lost. And when you get lost, you really start to look around, and listen. (Myerhoff, 1983:17)

Viewing these ideas through a post-modern lens 'challenges the "either/or" binary constructions that constrain our understanding of stories', and leads to a place where everything is interrogated 'rather than taken as is', (Brown and Augusta-Scott, 2007:xii). As O'Reilly reflects, this approach invites messiness:

Postmodernists accept and celebrate the complex, ambiguous, messy nature of the social world and of ethnographic research; they self-consciously abandon attempts to provide neat, ordered narrative accounts written in an authoritative voice. (O'Reilly, 2009:188)

To summarise, the research methodology as it developed needed to encompass an approach that invites a long-term commitment, 'being there', with an expectation of close working partnerships with experts in the field - in this case the friends, family and those paid to support the disabled participants. It required an approach that made visible the distributed competence of the networks as they operated in the every day, one that permitted access and openness to interrogate the processes as they were in operation. To achieve this privileged status it would be essential to forge trusting and non-judgmental partnerships, a time-consuming but necessary investment. It was necessary to place myself firmly within the research methodology and structure in a method to record my experiences, interpretations and reflections. A key concept in ethnographic approaches, this is termed 'reflexivity', and will be discussed in the next section.

### 3.4.3 Working with my thoughts - reflexivity

Reflexivity is a term that formalises the reflective processes of the researcher and acknowledges the researcher's place within the context of their study. As

O'Reilly (2009:189) points out, 'it is no longer possible to pretend we are not part of the world we study'. As researchers we bring our own experiences, preconceptions and interpretations into our areas of study. We also make choices, as O'Reilly states, about what and how our observations in the field are written up. Thus, as a contemporary ethnographer we must:

[B]e able to locate ourselves in our studies honestly and openly, in an admission that observations are filtered through our own experience, rather than seeking to provide the detached voice of authority. (O'Reilly, 2009:191)

Placing ourselves in the midst of our study and acknowledging our humanness and bias is, according to Plummer an essential quality of the humanities researcher:

If we wish to understand a life story, then, we need also to know where both the researcher and the teller of that story are coming from, what kind of relationship they are having together, and how this fits into the wider social order. (Plummer, 2001:208)

Anthropologist Geertz (1996), looking back over his research career understands and explains this concept using the metaphor of the *parade*. He suggests that we know what we know because of where we are positioned, but also as time moves on so our perspective shifts. Walmsley and Johnson (2003:38) emphasise the importance of acknowledging the 'researcher's attitudes and values' to all forms of qualitative research because the methods employed 'focus on the meaning which people bring to their worlds'. In addition, research conducted within a participatory frame, which adopts a self-conscious position alongside fellow research participants, has 'self-reflection' as part of its ideological foundation (2003:39).

It is anticipated that within a methodological frame of ethnography the relationships that are formed within the research context will develop and change as time goes by, in what Plummer (2001), describes as a 'continuum of involvement'. Therefore, the place of reflexive thought will also evolve over time as the researcher moves from 'stranger role' towards 'friendship role'. This is a complex and problematic ethical position for the researcher to straddle and an

issue exposed by the frank reflections of several researchers working in the learning disability field (Atkinson, 2005; Stuart, 1993).

Reflexivity through critical analysis of the research process also provides a structure in which to hold the iterative-inductive nature of the inquiry. Regular recorded reflections can be instrumental at a later stage in the study to tell the story of the research, the twists and turns, the dead-ends and breakthroughs. At the writing-up stage of the study this record can prove extremely useful, the research log leaving an 'audit trail' of the work (Riessman, 2008:191).

### 3.5 Working with life stories - a case study approach?

In the early stages of thinking about the best research methodology to bring to my specific area of interest, I was given an opportunity that brought about a substantial change in direction. The mother of a twenty-seven year old woman with PMLD who had expressed an interest in her daughter's participation in the study told me about the archive of documentation that she had accumulated during the twenty-seven years of her daughter's life. The archive included various projects her daughter had been part of, for example 'Intensive Interaction', the 'Big Mack' and various creative workshops. The mother explained that each of these projects had examined ways of encouraging communication and choice, what had been tried, what the impacts had been and what they had learned collectively as a family. She suggested that her daughter's story was there, in her strong presence and in her personal archive and what was required was a creative methodology designed to excavate what was already there to be told. The suggestion from our conversation implied that I was approaching the research question from the *outside in*, when what was required was the reverse.

Instinctively drawn to qualitative, interpretative and ethnographic methodologies, there was now an added dimension of incorporating life history research approaches. As the methodological design began its task of meeting the research enquiry, one thing became clear: this project would be time-consuming and generate a large quantity of data. Consequently, from this point on, it was agreed that I would work with a small number of disabled participants,

using a 'case study' approach. Case studies, according to Riessman (2008:194), produce 'context-dependent knowledge', can 'uncover social practices that are taken for granted' and focus attention on narrative detail', the little things. Yin (2014:2) suggests the case study as a useful approach when 'the boundaries between phenomenon and context are not clearly evident', and when, as is the case of this research enquiry, it is necessary to draw on a variety of data sources.

According to Simons (2009:23) the case study approach invites stakeholder participation, by acknowledging 'the importance of co-constructing perceived reality through the relationships and joint understandings we create in the field', thus reflecting my intention to positively encourage shared authority. Qualitative researchers working with people with PMLD recommended adopting a 'case study' approach (Goode, 1994; Simmons and Watson, 2014b). Simmons and Watson (2014b:199) defend the case study approach arguing that through their observations of a single child, 'traditional readings of children with PMLD as forming a homogenous group must be resisted'. This would suggest that single case studies have the capacity to open up big issues. Goode (1994:51) defends his research with two 'deaf-blind' girls by suggesting that a previously 'unknown world' could be displayed for 'scientific documentation', and that:

[A] study seeking to describe a single family with a severely disabled child could produce such an incredible body of knowledge, with potentially so much to be said, bears strongly on what a human science could and should be. (1994:147)

Critiques of a case study approach question the validity of results, when there are only a small number of participants, a position defended by Simmons and Watson (2014b:199), who maintain that 'we have to consider ways of capturing this individuality in order to tell individual stories'. As Stake (1995:4) points out, 'we do not study a case primarily to understand other cases', however 'an unusual case helps illustrate matters we overlook in typical cases'. This position is supported by Simons (2009:24) who maintains that generalisation is not the aim of the case study approach: 'The aim is particularization – to present a rich portrayal of a single setting to inform practice, establish the value of the case and/or add to knowledge of a specific topic'. Goode (1994:93) suggests that 'a

limited number of case studies' using ethnographic, observational methodologies, may 'serve to validate or discredit' alternatively obtained research findings and that this could be 'a way to use observational studies to "triangulate" data and results'.

### 3.5.1 Accessing Personal Archives

A further approach to triangulating and contextualising observable behaviour is to combine what is seen in the present time with records from the past. As Bogdan and Taylor (1975:7) report, personal archives 'enable us to view a person in relation to the history of his or her time and to examine how he or she is influenced by various social, religious, political, and economic currents'. The inclusion of rich archives of life history documents within the developing research methodology presented the possibility of framing individual opportunities for participation in current life story work within the context of participatory experiences previously held. Not having advanced or detailed knowledge of the contents of these personal archives was problematic, but also presented the opportunity for shared exploration. As such the process of excavation and developing knowledge regarding the life stories of the disabled participants was a further opportunity for experimenting with participatory practices. This opportunity reinforced the development of an iterative-inductive methodology as the preferred approach. As the documents were examined with the disabled participants we would be able to both chart individual past experiences and also observe their preferred patterns of engagement with the materials.

Recalling the words of Bogdan and Taylor above, access to the personal archives of the participants would reveal their individual stories as experienced within the wider context of disability policy with regard to legislative frameworks, educational provision, communication trends and societal attitudes. This process would invite methodological approaches employed in narrative and life history research with reference to documentary provenance, narrative mode, genre and form as well as personal significance.

Atkinson and Walmsley (2010:273) in their examination of the challenges of developing inclusive biographical histories with people with learning disabilities, argue in favour of the contribution of academic historians to 'a shared history of intellectual disability'. In examples of 'biographical reconstruction' they reference the use of personal documents to 'inform and enrich' more orthodox biographical archives. They suggest that:

[W]hile access to direct 'voices' is not possible for periods prior to living memory, there are possibilities for imaginative use of sources of personal experience in order to develop a more inclusive history of intellectual disability. (2010:277)

Could this approach be adopted for supporting a more inclusive methodology for accessing the 'voices' of non-verbal adults with PMLD? It would add to and potentially counter the otherwise dominant voices of those in the disabled participants' circles of support. It would seem that the combination of documentary and oral sources is, as Atkinson and Walmsley (2010:282) argue, 'one step towards an inclusive history of intellectual disability'. In this case they are referring to people who can, with support, 'tell' their stories, but the suggestion remains that the introduction of personal archival materials can invite possibilities for alternative views to be taken into account.

It is understood that our personal archives have the capacity to trigger memories of the people, places and events in our pasts (Clandinin and Connelly, 2000:114) and that examining these collections 'in the context of a narrative inquiry constitutes something that might be called an archaeology of memory and meaning'.

### 3.6 Working creatively - everything speaks

In Woolfson's (2014:6) narrative exploration of the lives of Lithuanian Holocaust survivors her approach was informed by the Hasidic belief 'that everything in the material world has its melody and meaning; that everything - stories, places and objects - speaks'. With the absence of access to first-person narrative accounts, the research methodology has, by necessity, to look beyond the spoken word for its sources. Artefacts, objects, photographs and the material

furnishings of the disabled participants' homes could provide additional information with which to answer my research inquiry.

### 3.6.1 Working with images

In a keynote presentation to the annual Visual Methods Conference, Rose (2015, Brighton University) discussed the centrality of visual images to our lives. Freund and Thomson (2011), open their work on oral history and photography with the following quote:

But photographs cannot tell stories. They can only provide evidence of stories and evidence is mute; it demands investigation and interpretation. Looked at this way, as evidence as something beyond itself, a photograph can best be understood not as an answer or an end to an enquiry, but as an invitation to look more closely and ask questions. (Gourevitch, 2009)

However, Rose argued that images carry their own argument and have 'agency'. She questioned whether there is such a thing as 'visual knowledge' or whether images required translation. Images, being 'open to interpretation', are generally framed by language. They prompt a 'different kind of talk' and are participatory in nature. What is particularly interesting about using visual images is that consequently, as Bell (2009:145) comments 'their meanings are open, shifting and multiple, and are dependent on audiences for producing and interpreting them'. It would appear that access to visual materials might further extend opportunities for the key participants in this study to take part. In this context photographs would be used traditionally as the 'data' which would serve to 'illustrate and/or document the ethnographic record' (Berg, 2004: 205).

A research technique called 'photovoice' was developed as a means to 'enable the investigator to gain perceptual access of the world from the viewpoint of individuals who have not traditionally had the means of imaging the world' (Berg, 2004:205). Boxall and Ralph (2010:173) lamenting that 'user involvement in research rarely extends to people with profound and multiple learning disabilities', considered developments in visual methodologies to offer opportunities for greater inclusion. Using the approach developed by 'photovoice', non-speaking residents of a hostel due to close, were supported by paid staff to take photographs of their home. Boxall and Ralph identified the

level of support given by hostel staff as problematic. However the concern about potential influence and bias was balanced by the depth and longevity of their relationships. Boxall and Ralph (2010:178) found that over a period of time the residents' interest became more focussed on the visual images as opposed to the verbal descriptions of them. The collected photos were given to each resident when they moved to their new homes where staff were 'surprised' not only by the extended attention span of a particular project participant, but also in her apparent ability 'to communicate through the use of photographs'.

For those who are motivated by visual stimuli, photographs have been found to be a useful, nonverbal method to document experience and support memory (Hollinworth et al, 2012). Photography has been used with people with learning disabilities in participatory life history research and is demonstrated as a creative technique in identifying values and priorities and improving communication (Kennedy and Brewer, 2014:1). The use of photographs and other visual stimuli can be used both 'receptively and expressively' and is an effective technique for people who use eye-pointing with communication partners (Goldbart and Caton, 2010:14) to both express preference and to anticipate and understand the order of forthcoming events.

The personal archives of the profoundly disabled participants in this study would, no doubt, include photographs and other visual images. These images were likely to have been made by those in the key participants' circles of support. Reflecting on the authorship of these personal archive collections brought to mind the thoughts of photographer Spence who, when explaining her body of work 'Beyond the Family Album', said:

I began to reverse the process of the way I had been constructed as a woman by deconstructing myself visually in an attempt to identify the process by which I'd been 'put together'. I still feel that personal is political. There is no way I could have understood fully the political implications of trying to represent other people (however well intentioned) if I had not first of all begun to explore how I had built a view of myself through other people's representations of me. (Accessed from Jo Spence website 5.11.16)

It was vital that these thoughts remained uppermost in my mind as I explored ways to share our examination of the participants' personal archives.



### 3.6.2 Working with rich media

With the advent of digital media, opportunities to create and share image and video have become commonplace. Visual and auditory sense memories can also be triggered through multimedia technology:

With more advanced computer knowledge it is possible to develop a fully interactive life story, using multimedia technology. It is then possible for the person to navigate their way through their life story, interacting with any elements they wish to explore further. Sound effects and digitised recorded interviews of themselves and significant others can be added. (Hewitt, 2006:59)

In spite of concerns regarding levels of assistance, which increase with people whose support needs are greater, it does appear that technological advances have the potential to create opportunities for people with PMLD to participate in their life story work in new and exciting ways. In their study to examine the potential of multimedia technology to empower young people with intellectual disabilities, Bunning et al (2009) found that:

The defining contribution of new technologies and applications of rich and multiple media lies in the forging of links between images and meanings, past and present, school and home, so that the need for conventional linguistic exchange is obviated. (Bunning et al, 2009: 371)

The authors considered the level of 'human mediation' an issue that required further consideration. However, as highlighted in Mansell's (2010) review of services for people with PMLD, low expectations of what it is possible for someone to achieve has resulted in limited opportunities to access technology that supports independent communication post education. According to Vorhaus (2016:131), researchers should prioritise the latest 'pedagogic, therapeutic and technological developments' to develop not only their ability to communicate with others, but also to enable them 'to participate in any attempt to document their lives and experience'. It is important to keep in mind that rich media applications are only effective if matched to communication repertoires of user, not vice versa, and as the design of phones and tablets requires use of the hands 'these devices and apps may not always be the best solution for people with complex communication needs' (Bradshaw, 2013:31). Light and

McNaughton (2013:299) warn that 'excitement over these new devices will result in our focusing on technology alone, to the neglect of what must be the central concern', i.e. those who require support to communicate. Understanding that 'technology has no inherent value', Light and McNaughton (2013:301) reinforce Bradshaw's (2013) argument, that communication assessments are required in order to determine need and support solutions with specific regard to AAC apps.

However, many of the design features of tablet computers and mobile phones make them useful tools for supporting communication. The touch screen, light weight design of the iPad with its range of functions including 'camera, video, typewriter and microphone' make it a practical partner in the facilitation of multimedia, including 'films, digital stories, texts and drawings' (Critten and Kucirkova, 2015:1). Using the 'Our Story' app designed by the Open University, Critten and Kucirkova (2015:2) found that in the case of two adolescent boys with severe learning and communication disabilities the app was 'helpful in facilitating sequential arrangements' of media and that its design 'harnesses the learning potential of story-sharing and story-creating'.

Multimedia Advocacy has been used to harness the opportunities rich media creates to improve the lives of people with learning disabilities (Kwiatkowska, et al, 2012). Using participatory action research methods, Multimedia Advocacy was developed by researchers at The Rix Centre<sup>10</sup>, based at the University of East London. The Rix Centre's definition of multimedia advocacy is that it enables people with learning disabilities to 'organise their thoughts, reinforce their memory, enhance their communication and develop their social and support networks' (FTRA Report). Mirroring the principles included in the conceptual framework of self-advocacy developed by Test et al (2005), researchers at the Rix Centre understand 'knowledge of self' to be a cornerstone of the development of self-advocacy. A simple web platform provides the learning disabled participants with 'a virtual space for creating knowledge, and sharing their experiences and views of work and life with others' (Kwiatkowska et al, 2012:363). Of particular interest to this research

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<sup>10</sup> For more information about the Rix Centre see <http://rixresearchandmedia.org>

enquiry is the way in which digital media in the form of film, audio, photos and text can be uploaded to the virtual space and demonstrate its interrelationship. This is a key advantage of the digital age where 'we can show the relationship of any number of different types of information, and we are not limited by different formats. They can be combined to build context' (Schneider, 2014:26). A long-term collaborative partnership between The Rix Centre and children and adults with learning disabilities in the UK and internationally has led to the development of accessible multi-media tools that serve to 'genuinely capture the voice, skills, aspirations and needs of the individual ([rixmedia.org/portfolio/what-is-a-wiki/](http://rixmedia.org/portfolio/what-is-a-wiki/) accessed January 2015). The Rix 'wiki' is described as a 'web-based tool that can be used to support education, health and planning for people with special educational needs' via a 'simple, accessible and easy-to-build personal website'. The design of the Rix wiki naturally reflects the methodological design of this research enquiry; it is non-linear, has multiple entryways, can be co-constructed and is inclusive and accessible. As such, its potential use and application as a collaborative and web-based record of the research journey and as a co-constructed story carrier for the resulting individual participant narratives, helped shape the research methodology. This was achieved because the nature of its design created opportunities for shared interpretation and the development of dialogic relationships. In addition the 'life story' and one's participation and engagement in it was organic and open to change and growth<sup>11</sup>.

### 3.6.3 Working with objects and materials

As an interesting counter-point to the concept that we frame ourselves in narrative, Miller's (2010:4) research, "Stuff", proposes that 'the best way to understand, convey, and appreciate our humanity is through attention to our fundamental materiality'. In considering how this approach might be a route in to developing a participatory methodology within this research enquiry, it became essential to include opportunities for sensory engagement with the personal archives. Inspiration for this approach was drawn from the work of Bell

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<sup>11</sup> The Rix wiki offered the participant families ownership of the sites once the research study was complete, and the freedom to add to, edit or delete elements of the individual stories as they saw fit.

sisters who found meanings and memories in objects as they sorted through the 'stuff' accumulated in their family home when it was put in to storage as a consequence of their mother's move to supported housing. Working in a 'silence of love and familiarity' (Bell and Bell, 2012:65), the sisters spent time in the storage space with the family archive each choosing a collection of personal 'treasures'. Feeling as though their job had failed to reach a satisfactory conclusion, the sisters chose to spend several days thinking about and engaging with memories of their chosen objects.

Objects can be sensed. They can be touched and smelled, picked up and put down, over and over again. These objects have been the vehicles to our memories of family and of growing up. (Bell and Bell, 2012:68)

Here we see that memories and remembering can be triggered through the senses, which may well prove more accessible to people with PMLD (Grace, 2015). Memories can be powerfully represented through sensory stimulation as 'when you taste or smell something from your past that was associated with a significant event, you immediately recall the visual and auditory images as well' (Grove, 2014:30). The sensory stimulation within story work 'supports the creation of memories', further reinforced through consistent delivery and repetition (Grace, 2015:58).

Established by Chris Fuller in 1993, 'Bag Books'<sup>12</sup> are described as sensory enhanced stories, which have been specifically developed for people with PMLD. The stories are short - often limited to ten lines of prose - and each part of the story is linked to a sensory stimulation. Sensory stimulation is found to support both the creation of memories and narrative coherence (Grace, 2015). In an evaluation of Bag Books, it was found that the multisensory stories were useful in 'the development of turn taking and anticipation, as well as with regard to remembering' and were viewed as 'an important tool to support social opportunities and interaction' (Preece and Zhao, 2014: 15). Sensory storytelling has been adapted to tell personal stories that support people with PMLD to deal with life events from the past and to prepare for the future (Lambe and Hogg, 2013). According to Grace (2015:67) sensory stimuli can be used by those who

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<sup>12</sup> To find out more about the charity Bag Books: <http://www.bagbooks.org>

are nonverbal to 'organise information', therefore supports reflection and preparation.

It is natural that someone with profound disabilities will find unfamiliar circumstances or experiences distressing. If they are not helped to overcome this distress they can end up leading lives where their access to new sensory experiences is limited. Sharing a range of sensory experiences within the safety of the storytelling space - in a location where the individual feels secure and in a predictable and consistent manner - can help people to become accustomed to new experiences. (Grace, 2015:44)

The charity '*PAMIS*'<sup>13</sup> was set up in 1992 and works in partnership with people with PMLD and their families and carers and interested professionals and has adapted Fuller's approach to produce personalised multisensory stories that were created collaboratively with parents, carers and teachers and were individually tailored to the needs of the child. The 'Real Lives: Real Stories' project concluded that over time the stories 'encouraged recognition and anticipation behaviour' and could be used as an 'effective learning tool' (PAMIS, 2002). As a narrative approach that is tailored to the individual, it is necessary to appreciate and identify the sensory preferences and abilities of the story experiencer for this approach to be effective and pleasurable (Grace, 2015:83).

In the context of life story work, memory boxes can also provide an accessible route to memory through a 'more sensory enhanced experience' (Hewitt, 2006:60). Memory boxes can be a particularly appropriate narrative approach for people who are visually impaired and can contain any objects that are personally significant (Hewitt, 2006:60). Sensory ethnographer Pink (2015) would urge researchers to delve further into the materiality of the lives of participants, and to embrace the 'multisensoriality' of the place in which research takes place, as:

It involves unanticipated smells, tastes, sounds and textures, and unexpected ways of comprehending them. This leads to similarly unanticipated moments of realisation. (2015:51)

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<sup>13</sup> For more information about PAMIS: <http://www.pamis.org.uk>

The suggestion here that we can encounter new ways of understanding through engaging with the senses further extends the potential for participatory practice. The personal archives, including materials from a range of past experiences offered potential for touch, smell, vision and sound, not simply a box of written materials to be worked through. As researcher I was not able to anticipate what those contents would mean to the disabled participants any more than I could anticipate what they might reveal to me. Pink (2015:50) encourages the ethnographer to 'occupy similar, parallel or related places' to the lives of those we wish to understand. This endeavour, Pink suggests, requires 'a personal engagement and embodied knowing'.

### 3.6.4 Embodied stories - working with the body

In order to appreciate and to develop opportunities for participatory life story practice for people with PMLD, it appeared necessary to observe the way in which the body is used in communication. This observation is not reserved for the disabled participant in isolation, but includes the non-verbal interplay between them and another person. Goode (1994:63) noted in his observations of a mother and her profoundly disabled daughter, that watching them communicating together was 'artful, ballet-like in precision, and uncannily accurate'. Goode suggests that the communication processes that he was able to observe within the family home are unlikely to 'travel well' and that they required researchers to 'listen and observe with even greater vigilance' (p.86). Goode concluded that in order to understand the children in his research 'the answers to the most important questions are found in the conversation with our bodies, and not in any text' (p.115). Goode argued in favour of using video to capture what he described as 'nonformal-language-related bodily expressions' (p.194) for two reasons; firstly to make a recording of the event itself, and secondly to 'destroy the unremarkability and mundanity of everyday events and leave in its stead an unfamiliar and new world with previously unnoticed features' (p.156).

A further approach for gaining access to the non-verbal experiences of people with PMLD is in being alongside them in their day-to-day activities so as to share those experiences with them. As Pink (2015:68) explains, 'the idea

behind this sensory ethnography is not so much to study other people's sensory values and behaviours, but to collaborate with them to explore and identify these'. Inspired by Pink's approach to ethnography, Woolfson (2014:15) discovered that by going to certain places with her narrators she was able to 'grasp the most profound type of knowledge: that which cannot be spoken at all'.

It was often during these visits to the special places, in the embodied acts of walking, digging, handling, talking that I received the most relevant information not only about the past, but about the narrators' current lives. (2014:20)

Pink (2015:95) proposes a reframing of these participant-observation type approaches, which take notice of the multi-sensory environments, archives and activities that are integral to ethnography, as 'a participatory practice, in which learning is embodied, emplaced, sensorial and empathic, rather than observational'. She argues for these shared moments to be conceptualised as 'research encounters'. Another type of encounter in this developing methodology involved cementing the contributions of those in the circles of support firmly into their roles as experts.

### 3.7 Drawing on the expertise of allies: asking questions

Having explored the potential of archival sources, and understood the necessity for being alongside the participants in their everyday lives, the methodological discussion now turns to the interview. I refer in this instance to the on-going conversational 'encounters' with those in the participants' circles of support and the opportunity to extend the net of expert knowledge beyond those in paid supporting roles to reach family and friends. In making time to request on-going clarifications and alternative interpretations of communication repertoires, it was anticipated that this approach would further triangulate and verify my growing understanding. In this way it would be possible to welcome multiple viewpoints and establish 'dialogical relationships, both internal and external with other voices' (Loots et al, 2013:109). Rather than following a formal interview procedure, I wished to create a collaborative, conversational dialogue, which enabled the allies as experts, and myself, as researcher, to discuss the

alternative interpretations of the research 'encounters' in an open and non-judgmental manner. In this sense I planned to adopt 'mundane interactions' that included 'asking questions and following up on various things the interviewees raise and allowing them the space to talk' (Rapley, 2004:25).

### 3.8 Stitching together a patchwork of approaches

The construction of this developing research methodology is drawn from many places; the life history materials contained in personal archives, the visual images, objects and materiality of the everyday, the experiences that are found in embodied activity and movement and interaction and the spoken stories that are made through verbal dialogue. Drawing on multiple methodologies, the researcher adopts the role of what Claude Levi-Strauss described as 'bricoleur' (1966).

The term 'bricoleur' has been translated and interpreted differently by various researchers. Denzin and Lincoln (2003:5) translate the term 'bricoleur' as 'a maker of quilts'; as an inventive and creative researcher who is able to draw on a range of methods - a description that Denzin and Lincoln (1998:49) imply has its focus on the researcher's 'inventiveness, resourcefulness and imaginativeness'. Crotty (1998:51) understands the role of the bricoleur as one of 're-vision' rather than invention: 'casting aside the purposes which they once bore and for which they were once designed and divining very different purposes that they may now serve in new settings'.

This latter interpretation of the term fits with my attempt to amalgamate a number of different methodological approaches that, although originally designed for one purpose, could be utilised in different ways to serve this research inquiry. In addition, the emphasis on recycling, rearranging and reconfiguring reflects the intention to examine the life stories that already exist in the participants' archives and re-present them in such a way that they are made accessible and amenable to participatory activity.



### 3.9 Some practical influences - ethical approval

Permission to begin the research fieldwork was required from the Social Care Research Ethics Committee due to the 'vulnerable adult' status of the participants whose experience was central to the research. As people with PMLD labels, they were considered potentially unable to consent independently to participate and were subject to the research protocols of an ethical body higher than that of University level. Progress in the development of a research methodology was made tentatively, but with a degree of urgency as dictated by the externally imposed timetable of the Social Care Research Ethics Committee (SCREC) from whom ethical approval was required under the provisions of the Mental Capacity Act 2005. It could be argued that in a time limited three-year funded PhD studentship, the requirement to have SCREC approval for a research proposal puts pressure on inexperienced researchers to define and fix methodological approaches at an early stage in the process. I consider the requirement to gain the approval of the SCREC to have had an impact on my research design because the process exerted external pressure to agree the methodological approaches within a tight time frame. This situation was exacerbated by the methodologically driven decision to spend an extended period of time with the participants and their circles of support.

The development and fixing of the methodology was no doubt influenced by time constraints, but fortunately as a first-time applicant I was not put off by previous experience of having made an application to an ethics committee. It would appear that 'tighter regulation of the UK Research Governance Framework' combined with the introduction of the Mental Capacity Act 2005 (MCA) has 'increased the complexity of ethical approval processes' (Boxall and Ralph, 2010:173). Consequently the process of making applications to ethical committees has the potential to discourage researchers from engaging people who come under the remit of the MCA, thus further excluding them from opportunities to participate, which creates an additional barrier to participatory research according to Nind and Vinha (2013:13), who state 'what we will not allow to happen is that because of the fears of ethics committees these people's lives get, or continue to be hidden'. Clearly, this is not acceptable.

Additionally the SCREC places an onus on those involving profoundly disabled adults in research to state in advance the potential benefits and burdens of the proposed research, many of which it is not possible to anticipate. Boxall and Ralph (2010:174) therefore emphasise the responsibility of those seeking ethical approval to 'highlight possible positive consequences'. According to Simmons and Watson (2014b), researchers are unsure about researching with people with PMLD due to the lack of methodological tools. This was a position I shared, and it could be argued that anxiety about ethical procedures combined with the time constraints of a three-year studentship have the potential to deter those who might otherwise pursue research in this area - a situation which, according to Boxall and Ralph (2010:174), 'may be viewed as part of a wider pattern of exclusion'.

Collaborative research approaches developed in the interests of people with PMLD imply an ethical approach, which according to Pink (2015:68) 'means engaging the subjects of the research as participants in the project rather than as the objects of an experiment'. From a broader ethical perspective this methodology has been developed within a post-modern and self-conscious position, which Plummer (2001:228) describes as 'full of fragmentations, risks, collapsing of grand narratives'. Although collaborative in nature it is necessary for me to own my position of authority as the project lead while all the time remaining sensitive to the status afforded that authority.

The human sciences need to be made human. The potential harm and damage, the sheer intrusiveness into someone else's life, the barefaced cheek to believe that one can simply tell another's story, the frequent arrogance of 'colonizing' their world view - all this needs to be considered. (Plummer, 2001:225)

And it is, in effect, all of the above to which the ethics committees hold us to account.

### 3.10 Models of Analysis

As the methodology was developed within its ethnographic and narrative frame, it became clear that the proposed research encounters would produce a great

deal of written, visual and sensory material, all of which would require some form of analysis. Bogdan and Taylor (1975) describe analysis as 'systematic interpretation':

[D]ata analysis refers to a process which entails an effort to formally identify themes and to construct hypotheses (ideas) as they are suggested by the data and an attempt to demonstrate support for those themes and hypotheses. (1975:79)

A description further supported by Riessman:

Theorising across a number of cases by identifying common thematic elements across research participants, the events they report, and the actions they take is an established tradition with a long history in qualitative inquiry. (Reissman, 2008:74)

However, Riessman (2008:53), distinguishing between grounded theory and narrative in her understanding of thematic analysis methods, states that 'narrative scholars keep a story intact by theorising from the case', as opposed to 'across cases'. This approach fits with the person-centred approach intended in my research and with the anticipated difficulty of interpreting the idiosyncratic and non-verbal repertoires of communication of individual participants.

Rather than a single stage in a 'linear process', and fitting within the frame of 'action research', O'Reilly (2009:13) describes ethnographic analysis as 'an iterative phase in a spiral'. In this context the analysis is ongoing throughout as a 'reflexive process':

[A]nalysis is so tangled up with every stage of the research process that it is difficult to talk of an analysis phase. Rather than proceeding in a linear fashion, it is far more likely that the ethnographer will progress as in a spiral, moving forward from idea to theory to design to data collection to findings, analyses, and back to theory. (O'Reilly, 2009:15)

Braun and Clarke (2006:21) argue that thematic analysis is a theoretically free and useful research tool. In their list of the multiple advantages of thematic analysis they include its flexibility and accessibility, the relative ease with which it can be learnt and used, the appropriateness of it as a method for collaborative, participatory research and its potential for revealing 'unanticipated

insights'. Reinforcing the non-linear nature of the method, Braun and Clarke (2006:93) in introducing their six phases of thematic analysis (see below), caution that rather than moving from one phase to the next, 'it is a more *recursive* process, where you move back and forth as needed, throughout the phases'.

**Table 1: Phases of Thematic Analysis**

Phase	Description of the process
1. Familiarising yourself with your data:	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.
2. Generating initial codes:	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3. Searching for themes:	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes:	Checking in the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis.
5. Defining and naming themes:	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells; generating clear definitions and names for each theme.
6. Producing the report:	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

Table1: Phases of Thematic Analysis (Braun and Clarke 2006:16)

As with other elements of the methodology the analysis of materials that are found or generated during the fieldwork phase of the research do not sit in an epistemological vacuum and it is necessary to take in to account their 'social and cultural contextual aspects' (Hyden and Antelius, 2011:606). Here I came up against the complexity of sharing interpretations of research data with research participants. Corinne Squire (2013:66) suggests that in order to avoid over-interpretation of materials we need to read 'from many angles' and that we must 'justify' our interpretations to participants, but that 'there will always be material that lies beyond the realm of our interpretation' because of the position we hold.

While the 'recursive' and 'iterative-inductive' process of analysis was made available to those in the profoundly disabled participants' circles of support to be challenged or agreed with, it was doubtful that this process could be made accessible to the profoundly disabled participants themselves. In their methodological review Nind and Vinha (2013) found that including people with learning disabilities on the 'analysis of data is less well developed and less transparent' (Nind, 2011). I am not aware of any research analysis that has successfully included people with PMLD as active participants. However, the intention remained that they would be invited to participate in, and would no doubt inform, the analysis process in creative and innovative ways as the fieldwork unfolded.

In the spirit of the bricoleur I visualised the process of analysis as one of unpicking a garment of clothing and in so doing winning an understanding of how it was made and how its component parts could be re-stitched to create something new. Working alongside the research participants day-to-day afforded opportunities to develop tailor-made participatory opportunities, repeatedly trying things on for size and making further adjustments. By untangling the complexities of the research encounters as they presented in their multiple forms, the intention was to make visible to all the research participants what Goode (1994:156) described as the 'unremarkability and mundanity of everyday events' so that they could be reassembled and re-presented in response to the research inquiry.

## Conclusion

In this chapter I have sought to clarify why I approached the research in the way that I did. As I explained, there is a danger that people with PMLD are further marginalised because we as researchers lack the skills and the confidence to do research alongside them. By drawing on the experience of those researchers who have made significant contributions to the field and working closely with the families of the profoundly disabled participants, a methodology was created to enable me to address the research questions. As the extended fieldwork phase approached, I found myself holding many 'unknowns' about what lay ahead, not least whether the participants whose families had

expressed an interest in taking part would indeed take part once they were better informed about the benefits and burdens involved, and in addition, whether having agreed to participate they would stay the course. Consequently, there was a need to adopt an exploratory and creatively open stance throughout the fieldwork and hold the enquiry lightly. The next chapter outlines how the methodological approaches described in this chapter shaped the method in practice. The chapter concludes by reflecting on that process.

## Chapter 4

### Research method in practice

#### Introduction

The previous chapter discussed the development of a mix of qualitative methods drawn from ethnography and life history research all of which informed how I approached my research design. In this chapter, I turn to the specific research methods and processes I developed in order to address my research questions. The methods used also had to be responsive to the needs of all the participants, so a degree of flexibility, creativity and spontaneity was required. In this chapter I cover the following aspects of my research method: (1) the ethical approval process in practice; (2) Phase One of the research fieldwork - developing communication baselines; (3) Phase Two of the research fieldwork - facilitating participatory life story work; and (4) Reflections on the research method.

#### 4.1 Seeking ethical approval

Because my research necessitated the involvement of people who may not have capacity to consent, it required ethical approval from the Social Care Research Ethics Committee<sup>14</sup> (SCREC). Within a few short months of enrolment I was advised to begin the application. The form was such that there was no place for ambiguity and I remember very clearly the daunting task of finding the information I needed to complete it. Every question required justification: Was it essential to undertake this research with these particular people? What was the balance of benefit versus burden? Boxall and Ralph (2010:176) wrote about their concern that while the intentions of the Research Governance Framework and the Mental Capacity Act 2005 are to 'offer protection to vulnerable research participants', their innate 'conservatism' may equally lead to 'apprehension about ('untested') creative methodologies'. The

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<sup>14</sup> SCREC reviews social care research that involves people lacking capacity in England and Wales and requires approval under the Mental Capacity Act 2005. The Social Care REC is recognised by the Secretary of State as an Appropriate Body for this purpose.

paper was written in anticipation of potential difficulties with ethics committees and encouraged researchers to report the beneficial outcomes of using creative methods with people with PMLD, hence their discussion of the 'photo album project' (2010:176). Boxall and Ralph (2010:177) talk candidly about the 'differing opinions and messiness of decisions', the 'ambiguities and multiple interpretations of the communications and behaviours' of nonverbal adults and the 'guesswork involved in working out whether or not they wished to participate'. Their observations are refreshingly honest. However, when composing the detailed responses to the scores of questions on the ethical application form, those messy realities have to be tidied up and a confidence found in its place.

The application to SCREC forced me to think very deeply about the purpose, detailed minutiae and day-to-day plan of the proposed fieldwork. It became a step-by-step guide for both me and for the families I was to work with, which in retrospect was an extremely useful aide memoir. The intensive and long-term involvement with the families could have become very confused but for the plans that I had written up for the ethics committee's scrutiny. In fact the body of this chapter is based on an elaboration of the bare bones of that application form and copies of the original recruitment letter, consent forms and information sheets can be found in the Appendix (Appendices: 1-11). Once the form had been submitted I was invited to attend a full SCREC meeting (comprising eleven committee members and the SCREC coordinator) in which the nuts and bolts of my proposal were thoroughly discussed and debated and I was asked to defend my proposal and to make several amendments to paperwork to secure their approval. Approval was subsequently received in writing in September 2014 (Appendix: 1b) and university ethical approval was sought and received in October 2014 (Appendix: 1c). The following sections report the ethics process and include suggestions and advice received from that committee meeting regarding (i) recruitment; (ii) consent; (iii) risks, burdens and benefits; (iv) safety, dignity and respect; and (v) confidentiality.



#### 4.1.1 Recruitment of the Research Participants

I knew the mothers of the three families who participated in the research project in a professional context because of their involvement in studies that I was involved in that examined the experience of mothers raising profoundly disabled children. I anticipated that this would be advantageous because prior work when seeking the support of families in life story work with people with learning disabilities had frequently been used as an opportunity for them to tell their own stories, an opportunity that they had not previously been given. The PMLD description of their adult children fulfilled the principle criteria for inclusion in the project. SCREC were keen to establish that the proposed research was compliant with the Mental Capacity Act (2005), and that it was connected to the impairing condition affecting persons lacking capacity. The key participants, two women and one man, were between twenty-six and thirty-one years of age, of white British ethnic origin and all lived in their family homes on the South Coast of England.

The families had heard about the present proposal and expressed an interest in becoming involved. As such they were not under any undue influence to participate in the project and volunteered on the basis that the project would benefit their adult children and families as a whole. They were aware of my extensive academic and practice-based knowledge of facilitating life story work with vulnerable adults. It was understood that the three families would not be a representative sample, but would provide an opportunity to explore the potential of the methodological approaches outlined.

As the fieldwork involved spending several hours a week in the participants' homes for up to eighteen months, it seemed preferable to have established research relationships with the families. Although I had developed research relationships with the mothers I did not know other people in the key participants' circles of support or the key participants themselves. Although the mothers of the families had expressed an interest in principle, once ethical approval had been given they were approached through the formal procedure of a recruitment letter and information sheet (Appendix: 5, 8). This process allowed them the opportunity to fully consider the burdens, risks and benefits of

the project prior to making an informed decision about participation. Having decided to take part in the project they were free to withdraw at any time without given a reason for doing so. All those who participated in the research agreed to consent in their own right. The participation of the individuals with PMLD was agreed to by either personal or nominated consultees and will be discussed in more depth in the next section.

#### 4.1.2 Consent

A total number of twenty-seven people participated in the different stages of the project. Those in the circles of support included parents, siblings, family friends and paid support workers. They were all informed through the appropriate information sheets about the purpose and nature of the research and what it would involve, and were invited to consent on this basis. The Social Care Research Ethics Committee (SCREC) were concerned that paid support workers would feel an obligation to participate. They requested that I made clear to the families that it was up to the support workers to decide to participate and if they chose not to, fieldwork visits would be arranged around them.

The Mental Capacity Act 2005 states that we must always assume capacity and every effort was made to communicate the research design with the participants, but this was - in practice - a very complex undertaking. Reference was made to the Mental Capacity Act's requirements and safeguards (MCA, 2005:17-20, Sections 32 and 33) and Chapter 11 of the Mental Capacity Act Code of Conduct regarding this matter. Efforts were made to make the information about the project accessible, including using pictures, symbols, aural and visual cues. It was decided that the three participants with PMLD descriptions did not have the capacity to comprehend the information about the study as a whole, or the implications of their participation, and therefore a decision to participate was made on their behalf.

Because we came to understand that the key participants lacked the capacity to formally consent to the research project in its entirety 'consultees' took on the role to decide what their wishes and feelings might be if they had capacity (Appendices: 6a, 6b, 7a, 7b). The SCREC suggested that because participating

in the project was in the general interests of the families concerned, it would be preferable for someone outside of the immediate family to act as 'nominated consultee' or a family member who was not directly involved to act as a 'personal consultee'. This was successfully achieved in the case of one of the key participants when a member of her board of trustees took on the role. All three families did consider the matter carefully and the parents of the other key participants felt that they were best placed to act as 'personal consultees'. Because SCREC had raised the issue as potential conflict of interest it was discussed at this stage. The families welcomed the opportunity to reflect on their responsibility regarding consultee status. Identifying this as an issue to be considered was received positively by the families and myself as it provided an additional level of reflection and consideration.

While a decision to participate in the project could not be made independently by the individuals with PMLD, it was agreed that they would be able to demonstrate their willingness to take part on a day-to-day basis, and this would guide my practice. Those that knew the participants well agreed to advise me in this matter, thus maintaining an active and continuous process of consent. The research was dependent on free and motivated involvement of the key participants and it would not have been in their interests or the integrity of the research as a whole to continue should they have ceased to demonstrate this. The key participants were free to pause or withdraw from the study for hours, days and weeks at a time if required. If at any time the research itself was understood to be causing discomfort of any description, the families concerned would be withdrawn immediately and permanently from the study.

#### 4.1.3 Risks, burdens and benefits

As the study took place in the family homes over an eighteen-month period, there was a risk that it would be intrusive and have a negative impact on the day-to-day wellbeing of the key participants. To minimize this potential risk the project was designed in distinct stages each using different methods. Within each stage additional time was factored in to allow for planned or unplanned breaks. For example, the first two-month stage took place at the family home for an average of three hours a week, analysing personal archival data. This was

followed by a two-month period of participatory practice, or ethnographic observation, which took place either in the family home or wherever the key participant was on that occasion. The timings and length of my visits were agreed with the families in advance and were designed to fit around and respect their routines at all times. Even within this flexible time-scale, the completion of planned work was frequently put under strain. Unforeseen events that included the illness and death of my father, the death of one of the disabled participant's grandfathers, general illnesses and the vagaries of the public transport system all added to the temporal mix and confirmed my understanding that there is never enough time to do everything that you intend when undertaking participatory collaborative research.

It was anticipated that the benefits would outweigh any potential risks or burdens. It was important to emphasise and make explicit what those benefits might be (Boxall and Ralph, 2010). For example, once identified, I suggested the communication repertoires would be of practical use to the participants in a variety of contexts. The research procedures were designed to be transparent and participatory and as such had the potential to create opportunities for skills and practice development. Evidence from previous research in a similar area (Goode, 1994) demonstrated an increase in interest and attention to communication with profoundly disabled people as a direct result of ethnographic practice. It was also anticipated that the facilitated life story project would be of use to the profoundly disabled participants as a way for them to explain themselves and their experiences to those around them. It was hoped therefore that there would be benefits to all participants beyond the life of the project. SCREC concluded that while the fieldwork was potentially intrusive, the benefits outweighed the risks (Appendix: 1b).

#### 4.1.4 Safety, dignity and respect

As the fieldwork was located in family homes there was a possibility that I would witness poor or even abusive practice. As part of securing the ethical approval from the SCREC, it was necessary to include in the information sheets and in a statement to the committee what action I would take and who I would contact in this event. SCREC were supportive in this matter, supplying me with a form of

words that could be used or adapted for inclusion in the information sheets. I was also asked for confirmation about exactly what I would do should any safeguarding issues arise and to supply the contact details of local safeguarding boards (Appendix: 4). This was a difficult subject to raise with the families and support workers and I was grateful to SCREC for making it a requirement that led to discussions at the recruitment stage.

I was also asked, as a condition of approval, to state in writing that I would stop recording if, at any time, the dignity of the disabled participants was compromised as a result of personal care requirements or ill health (Appendix: 3).

#### 4.1.5 Confidentiality

Initially it was intended that all participants would have the option of using their own names in publications following the completion of the project. However, due to the small number of participants the identification of one or more had the potential to identify those who wished to remain anonymous. Therefore it was decided that all publications would use pseudonyms. The families of the key participants chose pseudonyms for them and they are otherwise identified as the 'key participants'. All members of their circles are known by their relationship to the key participant, e.g. mother, support worker, sister and so on. At the time of application to SCREC I had not anticipated the implications this would have regarding dissemination. When sharing the research practice at conferences or seminars, the identities of the participants must remain confidential and, given the visual nature of the majority of the materials gathered, this limits accessibility of the research findings. Verbal descriptions of the observations and practices fall short of the actual events, because it is 'difficult, if not impossible, to describe the richness and dynamism of even the simplest human interaction in words alone' (Nind and Hewett, 2005:42). It is important to emphasise that anonymity was not an issue that SCREC required, but rather a position I assumed they would insist on. Therefore it was not debated at the committee meeting, but rather understood as given. Although not being at liberty to share footage that identifies the key participants, I am on balance glad that their personal stories were protected and remain private. It

may be that at some point in the future the participants are able to share our work together. In the meantime I am of the view that although this project has developed some interesting methods for extending participatory opportunities in life story work, the people who are central to the findings remain hidden.

## Summary

The first part of this chapter has outlined the way in which the methodological practices developed as required within the ethics framework, and resulted in approval to begin. Drawing on the work of Boxall and Ralph (2010), I reflected on aspects of seeking approval from SCREC. Boxall and Ralphs' article urged researchers and ethics committees to debate the benefits of involving people with PMLD in research. The paper encouraged researchers not to be deterred by tighter regulations, and ethics committees not to judge untried, creative methods conservatively. If it is agreed that we lack the methodological tools to engage people with PMLD in participatory research, the implication is that traditional methods are ineffective, and therefore there is a need to experiment with alternative methodologies. My experience of SCREC was positive in that the application process and subsequent committee meeting made necessary the thorough, well executed and justified fieldwork plan that was successfully implemented.

## 4.2 Phase 1: developing baselines of communication

The broad purpose of the first phase of the project was to develop relationships with the participants and their families and gain familiarity with their day-to-day lives, within a context of their pasts. The first phase was used to develop baselines of communication and agency for each of the participants and to gauge how the family accessed and used new media and other storytelling tools. The specific aim was to identify the individual nonverbal repertoires of communication of the three key participants. This was done in the following ways: (i) personal archives; (ii) participatory practices; (iii) conversational interviews; (iv) reflexivity; and (v) thematic analysis.

#### 4.2.1 Examination of Personal Archival Data: March-April 2015

Having spent a considerable amount of time planning the fieldwork it was with huge relief that I arrived at the homes of the three key participants in the first week of March 2015 to discover that large and diverse collections of personal, archived material had been made available by their families. The material included photos, videos and written records from a range of sources including school, college, adult services, projects, and family memorabilia. This first stage involved me spending up to six hours a week with each of the key participants and usually took place in their homes. I was guided by the families' wishes regarding how best to arrange these weekly visits, as my aim was to fit in to the rhythm of family life as much as possible to minimise disruption. During the next eight weeks the life history materials were examined to uncover and chart lifelines of the key participants with specific reference to visual and written narratives of communication. Locating this process in the participants' homes provided multiple opportunities for participation. Because I did not know what the archives contained, their exploration was a shared endeavour and the engagement of the key participants in this scrutiny acted as a reminder of the provenance of the material and thereby contributed to the respect afforded it. We were able to approach the task with genuine anticipation and playfulness, which encouraged the key participants to demonstrate their interest. Items from the archives were selected at random and without respect to chronology. The key participants chose what they would like to examine next with increasing confidence and apparent curiosity. The majority of the archives were visual, which opened up opportunities for multiple interpretations (Bell, 2009). However it was difficult for all but close relatives to furnish us with narrative accounts; although we could enjoy looking at the visual materials together, if the key participant was particularly interested in something, we were unable to frame it with story.

The sessions were filmed, photographed and written up in field notes (Appendix: 12) all of which was subject to thematic analysis (Appendix: 15). Using video to capture the actions and interactions of the key participants proved particularly useful as it enabled those who were not present to 'to assess and interpret the individual's reactions' as well as capturing 'very brief,

or small reactions to be observed' (Ware, 2004:177). To encourage discussion, a selection of filmed observations of the key participants' examining their personal archives was written up as 'vignettes' (Appendix 13: Vignettes). It was through the thematic analysis of this archived data that several areas for further inquiry emerged.

#### 4.2.2 Ethnographic Participatory Practices: May-July 2015

This stage included joining in with the everyday activities and experiences of the key participants in the study. This was intended to reveal aspects of the key participants' communication repertoires outside of the family home and with different people. What was the impact on their communication when in another environment with people who knew them in different ways - for example through creative arts or hydrotherapy? I was also curious to be alongside them and to share what they were experiencing, an ethnographic method encouraged by Pink (2015). Additionally, joining in with activities that the key participants were engaging in contemporaneously allowed for reflection regarding which aspects of their communication repertoires had changed or stayed the same over time.

Video ethnography and extensive field notes formed the key components of recording this stage (Appendix: 12). The use of video recording provided the opportunity to evidence the individual communication repertoires of the three key participants and allowed for further analysis and note-taking, thus freeing me to focus on participation. Observations of participatory practice were written up as 'vignettes' (Appendix: 13) and included in the thematic analysis.

It was interesting to note how quickly the key participants had grown accustomed to me spending a regular time with them each week as we had done in the first few months of fieldwork and how my arrival at their various regular activities during this second fieldwork activity, out of context, was met with some confusion. The irregularity of our research encounters during this time also resulted in frequent problems regarding times and rendezvous.



### 4.2.3 Conversational Interviews: August-November 2015

Information resulting from the shared examination of archived materials and participatory practices formed the basis of semi-structured conversational interviews with members of the circles of support for each key participant. SCREC were keen to receive the proposed interview guide in advance and this was used as a foundation for the interviews (Appendix: 2). Members of the circles of support who participated in this stage of the fieldwork varied, but included one or both parents, up to two siblings, between one and four support workers and one or more family friends (Appendix: 12).

The focus and timing of the interviews was specifically designed to develop a further understanding of the personal communication repertoires and life stories of each of the key participants. The conversations offered the opportunity to examine and reflect on specific aspects of communication with those who know the key participants best. Questions built on the examination of the archived material, clarified any inconsistencies and established the parameters of best communication outcomes, for example, specific qualities of relationships, environments, purposes, motivations, structures and routines which provide optimum conditions for the three key participants to employ the communication repertoires that are available to them.

The conversational interviews lasted for between 1 and 3 hours and were conducted in the family homes, in cafes or via telephone, at the interviewee's convenience. On several occasions those taking part preferred to be interviewed with others, as in the case of the four members of one of the key participant's teams. In all cases the conversational interviews were transcribed and comments or edits by the participants were included prior to thematic analysis. The intention of this fieldwork stage was to invite those with expert knowledge to challenge existing interpretations of communication repertoires and alternative viewpoints were actively welcomed.

#### 4.2.4 Reflexivity: March 2015 - April 2016

I built in time for regular reflection on the research method as the project progressed. This process acted as a routine reminder of the key aims and timescales, researcher impact and also told the story of the project as it developed. Reflexivity, a key concept within ethnography, is a term that formalises the reflective processes of the researcher and acknowledges the researcher's place within the context of their study (O'Reilly, 2009). Reflexivity through critical analysis of the research process provided a structure in which to hold the iterative-inductive nature of the inquiry. The notes taken during the entire period of fieldwork were initially written by hand in a journal before being written up on the computer and included in the analysis process.

#### 4.2.5 Thematic analysis: December 2015 - January 2016

Throughout Phase 1 iterative thematic analysis was used as a tool to explore, examine and understand the experiences of the three participants, with particular focus on communication. The analysis provided a clear route for triangulation of the data through detailed examination of the different perspectives of both found and made narratives. Thematic analysis lent itself to this specific study due to the large quantity and wide range of data both available and generated, but also because of the transparency of the method. It was important that the research design and methodology was accessible and that those contributing were able to participate actively in a dialogue about the research process, analysis and findings. The careful and methodical analysis of the various types and sources of data encouraged a nuanced, in-depth understanding of the way in which the three people with profound and multiple disabilities were communicating day-to-day.

One of the aims of the study was to adopt a research process that offered clarity, transparency and accountability and for these reasons reported previously the six phases of thematic analysis as defined by Braun and Clarke (2006) was adopted. I found Braun and Clarke's detailed description of the six key phases involved in thematic analysis particularly useful. As well as providing me with a step-by-step guide to iteratively processing across narrative

modalities, it provided a guide that could be clearly communicated to the people in the three circles of support that I was collaborating with.

Thematic analysis involved the in-depth and methodological 'reading' of visual, written and recorded material. The reading of the material, which was done manually, focused on communication in order to excavate a number of narratives and revealed chronological lifelines detailing communication milestones, use of augmentative and alternative communication tools and life events (Appendix: 15). The analysis was iterative and each stage provided building blocks for the gradual accumulation of knowledge about how each of the key participants communicated. The analysis paid attention to particular contexts within which communication took place, for example, environment, structure and routines, relationships, purpose and motivation.

Communication was coded for analysis and there was a recursive process in play as the list of applied codes grew and became more refined as more material was gathered. The final list included fifty code names (Appendix: 15). Regular updates to all participants were provided formally as summaries of findings as the study progressed and informally through conversational dialogue. Discussions about the code lists and emerging themes were encouraged, and this ongoing dialogue subjected my interpretations to rigorous reflection. Comments and reflections made by members of the key participants' circles of support were included in the analysis summaries. Additionally I discussed this process at regular supervision sessions and the critical analysis provided by my supervisors further contributed to the production of fair representation.

However the analysis of the materials stopped short of describing themes related to the psychological processes that might or might not underpin the observed behaviors of the participants. The purpose of this project was to untangle the many and various ways in which the disabled participants were communicating and how that communication was supported, in order to create and extend opportunities for participation in life story practices, rather than identify the possible, but unverifiable psychological basis at their root. The process of thematic analysis involved interrogating the data gathered in Phase One to identify codes relating to communication and was begun with the

intention of finding out how the participants employed their idiosyncratic communication repertoires. It became clear as time went on that the themes emerging fell in to four main areas (within which some codes appeared in more than one theme):

1. How the key participants communicated, broken down into sixteen codes, for example 'eye-pointing', 'vocalization' and 'embodied communication'.
2. How the key participants' communication was supported, broken down into fourteen codes, for example 'repetition', 'interpretation' and 'songs'.
3. Interpretations of personality that brought the key participants alive, broken down into eleven codes, for example 'loss', 'humour' and 'personhood'.
4. Issues relating to life story work, broken down into fourteen codes, for example 'value of life story work', 'barrier to life story work' and 'missing materials from archive'.

A record of how these emerging themes worked together was maintained through the analysis of the reflections kept in the research journal.

#### 5.2.6 Drawing on technical expertise: December 2015

A key aim of my research was to explore the potential for how new and digital media might facilitate participatory life story work and it was with this intention that a group of technically knowledgeable experts gathered at the Rix Centre at the end of the first research phase to consider the initial findings. A 'Diagnostic Sandpit' was arranged in December 2015, which brought together members of the Rix Centre team and used their technical, multi-media and communication expertise to scope ideas for potential opportunities for participatory life story work. The 'Diagnostic Sandpit' was recorded graphically (Appendix: 14) and shared with the participants. Baselines of communication capability and new or digital media were presented and the group suggested potential avenues for application in the second fieldwork phase. It became apparent in this workshop that there is a big difference between access to and affordability of new and

digital media in educational as opposed to domestic settings. It also became apparent that this small group of participants were of an age (between 27 and 32), which meant they had just missed out on many of the recent innovative advances in accessible technology. Outside of the educational environment and with limited finances or access to speech and language therapy support, the three participants I was working with appeared to have few options. In a systematic review of the use and application of advanced technology in the lives of disabled people in the UK the 'cost of both mainstream and 'specialist' devices' was found to be 'prohibitive' (Harris, 2010:427). At this point I was reminded of the need to begin where your participants are, rather than where you might wish them to be. The options for using new and digital media to enhance participatory opportunities in life story work were however thoroughly explored. The results of this workshop combined with the detailed information revealed through the thematic analysis from Phase One provided the framework on which to develop an action plan for each of the participants to engage in life story work.

#### 4.3 Phase 2 Putting what we had learnt in to practice

Phase One of my research focussed on identifying the communication repertoires and supporting structures of the three key participants. In Phase Two, the research explored how these could be used to facilitate participatory life story work. In the next section the following processes are outlined: (i) life story facilitation; and (ii) follow-up interviews and feedback.

##### 4.3.1 Life Story Facilitation: February-April 2016

The purpose of Phase 2 was to explore creative and meaningful opportunities for the key participants to use their individual repertoires of communication, communication scaffold, life story materials and individual preferences as identified in the thematic analysis (Appendix: 15) of Phase One of the research process, to engage in the research, production and sharing of their personal life histories.

Multimedia approaches were utilised in the facilitation process and the intention was for each participant to participate in the production of a multimedia life story website, using the Rix wiki (see pp58-59) – a simple and accessible web-based tool that supports personal storytelling. The resulting life story websites - called 'Memory Sites' were, in effect, co-constructed story carriers that held the key participants' narratives. It was anticipated that the end product would be of use to the individual participant, their families and paid care support staff in a variety of ways; to support choice and decision making, enhance opportunities for communicating themselves to the world, and provide insight into their past experiences and opportunities for forward planning. This phase of the project was based in the homes of the key participants where I worked with them and their families and support staff for between 2 and 4 hours a week for 3 months. A full account of the individual narratives that record this process can be found in the three Case Studies that follow this chapter.

#### 4.3.2 Follow-up interviews and feedback

Within two months of the end of the fieldwork I met with members of the key participants' circles of support. There were a number of purposes to these meetings. It felt important to spend some time with each family and find out what they had found valuable about the project and if they had been using the Memory Sites, and if so to what effect. Additionally the final visit provided me with the opportunity to formally thank the families and all the participants for their contribution to my research and bring the fieldwork to a formal close. These meetings were captured in note form and are referred to at the end of each of the Case Studies that follow this chapter.

#### 4.4. Reflections on the research method in practice

The final part of this chapter includes some reflections on the method in practice: (i) insider-outsider status; (ii) collision of past and present; (iii) opportunities to participate; (iv) the iterative dialogic process; (v) analysis in practice; (vi) accessing the past; and (vii) the benefits and values.

#### 4.4.1 Insider-outsider status

There were several key purposes to the ethnographic fieldwork. Above all I wished to develop trusting and effective working relationships with each of the participants and those who were supporting them – including family, friends and support staff. This trust developed over time and allowed us all to work effectively and honestly together to develop the project aims. The trust was achieved through different strategies. Initially I sensed that members of paid support staff were wary of me and were perhaps conscious of my outsider status. This natural concern was addressed in a number of ways. Over time we all gradually got to know each other and I shared my experience of having worked in similar roles in order to allay their self-consciousness. I was transparent in my observations and regularly printed out my notes in order to share and discuss and alter as required. By making the research process very open and explicit those in a supporting or family role were able to disagree with me and challenge my views. This further established a sense of us all being involved with a shared purpose within a non-hierarchy of expertise, a position supported by Sheehy and Nind (2005). I made sure that I kept in regular email and text contact with everyone and arrived on time and stayed for pre-agreed periods of time, thus becoming a reliable and punctual visitor.

Towards the end of the fourteen month fieldwork I began to be treated as ‘one of the team’. Many life events took place during that period. Particularly around the time of my father’s illness and death the families and support workers were incredibly supportive and kind. In some ways, as the intimacy between us all increased, I regretted losing ‘outsider’ status. It became increasingly difficult on occasions to get down to work together and complete the project. This difficulty was made apparent in a number of ways. On some occasions paid support workers used my presence to voice grievances about unrelated aspects of their working practice and I got the sense that their meeting with me was used as a sounding board to rehearse their (minor) grievances. On other occasions, towards the end of the fieldwork, support staff were keen to include me in social

arrangements and defer the planned project tasks. Although there were times when this was flattering, it became increasingly difficult to maintain 'outsider status' and complete the fieldwork. Consequently as the end of the fieldwork approached it became important to manage expectations about future contact. Fortunately the fieldwork tailed off very gradually and the visits designed to gather feedback supported this process.

My relationships with the three participants developed organically. Their initial distrust of me, and possible sensitivity to the change in atmosphere that having someone new naturally entails, eased over time as I relaxed into my role and their teams relaxed about my being there. In other words I became 'familiar' and a regular visitor who was seen to do regular activities. These relationships all became overtly accepted at the same point in the fifth week of fieldwork. Jack reached out to hold my hand, Amelie made eye contact with me and smiled, Marian got up from her armchair and came to sit next to me, resting her head on my shoulder as I read aloud from and shared photos in her school folders. It was an extraordinary week and reinforced the anticipated value of long-term ethnographic method (Goode, 1994; Simmons and Watson, 2014; Vorhaus, 2016). Once my being in their homes was accepted, the regularity of my visits maintained and developed the rapport between us.

#### 4.4.2 Collision of past and present

Secondly I wanted to understand the individual and idiosyncratic ways in which each of the participants communicated through a knowledge of their communication histories as found in the personal archives and in the present time as witnessed when accompanying them on current activities. When revisiting the participants' 'pasts' I was surprised to encounter their presents, their 'nows'. The meeting of the past in the present moment (Rothberg, 2009:3) allowed me to build up a picture of them that combined then and now in an historical context. Frequently, as we looked through old school records and educational statements, support staff commented that the participants' communication skills and interests had remained the same. Not only was I finding out about the participants' pasts, but also I was gaining insight into their presents.



#### 4.4.3 Opportunities to participate

The first phase of the research was structured in such a way as to reveal the potential possibilities for participatory life story work. What I hadn't anticipated was that the three participants would be interested and actively involved in this process. Every effort was made to encourage interest, for example through physical handling of documents, vocalizing and dramatizing written records, and so on. Their ownership of the personal archives was demonstrated in their interest in the various documents and artifacts. By remaining open to the unfolding exploration of the participants' pasts we were able to develop strategies for maximizing this unexpected level of interest. These strategies were then tested in subsequent weeks and those that worked became incorporated into the research practice. For example when Amelie's support worker noticed a slight change in her body language when she was able to hold a photo, as opposed to looking at it in an album, we began to take note of her responses, and when satisfied that this minor adjustment increased her level of interest and participation, made the holding and handling of photos and artifacts routine. In this way we were collaborating within the key premise of action research, as referred to in the previous chapter and described as 'the notion of exchanging expertise and working together in a process in which action and research are simultaneous and inseparable' (Nind, 2014:9).

#### 4.4.4 Iterative dialogic process

These insights were not the singular work of me in my role as 'researcher'. The participants guided us by indicating in subtle ways how they preferred to examine their archives, and their supporters, being tuned into noticing nuances in mood and fleeting moments of communication, voiced their observations of this. Once articulated these apparently minor adjustments to practice were noted and recreated as the weeks progressed. Thus an iterative and dialogic research process slowly revealed how the participants would prefer to participate in their story work by how they were guiding us. As for example,

when Amelie was able to hold and handle photographs she expressed her pleasure through her body movements and facial expression. The participant-practices in stage two further supported this process. The interviews reinforced and opened up, through multiple perspectives, the range of opportunities that there were for participation. In this way multiple voices (Bakhtin, 1982) and multiple entryways (Loots et al, 2013) were opened up to access a range different and unique perspectives.

The research encounters of the first phase were recorded in field notes, still photos, film and interview transcripts. I used digital cameras and sound recorders to capture the (often fleeting) moments of participatory interaction. With the intention of creating opportunities for convenient and free access to this iteratively developing body of raw data, I set up a website for each of the participants. The sites were confidential and password-protected and the circles of support could access at any time. The websites employed the RIX wiki model as identified in the previous two chapters and reflected the different stages of the fieldwork as illustrated in this image of Amelie’s (Phase 1) site:



Figure 1: Amelie’s wiki site (Phase 1)

- ‘About Me’ included information relating to life story timelines and was illustrated by photos from the family albums. These photos were supported by voice-overs from family, friends and support workers.

- 'My Archive' used photos of personal archive materials and films of the participants interacting with them and provided a fuller, more nuanced picture of their stories.
- 'Everyday Agency' used photos and films of the participants illustrating how they interacted with people, places and objects in their daily lives.
- 'My Circle' introduced the people who matter to the participants- their families, friends and support workers and was illustrated by photos and sound extracts from the conversational interviews.
- 'My Story' was planned as the wiki section that would trace the process of creating the participant's individual story and record how opportunities for participation were created, tried and tested. However new wikis, described as 'memory sites', were set up as story carriers to record this process.
- The last section, 'Other Stuff', remained open for use by the families in whatever way they found most useful.

#### 4.4.5 Collaborative analysis

In this way a picture of each of the key participant's life story, communication repertoire and communication support structure began to develop. A vast amount of material was gathered, of which only a fragment found its place on the individual wiki sites. Those films that were uploaded to the sites were open to interpretation by all of us and this enabled evidence to be scrutinized collectively and thus continued the effort to establish transparent and collaborative research practices. I found that although this information was available for review at any time the supporters demonstrated minimal attention to the wiki sites in my absence. I think this was due to the busy-ness of their day-to-day lives and the limited time available for reflection. To encourage dialogue I decided to incorporate time for sharing and challenging interpretations of the wiki sites into the structured weekly sessions. In this way the key participants were also included in the process. Through the detailed

accounts of the participants' individual communication repertoires and an understanding of how their communication is supported we found that creating opportunities to participate in life story work was no different from creating opportunities to participate in other aspects of every day living.

The thematic analysis revealed four emergent themes, which were kept deliberately simple to encourage discussion. The four themes broadly included: the communication repertoires of each key participant; the support structures that supported those individual repertoires; the kind of people they are; and life story materials and processes (Appendix: 15). A close analysis of the communication capabilities and the external structures that supported that communication allowed these complex operations to become visible. It was found that neither the individual capabilities of the key participants, nor the structure supporting that communication was effective in isolation. It was necessary to appreciate both the internal and external communication operations in order to create bespoke opportunities for participation. It was in the overlap between these two areas when combined with access to life story materials that participatory opportunities were located.

#### 4.4.6 Access to the past in the present

Having established that the key participants all used a range of very effective nonverbal repertoires to communicate their preferences, needs and wants in the present time, or within a very short time-scale, it also became apparent that this capability did not extend to 'telling' us about experiences that lay outside of 'now'. Thus the first phase of the fieldwork established a clear insight, as anticipated in the research literature. People with PMLD are not able to tell us their stories (Bellamy et al, 2010). Their stories can be found in their extensive personal archives and in their artefacts and in their relationships to people who know and understand them well, but they are not sufficiently sophisticated communicators to do this independently.

What became apparent throughout the fieldwork was the understanding that the participants were dependent on those around them to interpret their communication and meet their needs (Lacey, 1996; Grove, 2000; Larkin, 2007).

The communication, being limited and subject to interpretation was, on the whole, focussed on meeting their immediate needs in the present time. Needs that were frequently expressed and communicated included for example hunger, thirst, pain, boredom, and personal care requirements. Because these needs were commonly expressed throughout the day those in the participants' circles of support developed short cuts to respond quickly and effectively and interpret communication. The key participants' supporters often had a range of potential interpretations of non-verbal communications, which they checked through routinely. Typical responses to a communication would be 'Are you hungry? Are you thirsty?' and so on.

It became clear that the 'past' and opportunities for reminiscence and shared remembering was too broad and open a subject to be offered as part of this range of options. However, remembering is a contemporaneous activity- exploring what has happened in the past in the present moment- and by making each of the key participants' pasts available and accessible in the present moment further opportunities for them to participate in life story work were created. In the final part of each of the key participant's individual narrative journeys, presented as case studies in the following chapter, the ways in which this was achieved is addressed.

#### 4.4.7 Benefits and values

The task of the second phase of the fieldwork was to work with the established baselines to develop a range of opportunities for each participant to participate in their stories through making choices regarding how they might access them, which story they might prefer to experience, and who they might share them with.

Having built a knowledge base of each of the key participants' life stories, communication strengths and the ways in which their communication was supported, it was agreed that new Rix wiki platforms would be set up to specifically present co-curated 'memory sites'. These new sites were developed collaboratively in the second phase of the fieldwork to meet the accessibility

needs and participatory opportunities of the individual participants and will be discussed fully in the next chapter.

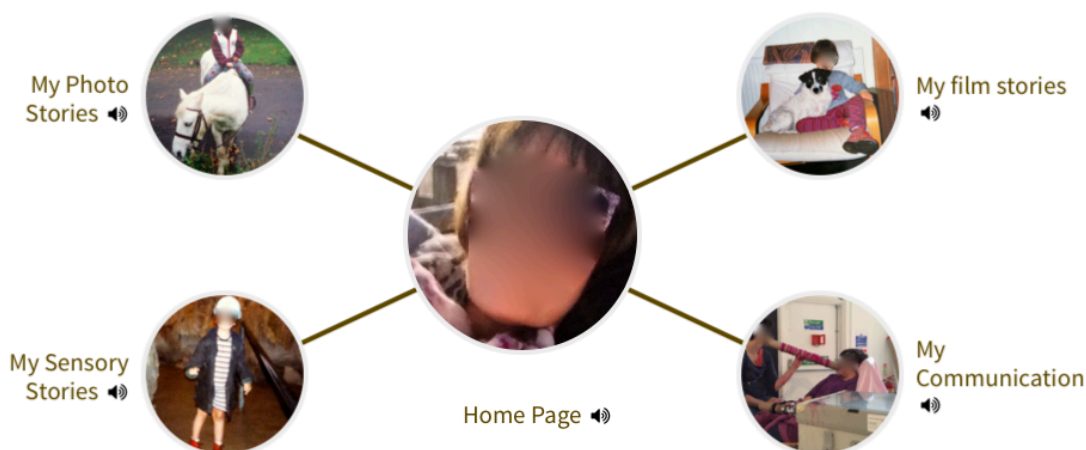


Figure 2: Amelie's Memory Site (Phase 2)

## Conclusion

This chapter reported the practical application of the methods used to identify and extend the opportunities for people with PMLD to participate in life story work. The detail of the successful application for ethical approval to SCREC was outlined, as was the choice and application of thematic analysis. Phases 1 and 2 of the fieldwork were described and some of the findings and challenges reflected on. In the next chapter there follow three case studies in which Jack, Amelie and Marian are introduced through: (i) their stories; (ii) their communication capabilities; (iii) how their communication is supported; and (iv) opportunities for participatory life story work. Finally, (v) the benefits and values of participatory life story work are explored - both in relation to life story work per se - and in other aspects of the participants' lives, reaching beyond the project scope.

There were many choices regarding the presentation of the findings that emerged in response to this research enquiry and it was finally decided that the individual narratives should remain in tact as case studies. This decision came from a desire to maintain clarity and comprehension for the reader, to reinforce

the person-centred, iterative methodology employed and specifically to honour the individual stories of each key participant. As Simons asserts:

Case studies written in accessible language, including vignettes and cameos of people in the case, direct observation of events, incidents and settings, allows audiences of case study reports to vicariously experience what was observed and utilize their tacit knowledge in understanding its significance. (Simons, 2009:23)

As discussed in chapter 3, the case study approach is a way to capture, what Simmons and Watson (2014b:199) describe as 'individuality in order to tell individual stories'. The case studies that follow aim to emulate Simons (2009:23) and 'document multiple perspectives, explore contested viewpoints, demonstrate the influence of key actors and interactions between them in telling a story'. The case studies are presented without reference to research literature. This was a deliberate decision and designed to improve access to the individual narratives and research methods. As indicated in the previous chapter, the limited papers that do research the lives of people with PMLD reveal little of their methodology and lack transparency, thus making it virtually impossible for such work to be 'judged, replicated and learnt from' (Nind and Vinha, 2013:7). The discussion chapter that follows the three case studies cuts across the individual narratives and brings them in to conversation with each other and with the research literature.

# Case Study 1

## Jack

### Introduction

My weekly arrival at Jack's house coincides with a daily readjustment in his parents' lives. He attends a local day service for people with learning disabilities and is out of the house between nine and three-thirty five days a week. On a typical visit I knock on their front door a short time before Jack gets home and his parents are busy completing their daytime commitments and preparing to shift into their roles as carers. Jack's father lets me in and offers me tea and tells me his wife will be down in a few minutes. I go into the lounge and prepare for the afternoon, setting up audio recorders, checking where we are in the research and where we might go next. Jack's home is at the edge of a large twentieth century 'new town'. The street where he lives is relatively quiet, with regular traffic and a twice-hourly bus service in to the nearby city. The house and back garden are full of 'nick knacks' and seasonal décor reflecting Jack's mother's personality.

Jack's mother comes down and we have tea. I am offered cake or biscuits. Jack's parents are conversationalists and chat about their day, their week, and their on-going challenges with regard to respite care-provision. A few minutes later there is a knock at the door that signals Jack's return home. Jack's parents spring back in to their roles as his main carers, welcoming him home, removing his coat, letting him know that I am there, checking his 'link book' for the daily report about how he has been, opening his lunch box and letting him choose something to eat and offering him a drink. Jack sits in his wheelchair in the centre of the lounge and we sit around him on the sofas and armchairs and as the weeks go by he seems to adopt an expression of recognition and anticipation, as his mother explains,



And I've been amazed at how he's just homed in on what's going on. It's like he's got into a little routine where every Wednesday he knows you're coming, 'Oh, it's Noelle today', and it's really, he just sits, and the expression on his face as if he's waiting for something to happen, 'OK guys, what's happening today? What are we going to talk about today?' (Feedback Interview with Jack's parents April 21<sup>st</sup> 2016)

And every week we have talked and looked through his personal archive of materials with him, and sung songs or read stories from Jack's childhood, and as the weeks have gone by I have begun to piece together a portrait of who Jack is and how he has lived his life. Towards the end of the first phase of the project I interviewed people in Jack's circle of support - his parents, his sister and his day service keyworker. The last interview question asks about what is essential to Jack's story and prompted the following ideas: His younger sister's spontaneous response was Jack's story should include music, family and hydrotherapy. His day service keyworker, who has supported Jack for more than ten years, approached the subject from an alternative perspective. She thought that the big changes in Jack's life - his back surgery and sight loss - should be addressed.

In an interview with both Jack's parents I asked them about what they thought was essential to their son's story. I mention his keyworker's reference to back surgery and sight loss and Jack's mother explained why she disagrees:

When I think about things like the back operation and the eye sight I always think they were things that were done to Jack to put him right, to make his quality of life a little bit better. So I guess I look at those things as fixing him a bit, if that makes sense? (Interview with Jack's parents November 25th 2015)

Rather than focussing on what required 'fixing' Jack's mother wanted his story to include all the activities and people that are important to her son. And in many ways I agreed with Jack's mother - why are the narratives of people with complex needs dominated by stories about being 'fixed'? However, his keyworker also made a useful point. Jack has experienced a great deal of pain and loss in his life. Should that be airbrushed out? How can we know what is important for Jack to have included in his story? Are we doing him a disservice by excluding difficult and challenging life events? As I got to know Jack I was

struck by the degree of loss he carried, and wondered how the failure to address and share those experiences might impact on his mental health.

As Jack, his family and I worked through his personal archive we became aware of how the language used to describe Jack's impairments has changed in the course of his lifetime. On one occasion when I arrive shortly before Jack's return from the day centre his mother showed me a document from when he was four years old. I asked her if she could read through it with him when he got home, but she refused, saying 'I can't read it out loud to him because it's all about what he can't do' (FN April 2015). After reading through the notes I'd made during the first stage of the fieldwork and commenting on this particular record, Jack's mother added,

It's interesting looking through notes from Jack's early years. A great deal of developmental notes about young children are ability-related. When a young person has a learning disability they don't follow the normal, or what is seen as the normal, routine. Jack has developed, grown, learnt, but in his own way. I have always focussed on what he can do, rather than what he cannot do. (Additional written comments to thematic analysis by Jack's mother Autumn 2015)

In the following section (1) a portrait of Jack is presented. 'Jack's story' is made up from a montage of biographical detail, interpretations and reflections and is drawn from a variety of sources including his personal archive, the conversations with those who know him well and my own observations. This portrait is placed at this point in the case study with the specific intention to orient the reader in preparation for the sections that follow and constitute the main body of the research. The following sections present (2) an outline of Jack's communication repertoire and (3) ways in which that is supported. The next section (4) reflects on the various ways in which we worked together to extend Jack's opportunities to participate in his life story work. The final section (5) reflects feedback that was gathered through follow up interviews and correspondence. Throughout this written piece the iterative and recursive core processes of the fieldwork are referenced.

## 1. Jack's story

Jack was born in the West Midlands on a hot August day in 1984. Because his mother had an infection he was put on antibiotics when he was born and incubated. While looking through his baby book Jack's mother commented that she had only stuck in one photo from when he was in the incubator. She was woken early in the morning the day after he was born and told his heart had stopped, but he'd been resuscitated. Jack was allowed home after ten days and the family began their lives together. However when Jack was six weeks old he was rushed to hospital, having more than twenty seizures in one day. As a result of epilepsy medication Jack was 'comatose' in his first year, but as his medication reduced he began to engage more, sitting up independently and using a few words. However, when the epilepsy returned these developments were lost.

Three years later his sister was born. Jack attended a 'special needs' nursery at a mainstream school aged four. In 1989, aged five, the family moved to Kent and Jack was enrolled at a special needs primary school. The family moved again, to where they currently live in East Sussex in 1993, and Jack attended a 'co-located' primary and secondary special needs school in a nearby town. It wasn't until Jack was twelve that the family finally received a diagnosis,

He has a deletion in chromosome 22, bar 4, like a hairline crack. Technically and medically you wouldn't expect it to have so much impact. One doctor said: "For so little it has done so much". Not helpful. (Interview with Jack's mother August 28th 2015)

Although Jack's chromosome abnormality is unique, and therefore doesn't help explain anything about his specific disability, his parents feel it is useful as it means that no one is to blame for his condition.

We spent a number of afternoons looking through reports from Jack's school years. His Further Education records report that he 'flourishes' in activities that involve music, singing, sensory engagement and swimming. The photographs dating back from this period would support this. Jack was able to use eye pointing and touch to make choices. He used a 'choosing board' with up to 6 pictures to support communication. The 'choosing board' was a piece of black, felt board and a limited range of Velcro backed symbols. Use of the

communication board was geared to time of day e.g. time for a drink. Jack would touch a photo or symbol to express his preference. He continued on to the further education department for three years until leaving full-time education in 2003. The adult social care services allocated a dual package of day care at two different day services, which continued for one year.

Jack is usually in good health. He had lots of coughs and colds when he was younger but his mother says his health improved, as he got older. He has had major surgery. On one of the first visits I made to Jack's home I asked if he liked being out in the day centre bus. His father said no, not really, because it was uncomfortable. He'd loved the old Rover they'd had. He used to sit in the back with the armrest down. In 2004 Jack underwent major back surgery in London to correct severe scoliosis and his educational provision was suspended for nine months while he recuperated at a post-operative care placement. After his back operation he gained 6 inches in height and it was awkward getting him in and out of the Rover. I took the opportunity to ask more about the operation and we talked about it for the remainder of the session once Jack had returned home.

The problem had been picked up when he was about 11 years old. He had to go every 6 months and have his back X-rayed. He had to wear a brace, which he hated. His parents don't think it made much difference, but it caused a lot of discomfort. The condition deteriorated and he was unable to sit up and so it was decided to have an operation. There are no records of this difficult time in Jack's archive, which I note:

There are no photos or records. Dad said, 'You don't record difficult or painful times do you? We wouldn't want to be reminded of that time. It was very difficult'. (FN March 2015)

The operation was difficult to arrange because post-operative care was required and neither could be arranged without the date for the other. Both parents were very impressed by the orthopaedic surgeon. Throughout the afternoon as Jack's parents reminisced about this major life event, Jack listened with a look of concentration on his face. He became very vocal at times, making loud noises that drowned out his parent's voices. It appeared that he was joining in

the conversation and his mother interpreted his vocalisations as if he were using words (Appendix 13a: Vignette 3). He'd left his present home on January 30<sup>th</sup> 2004 and returned in December. Once recovered and back home Jack was, once again, assessed for adult social care and was offered a placement at a day centre nearby. This centre closed in 2008 and new provision was found at a newly refurbished day facility close by, which he continues to attend.

While certain events regarding health and illness have punctuated Jack's life to date, his strong personality and irrepressible humour tell a different story. He is in many respects a 'people person'. According to his parents, Jack is sociable, sensitive and doesn't suffer fools, or anyone who fails to treat him with dignity and respect. Jack's mother described him as a person who pays close attention to how people respond to him and works out, in an intelligent way, what they need from him:

But I think Jack likes people. He's quite interested. When he hears a new voice you can see him thinking 'Ooh, this is a new voice', and he'll listen to that person speak and then we'll introduce them to Jack, or vice versa. And you can see him sometimes, just listening to that person, working out what that person's like, working out what sort of personality they are, what makes them laugh. It's just the same as you and I would do, working out a person's personality. (Interview with Jack's mother August 28<sup>th</sup> 2015)

The relationships that Jack has built seem to be reciprocal, survive over long periods of time, even after regular contact has ceased, greeting people enthusiastically should he come into contact with them and also when his family talk about them, as his mother notes when she said 'I can think of two or three carers we've had who he's really, really loved. And they've all adored him, interestingly' (Interview with Jack's mother August 28<sup>th</sup> 2015).

Jack's parents describe how they think he would be if he weren't disabled. His mother thinks he'd be 'very inquisitive, romantic and loving' and his father says that he thinks Jack would be 'quieter than me and perhaps more confident'. His mother finds this a useful reflection, adding,

It's interesting looking beyond the disability to Jack as a person. I have always tried to do that. Disability can be a barrier in that there is so much

to Jack as a personality. He is charming, strong, funny, loving, caring, intelligent and driven. Even though he has a physical and mental disability he is still has all these qualities. He is still a lovely young man and a beautiful human being. (Additional written comments to thematic analysis Jack's mother Autumn 2015)

Over the time I get to know Jack and his family I begin to see his character and how he holds his own. His parents comment that he 'affects' those around him, for example on one occasion his father tells me about an incident that occurred at Jack's day centre that had been recorded in his link book. He had reached over with perfect timing and held the fret on the guitar as a member of staff was playing. Jack's father commented that he is, 'Full of surprises. At times like that he really gets to people, really affects them' (FN May 2015). Jack's mother explained this further when she said,

Jack lets people see who he is. He isn't worried about showing his emotions, which are indeed a quality. He also shows his vulnerability to the world. He exposes feelings that people spend a lifetime hiding. I believe people find this endearing about him. (FN May 2015)

Jack is a highly sensitive and emotionally responsive person. His family and friends and support workers are very careful to reduce situations that they know will upset him. Because he is so emotional it makes it very difficult for those around him to express their feelings. If Jack does get very frustrated about his communication difficulties, it can lead to expressions of anger, as his father reports:

It follows on that if the screaming and the shouting don't work and he's really upset about something and he's in his chair he'll grab you. He'll grab your shirt as though to say 'For God's sake'. He's so frustrated that he can't get his message over and he's desperately trying to let you know how he feels or something. And he will do that, grab, as if to say 'I'm really angry' and he can be angry about something. It's awkward, isn't it? It's a language problem. (Interview with Jack's father August 28th 2015)

However Jack's emotional responses equally demonstrate concern about others. He hates to hear a baby crying and can become distressed. As his mother says, this shows that he cares 'He isn't just absorbed in Jack. He's concerned about people out there as well' (Interview with Jack's mother August

28<sup>th</sup> 2015). In a second interview Jack's mother describes what she notices as emotional intelligence in her son:

Yes, I like the words 'emotional intelligence' because I think it describes Jack, the way he taps into people. I think he takes it beyond - because he can't see how people are feeling - he has to work a bit harder to understand their voice, their body language, the way they hold him or touch him or connect with him. He has to work so much harder to understand what people are feeling. So I think he takes it a stage further, Jack, to tap in to the circumstances of what that person is feeling, rather than just what they are saying. And it is an emotional intelligence and Jack has worked that out all by himself, which I think is amazing. (Interview 2 with Jack's parents November 25<sup>th</sup> 2015)

Most of the time Jack has a very happy disposition, which he expressed through laughter, clapping his hands and smiling. All Jack's family are very chatty and warm. Conversation was peppered with laughter and Jack appeared very content in this type of environment. Jack laughed easily and had an infectious giggle. When I record him making sounds Jack is amused, as I recorded in field notes (Appendix 13a: Vignette 5). His father described Jack's humour further when he said 'if someone bangs their knee or drops a plate he thinks that's hilarious' (Interview with Jack's parents November 25<sup>th</sup> 2015).

Loss has played a significant part in Jack's life. Loss of vision, as the result of failed eye surgery in 2006, had a profound impact on his independence, relationships, emotional wellbeing and communication skills. His mother explained that 'it was worse than the back surgery. We found that there's no vision in either eye' (Interview with Jack's mother August 28<sup>th</sup> 2015). As a result Jack needed more 1:1 support and lost much of what independence he had. It's also had a significant impact on his communication. He had been able to use a communication board. Through the time spent with Jack and his family and his keyworker I gradually came to understand how they have all adapted to this loss of vision and changed the ways they support him accordingly.

Little is understood about long-term biographical memory of people with PMLD, as discussed in Chapter Two, therefore it was interesting to investigate how those close to Jack understood his ability to remember and what their evidence was based on. His family and day centre key worker all appeared certain that

Jack remembers people, places, music and objects. They saw his emotional responses as evidence of memories that he has, but is unable to communicate. Jack's sister thought that 'Jack has memory like everyone does' and that 'He definitely knows things from the past'. She cited as evidence his responses to music that he liked when he was a baby (Interview with Jack's sister October 21<sup>st</sup> 2015). His touch sense is supported, his mother believes, via his visual memory. When Jack was still able to see he had a favourite toy and this is now regularly replaced as it has such value in his life as a familiar and loved object. His memories of experiences are reinforced through the conversations he engages in with his family:

If we go out for the day when we get home we say 'What did we do today? What happened when we were there? What did we smell when we were there? When we went into the shop what sort of things did you smell?' And all the things we got him to smell we talk about, and you can see him thinking about that. And at certain places he'll laugh or smile if it's been a particularly nice experience or memorable. So he follows a story when we tell him things. You can see him really listening and you know he's remembering because he'll either smile or prompt at the right place. (Interview with Jack's mother August 28th 2015)

His childhood memories are also reinforced through stories, nursery rhymes and songs that the family enjoyed together as Jack was growing up. His father used as evidence of what he described as Jack's 'brilliant' memory his response to a childhood song, 'Sing a Song of Sixpence', that hadn't been sung for many years but when it was triggered anticipation, which Jack expressed through his gestures as well as laughter:

Yes. But with 'Sing a song of sixpence' he's not just laughing because it's a funny song. He knows how it goes, because when you stop (pauses), he knows what the next bit is you see. He knows it and you know he knows it by his expression when he's just waiting for you to do that extra bit. Because otherwise it could be a song that you've just finished. But he knows it isn't because he knows there's another bit, because I've stopped and he knows it's going to come. (Interview with Jack's father August 28th 2015)

Repeated and structured activities also reinforce Jack's remembering and support his acquisition of new skills. This is demonstrated in the weekly



hydrotherapy session I observed in which his therapist uses repetition as a tool (Appendix 13a: Vignette 6). Verbal prompts and objects of reference that rely on memory support regular routines like hydrotherapy, but it has been found that the timing of these is critical and needs to be within approximately ten minutes of an activity to avoid anxiety on Jack's part. Jack's mother has come to realise that this is probably due to his difficulty judging periods of time:

Because Jack can't comprehend time. So now we tend to do that when something's quite imminent and that seems to work much better, because Jack is still thinking about it, or at least we think he is. Again this is a bit of guesswork. We think he is anticipating that that's imminent, so now we have a five, a five to ten-minute lapse on things before we say it's going to happen. And that seems to work really well. (Interview with Jack's mother August 24<sup>th</sup> 2015)

Jack's long-term memory appeared to be supported by a range of factors that included opportunities to revisit the past through music, through conversation, touch, repetition and routine.

## Summary

Having introduced Jack through the biographical information, thoughts and interpretations of those who know him well and my own observations I turn now to the main research findings from Phase 1 of the fieldwork and present a snapshot of how Jack communicates in order to identify the key ways in which to extend his opportunities to participate in his life story work.

## 2. Phase 1: How does Jack communicate?

This section highlights the communication capabilities that Jack demonstrates on a daily basis and is informed through an understanding of his communication history as revealed through his personal archive of life history materials and his interaction with it, his day-to-day participation in activities and via the conversational interviews with his parents, sister and key worker. It follows the senses, and how we understand them to be used for communication purposes, and includes communication through the body and gesture and an account of what is understood as Jack's communication intent and comprehension.

Understanding Jack's individual repertoire of communication was an essential component in extending opportunities for him to participate in his story.

### Hearing and Sounds: Listening

Jack appeared to have very good hearing right across the range. This was confirmed by a hearing test at Brighton Hospital when Jack was 10 years old. He doesn't use hearing aids. He occasionally has ear infections. He is an active listener. You can almost see him listening. He cocks his head to one side and opens his right eye slightly wider. He enjoys being read to and listening to audio books, conversations, audio descriptions in films. Listening to music is one of Jack's main pleasures and he enjoys hearing the sound of his own voice:

I stop filming and play the film back to Jack. He holds the iPad and pulls it towards his right ear, apparently listening closely and concentrating on the sounds. (FN April 2015)

He uses his hearing ability to track the movements of his family in the house and responds by making vocalisations, as if to say 'I know I'm in another room, but I can hear you' (Interview with Jack's mother August 24<sup>th</sup> 2015). His hearing is sensitive and Jack doesn't like loud or unexpected noises, like fireworks. His keyworker thinks that Jack's hearing may have become more sensitive since he lost his sight because he is using it more actively to make sense of his world.

### Making sounds and vocalising

Jack makes a wide range of sounds and has an extensive vocal range. He laughs, giggles, squeals and cries. He plays with sounds and enjoys acoustic spaces and making sounds that echo. He joins in what his keyworker describes as verbal banter that results in a 'vocal conversation' made up from 'noises and sounds' (Interview with Jack's keyworker September 28<sup>th</sup> 2015). Jack uses his vocal range to express how he's feeling in an assertive and uninhibited way. His father described how Jack uses vocalisations to communicate a range of emotions:

In the morning for example, you'll hear him, because if he's not happy he'll be moaning and slapping himself and making quite a loud noise, so you'll know he is unhappy. Sometimes he'll be awake and be happy and to get your attention he might just giggle on and off. (Interview with Jack's father August 28<sup>th</sup> 2015)

Jack's parents commented that he was more vocal than usual when I made the weekly fieldwork visits. He made sure his voice was heard and appeared to be participating in conversations about his past experiences:

I have been visiting Jack and his parents every Wednesday afternoon since the beginning of March and Jack has become more and more vocal. His father notices this and says that Jack always seems happy and vocal on my visits. He appears to enjoy being recorded and listening back to his voice. On this occasion Jack is making a range of sounds that are from his repertoire, but are new to me. He is sitting with his arms bent, his hands up, smiling broadly and making laughing, high-pitched sounds. (FN April 2015)

### Vision and Sight

Jack is registered blind after a failed cataract operation in 2006 and he and his family and friends have adapted new methods to support communication, choice and control in his life. During my weekly visits we talked about Jack's loss of eyesight and how it has affected his communication. Being unable to use eye contact means that Jack's sight loss has had an impact on his relationships as well. Jack's mother described the loss of eye contact after the failed eye operation as 'devastating' and 'cruel'. However, she goes on to report that Jack never seemed 'upset or angry' and became her teacher, giving her the confidence to adapt to the new situation, as if to say 'It's OK Mum, we can do this' (Additional written comments to thematic analysis by Jack's mother Autumn 2015).

### Smell and taste

Jack uses his sense of smell, in addition to touch, to identify different people, foods, places and objects. His sister describes how Jack uses his sense of smell to orient himself, for example when visiting friend's homes.

## Touch

Jack is understood to have superb tactile sense skills. Since his sight-loss he uses touch to help identify different people, foods and objects. He holds hands to say hello, and uses a range of ways to explore people to confirm who they are. At his day centre the staff team are aware of this and try to be consistent:

People who work with Jack on a regular basis tend to keep the same watch, jewellery, rings that he tends to look for, especially now that he's lost his vision. He'll touch your hair. Or anything like that that helps him confirm that you are who you are. (Interview with Jack's keyworker September 28th 2015)

Interestingly he will touch the faces and mouths of his close family to gather more information about the context of what is being said. His mother says this has developed since Jack lost his visual sense:

Sometimes he'll feel us if we're talking or sometimes I'll get him to feel my face if I'm talking. Sometimes he'll put his finger actually in my mouth if I'm saying a certain thing, he'll just have his finger sitting there. It's almost like he's feeling something from that feel because he can't see it. So it's interesting for him. (FN May 2015)

Jack's mother thinks that Jack needs confirmation from more than one sensory source to make sense of his world:

And it's almost like he wants to feel the words, because he can't see, it's almost like he wants to feel them inside. I can't quite explain that, but he's obviously getting something from that. For him, he's got to touch as well as hear. He's got to do another physical thing to get to that understanding. (FN May 2015)

He eats independently, using touch to distinguish foods, and Jack's mother believes that Jack has a visual memory that allows him to anticipate the size and shape of a range of foodstuffs, 'If you say it's a small grape he'll do that

finger-thumb pinch to pick it up, whereas if it's a biscuit it's more of a whole hand grab' (FN March 2015). He uses touch to choose between objects e.g. CD and DVD. An invitation to touch is used together with verbal descriptions of visual images to add information as illustrated by a scrapbook from the day centre:

And they've put little pictures here of cars. Can you feel them?' As Jack's mum reads the photo caption she takes his hand and places his fingers on the small felt cars that are placed at each corner of the photo. (FN April 2015)

And since his sight loss Jack finds touch useful when listening to stories (Appendix 13a: Vignette 2). Jack's mother has been borrowing books from a charitable organisation called 'Living Paintings'. The books have braille inside them and a few raised pages where you can trace people and characters from the story. During and after reading the different stories to Jack his mother traces his finger over the raised objects which 'Jack seems to understand very well. He doesn't always want to trace, but it is a good aid to help him understand the story' (Additional written comments to thematic analysis by Jack's mother Autumn 2015).

In the lounge at Jack's house there is a large drawer full of the kind of objects that he likes to hold, touch and play with. If he's upset or agitated he settles when given beads and other sensory objects to manipulate. One of his main pleasures is to lie on a blanket in the back garden and touch the grass (Appendix 13a: Vignette 4).

### Body gesture and facial expression

Jack uses a wheelchair and is not able to walk independently (except with buoyancy aids when in the swimming pool). He had a back operation to correct severe scoliosis and has metal rods to support his spine. This has resulted in further limitations of his independent movement. He moves his head and limbs freely. Jack 'says' "No" by shaking and turning his head as illustrated by his father, however sometimes he shakes his head and laughs at the same time, which can be confusing and is one aspect of Jack's sense of humour. When he is happy and excited he lifts his arms in the air and sometimes claps his hands together. He also uses his body very clearly to express anger and frustration.

He slaps his head and bites his arm. He pulls people towards him or pushes them away or moves out of their way to express his feelings.

Jack uses his body and head to let others know they have his attention. Jack's mother thinks that he does this for our benefit suggesting that he understands that if he turns towards someone they will know he is listening. He also uses body language to express his appreciation of people's attentiveness to him, by turning towards them. However, 'if people are a bit dismissive he will quite often turn his head away, even if he hasn't visually seen them' (Interview with Jack's mother August 28<sup>th</sup> 2015). When people know Jack well they are able to interpret his body language with greater accuracy. Jack's mother describes how Jack uses his body as we all do, to communicate how he's feeling:

And also sometimes with a sound he might gesture with his body, gesture with his hands or his head, or just look a certain way. People can, can't they, even if they don't speak, you can tell can't you, if someone's not telling you if they feel sad, you can tell from their expression, by the way their eyes are, by the way their body is, their body. Not just facially. Their whole body seems to almost hunch over and look sad. So it's quite interesting when someone doesn't say 'Oh, I'm sad', you pick up on that visual imagery really strongly. So that works a lot with Jack. (Interview with Jack's mother August 28<sup>th</sup> 2015)

Jack also demonstrates how he is feeling through his facial expressions. He smiles broadly when he's happy and has a serious expression when concentrating on a task. When I observed him during a hydrotherapy session I recorded that his 'expression alternates between concentration and delight' (Appendix 13a: Vignette 6).

### Communication intent and comprehension

Jack is able to express himself through sounds, facial expressions and physical movements to those people who know him well. He doesn't use any form of signing, visual symbols or speech output devices. His intended communication is somewhat limited to what is happening in the present moment as a result of his communication repertoire and our difficulties in interpreting it. This can result in feelings of anxiety and frustration on Jack's part as described by his key worker:

I think he's very much a 'what's happening at the present time person', if I'm honest. I'm not saying he doesn't instigate things either. Obviously if he's upset there's always a reason for his anxiety. You've just got to find out what that reason is. There will always be a reason. It might be that he's uncomfortable in his chair, or that he's too hot, or that he needs to get out of his chair, or he's thirsty, or he's hungry or he's not feeling well. There will always be a reason - you just need to find what the reason is. And while I think we have got better at finding the reason and understanding I think Jack has, over the years, got better at saying 'I'm not right. Help me. Fix this. Solve it'. (Interview with Jack's keyworker September 28th 2015)

While Jack's ability to communicate might be limited, those in his close circle of support believe he has a good level of understanding. This is illustrated by Jack's irritation when people within earshot talk about him without directly addressing him, 'if you talk about him for too long and he's in the same room he'll get irritated and he'll throw a wobbly' (Interview with Jack's sister October 21st 2015). Jack's key worker thinks that his level of comprehension far outweighs his ability to communicate:

He's very intelligent. He absorbs a lot of information and he has a high level of understanding. I think he knows exactly what's going on. He comprehends what you ask him. He can't always answer directly because of his limited communication but he will always let you know. Sometimes if he is upset or distressed I have said to him, 'Jack you need to stop, listen, tell me what the problem is. Just let me know what the problem is'. And he has a way of indicating that certain things are bothering him, so he obviously understands the question. (Interview with Jack's keyworker September 28th 2015)

Jack's parents agree, believing that Jack's level of comprehension far outweighs his communication ability, which his mother demonstrated using Jack's response to comedy as an example, 'I mean things on TV sometimes, when they have comedians on and they say the punch-line and Jack has laughed to the point where we're like, [pauses], 'Has he understood that?' But the timing is just bang on' (Interview with Jack's mother August 28<sup>th</sup> 2015).

## Summary

In this section, information gathered during Phase 1 about Jack's individual communication repertoire was presented. His listening skills appear to be very good and have possibly improved since he lost his vision. He uses a range of vocalised sounds to express himself and to join in with conversations. He uses touch extensively to make sense of the world around him and appears to utilise visual memory in this. He expresses his emotional state through his body and facial expression and gesture. In the next section of Jack's Case Study, the way in which his communication repertoire is supported is introduced.

### 3. Phase 1: How Jack's communication is supported

This section includes the role of people and of communication tools and approaches that are 'outside' of Jack, but working in tandem with his individual communication repertoire allow his 'voice' to be heard.

#### How people support Jack's communication through relationships

Long relationships are particularly important to Jack. At his day centre new staff are introduced slowly and with support from long standing members of the team. This helps to reduce anxiety on Jack's part:

If somebody doesn't know him particularly well and he's feeling anxious or upset and they say 'Can I help', you can almost see that look on his face, [sharp intake of breath], 'That person's come along and they don't really know me and they won't be able to solve my problem'. (Interview with Jack's keyworker September 28th 2015)

Trust and rapport is developed over time as staff members follow through vocal descriptors with actions. It is important that Jack has a sense of control through his recognition of how different people work with him. Jack's key worker explains that like everyone he doesn't get on well with all those he is contact with, regardless of how good they are at their job 'we prefer some people to others. Why not make that known?' (Interview with Jack's keyworker September 28th 2015). Jack's mother understands that the warmth of his character and his humour and sensitivity make him very attractive to others, 'I really believe Jack



has an understanding of people, their personality and, over time, their nature' (Interview with Jack's mother August 28th 2015).

### How people support Jack's communication through interpretation

My observations of Jack suggest he doesn't feel inhibited about expressing his views through his vocalised sounds, his body language and gestures and facial expressions. However, deciphering the subtleties of his communication repertoire takes time and requires detailed noticing of a range of responses, as his mother reflected that 'you have to really almost get in to their bubble, get in to their world, the way they think, the way they do things. And when you do, isn't it amazing, because that bubble can tell you so much about them, so much about that person' (Interview with Jack's mother August 28th 2015). Jack's mother often interprets his vocalisations as though she's translating from a language I am unfamiliar with. I ask her about how she does this:

He vocalises a lot and because we understand Jack we know what his different sounds mean. So if he made a different sound for a specific thing we know what that is. Other people who don't know him wouldn't know that. But I think that's come with spending more time with him. So if he makes a certain noise for a dislike of something it's 'Ah he doesn't like that', because he's done that before at that time. (Interview with Jack's mother August 28<sup>th</sup> 2015)

Jack's sister agrees that knowing Jack all her life has given her the same intuitive ability, explaining that when you 'live with someone, you know like anyone, you get used to their little tics and what their little sighs and noises mean. It's exactly the same principle with Jack. You get used to that little noises mean certain things' (Interview with Jack's sister October 21st 2015).

On one particular occasion, as his parents discussed his response to major back surgery, Jack began to vocalise loudly:

I say 'It's really nice you're joining in the conversation'. Jack appears to listen and raises his eyebrows and opens his right eye slightly, looking in

my direction, vocalising more strongly again, 'Da, Da, Da,' His mum touches his right shoulder and says 'You're telling everybody you're strong. You're so strong and brave, Jack'. Jack laughs. (Appendix 13a: Vignette 3)

However much I try to enter Jack's 'bubble', I do not have the skills that his family and long-term team have acquired over many years. I felt on many occasions that Jack's mother particularly is acting as an interpreter. In expressing in words her interpretations of Jack's non-verbal responses, his mother is drawing on what she described as 'telepathic communication', which she considers a key element in any close relationship. When I asked Jack's mother how she feels confident that she is interpreting him accurately, we were able to explore this further:

Yes, sometimes you'll say something and he'll shake his head, as you've said yourself, Noelle, sometimes he'll just randomly shake his head. Sometimes he'll shake his head and laugh and I think that's because he's being quite cheeky, because he's got a sense of humour, there's a sense of humour about Jack. Absolutely, 'Ah, fooled them again!' And that's quite endearing as well (laughs), little monkey. Yes, I think so. Sometimes he will do that. But we just say it anyway, because sometimes you're going to get it right. I think most times we get it right, but sometimes you're going to get it wrong, but hey ho, you've said it anyway, let's just go with it. (Interview with Jack's mother August 28<sup>th</sup> 2015)

This sense of accepting that it isn't a fail-safe method and sometimes they'll get it wrong is refreshingly honest and indicative of the pragmatic 'good enough' model of communication that seems to work extremely successfully for Jack most of the time. However, as his father made clear in conversation, when Jack is distressed it could be for any number of reasons including an illness, discomfort, hunger or thirst, tiredness and their task is to systematically work through a number of possibilities. Because of this, Jack's communication repertoire has been limited to the 'here and now', or within a very short time frame. This makes any other form of communication extremely challenging, if not impossible. When Jack returns home in a distressed state, as he did on one of my visits, his parents worked in tandem - one soothing and drawing on familiar and secure toys or songs, while the other sought out information via his communication book to discover a potential reason from earlier in the day.

When it was discovered that Jack had been unable to attend his hydro session - quite probably the highlight of his week - due to staffing problems, the parents were able to offer sympathy and I observed Jack physically relax, as if to say, 'I needed you to know that', even though it had happened several hours earlier.

### How people support Jack's communication through vocalisation

The family and team who support Jack all come across as being natural conversationalists. They describe what is happening, or has, happened constantly. This is something they have always done, but it became more important after Jack lost his eyesight. As his mother commented: 'I try to be as descriptive as I can. When I'm wheeling him I tell him what I'm doing, where we're going. I've become much more vocal and descriptive' (FN April 2015). As we go through the range of materials in Jack's archive, most of which rely on visual skills to decipher, Jack's mother demonstrated how she provides information (Appendix 13a: Vignette 2). Verbal descriptions of what is happening or is about to happen not only show due respect, but also reduce the anxiety Jack might otherwise experience, as his keyworker reported:

I think it's the not knowing that sometimes causes the problem. I mean if you suddenly, if you're in a wheelchair, go out the door and it's freezing cold, it's a bit of a shock, isn't it? But if someone says 'OK, Jack, we've got to put your coat on now. We're going to go outside. It's probably going to be chilly', so he knows, rather than being wheeled over a bump and whoosh a cold wind hits you. I mean what's that about? It's a bit of a surprise. So we try not to do that. (Interview with Jack's keyworker September 28<sup>th</sup> 2015)

The family use retrospective vocalisations via conversations reflecting, for example on a day out, and this also reinforces Jack's memory of experiences, as his mother explains 'What did we do today? What happened when we were there? What did we smell when we were there? When we went into the shop what sort of things did you smell?' (Interview with Jack's mother August 28<sup>th</sup> 2015). One of the difficulties the family experience with the agency staff that support Jack in the weekends and evenings is their lack of skill regarding vocalisation. This may be due to poor communication skills generally, lack of

training, or short-term relationships and lack of rapport, but it impacts on Jack's sense of security and well-being, as his mother explained when she said 'Because they don't talk to him, like we do, so much. Or it might just be "Oh, Jack we're going to move you", or "Jack I need to give you a drink now" or "Jack, I need to give you lunch". And you can just see Jack, like, humph' (Interview with Jack's mother August 28th 2015). In an addition to the original notes Jack's mother reinforces and usefully summarised the importance of vocalisations:

Talk, talk and more talk. It is so important in our world and really important in Jack's world. The more vocal information we can give Jack the better it seems for him. Vocal communication ticks lots of boxes - information (Where am I?), pleasure (hearing something funny), reassurance (I feel happy and loved), belonging (someone wants to talk to me) and safety (someone is helping me to understand my world). (Additional comments to thematic analysis from Jack's mother Autumn 2015)

In the first part of this section I have reported how Jack's individual repertoire of communication is supported by the people around him, through their relationships with him that have developed over time and how that reduces anxiety and permits interpretation and, also the role of vocalisation - to be Jack's eyes - which has become particularly important since his sight loss. Now attention turns to other ways in which Jack is given opportunities to express himself.

### How Jack's communication is supported and given agency

Jack's family believe strongly in creating as much opportunity as possible for him to make choices in his life. This was demonstrated on a visit to their home during the first stage of fieldwork when Jack was offered food left over from lunch and his mother explained 'We try and give him as much opportunity for independence as possible. You can see I've got him to hold the container; he can feel and smell the food. He can pick up what he wants. We'd rather he made a mess and we can just clean up, than do everything for him and keep things tidy' (FN March 2015). Jack is given time for tactile exploration and his family appears to sense when he has had long enough. In a similar way Jack's

mother pauses when asking him questions or making conversation, allowing for his opinion or comment:

I think sometimes Jack needs time to process information. You've probably noticed I might say something and I might pause to wait for a reaction. Then I might say it again. And I might not need to say it again, but I will anyway if there's been no kind of - rather than rush on to something else, to give him time if he wants to say something or make some kind of comment. Because it's all about him commenting, in the way that he can comment, isn't it? Rather than just saying stuff where he can't intervene or say 'Oh Mummy, it's this' or 'Yes Mummy, I agree with that'. I try and give him a way of being able to give back to the comment really. And that's something we've learned to do. We've tried to do that for Jack to give him a chance to be involved, even if it's just a da, da, or a urgh urgh noise. It's just something that he's doing in response to what you're saying to him, as a mark of respect really, for Jack. (Interview with Jack's mother August 28th 2015)

In this way Jack's mother is demonstrating her respect. Jack might have a rudimentary way of making a sound or slapping himself to alert his supporters that he needs something, however he then uses sophisticated thinking to get what he wants, by first refusing a secondary need. As his father recounts: 'he knows that if he accepts the drink first he doesn't get offered food afterwards. So he'll refuse the drink, even though he's thirsty in the hope that you'll give him something else' (Interview with Jack's father August 28th 2015). In a similar way if his father thinks he is in pain and offers him a painkiller, Jack won't accept it unless he is in pain. 'If he wants that he'll take it and if he doesn't he'll just move his head away as if to say "No, I don't want that"' (Interview with Jack's father August 28th 2015).

### How Jack's communication is supported by routine and repetition

Established routines clearly appeared to support Jack's communication. He flourishes when he is familiar with an established routine e.g. mealtimes and day centre activities. Prior to losing his sight Jack was able to use a communication board with up to six symbol pictures to provide choice. These choices were geared around routines, for example drink and meal breaks. His family recognise his reliance on routine and use this to decipher communication intentions. His keyworker understands how regular routines reduce 'sensory

overload' for Jack, thus alleviating his anxiety and allowing for more constructive opportunities for communication. Repetition is especially important to help Jack adjust to new activities and environments, as I summarised in the interview with his key worker; 'information overload makes it difficult for him to process. He experiences a lot of anxiety when something is new. As an activity is repeated he can absorb more and more information, which he can remember, and that gives him a sense of security' (Interview with Jack's keyworker September 28th 2015). Jack's father reinforced this idea that for Jack routines reduce anxiety by helping him to accurately anticipate events and experiences:

I think the thing is then he knows what to expect. If you break it up and made it different every time I think it would be less effective because he would be stressed about it, because he wouldn't know what was going to happen. (Interview with Jack's father August 28th 2015)

This was demonstrated clearly on my visits to Jack's home. I was there on Wednesdays when he arrived home from the day centre and after about five visits there was definitely a relaxing into our time together. His hydro-therapist has tapped in to this specific need and uses the repetition of their exercise routine to advantage. Jack's family and team of support workers utilise familiar and often repeated stories and songs in a variety of ways. They are used to distract, to soothe and to have fun and are also a useful tool for recognising Jack's facility for remembering via anticipation. Songs like 'Sing a Song of Sixpence' and 'Old McDonald Had a Farm' are typical of the repertoire of repeated songs and nursery rhymes (Appendix 13a: Vignette 1). Repetition, once established, can be used as a sign during various activities, to signal change, as observed during Jack's regular hydrotherapy session (Appendix 13a: Vignette 6).

### How Jack's communication is supported by augmentative and alternative communication (AAC)

As previously discussed, in the past Jack has used symbol pictures on a communication board to make choices, for example, which drink. However since his sight loss it has taken some time to find an effective alternative. This is

partly as a result of Jack's difficulty understanding time. As his keyworker indicated, if objects of reference are given too early Jack can become quite agitated, 'I think if you gave him things too soon, before the activity is actually happening the time span was too long, if that makes sense. And I think he was thinking 'this is not going to happen. Why is this not happening? You told me it was happening' (Interview with Jack's keyworker September 28<sup>th</sup> 2015). Jack's mother finds that objects do support communication, given in an almost immediate timeframe, as she describes:

"Even if I'm reading a book to him I get him to feel what size the book is, so he can feel if it's a big book, the number of pages, I'll say 'It's got so many pages. It's got pictures in it', what pictures it has in it. So Jack can physically get hold of the book and have it in front of him, then I'll say 'OK, so now you've had a good feel of the book, can Mummy read it now?' It's almost like he wants to be part of that by holding it before you read it." (Interview with Jack's mother August 28<sup>th</sup> 2015)

### How Jack's communication is supported by rich media

Though Jack didn't have access to a tablet or touch screen computer, he did have a large collection of toys that make sounds as a result of different actions. These are part of his daily life and he gets much pleasure from playing with them. His keyworker didn't expect that a tablet would be interesting to Jack because they lack sensory features, unlike his toys which are 'very sensory, noise and response and he knows how to operate them' (Interview with Jack's keyworker September 28<sup>th</sup> 2015). However, Jack appeared to enjoy the immediate playback features of digital media, as I found when recording his voice, 'I play the film back to him and he listens attentively' (FN April 2015). His mother was also struck by this apparent interest and thinks Jack understood its purpose:

The day, literally when you were playing something back to Jack when he was being very vocal. And he just held it there. I almost wept, it was just [pauses], and he held it quite close to his face, didn't he, for a few minutes just really listening. And it was fantastic. 'Yeah guys, I get it. I totally get it'. And it was just so powerful, that. (Interview with Jack's mother August 28<sup>th</sup> 2015)

His keyworker was surprised by this and would have anticipated a negative response:

Well I'm surprised because I'd expect him to tap it on his head or tap it or just drop it, because some things like that, square and solid and don't really do anything, he'd just think, 'Chuck it'. Yes, I think I would have been. He likes touchy feely. He likes touchy feely things. It needs to do something, to respond. If it doesn't respond, if it doesn't give you anything, then what's the point? (Interview with Jack's keyworker September 28th 2015)

His father considered Jack's positive response to the iPad in the context of the life story work we've been engaged in together with communication that has informed Jack:

I think he's held it [iPad] because he's interested in it. You know, a lot of it for Jack is if you explain to him what's going on. And I think he does enjoy it. I mean he wouldn't pick it up if he didn't want to, he'd just push it away, which he does. If you give him something he doesn't want he just pushes it away. But obviously he has been interested and it has probably stimulated him hasn't it? That's why he's grabbed it. It's attracted his attention. (Interview with Jack's father August 28<sup>th</sup> 2015)

In this context Jack defied the expectations of those in his circle. It became apparent that although I was reliant on them to guide my understanding of both Jack's communication repertoire and the ways in which that was supported, their expertise and knowledge was limited by their own exposure to untried and untested approaches. Because the tablet did not mirror characteristics found in the objects Jack was known to be stimulated by, they anticipated that he would find it uninteresting.

The photos, films and stories gathered during the first phase of the fieldwork were placed on a Rix wiki site, which the family and Jack were only able to access via my iPad when I was with them or on the desk top computer that was located in Jack's father's study.

### How Jack's communication is supported by music



Music plays an important part in Jack's life and has a big impact on his wellbeing. I picked this up within a few visits to his home. Music is playing, the family sing and many of Jack's toys have musical elements. Jack expresses his musical taste by moaning or becoming agitated if he doesn't like something and laughing and smiling when he does. Jack is emotional and sensitive to lyrics and tunes and there are particular artists who he has difficulty listening to because he gets upset, as his keyworker has discovered:

I've made up CDs in the past for him for different things and I've put a variety of stuff on it and occasionally I've found that certain things, like Adele for instance, that some of her tunes are a bit sad and he started to get a bit upset. And I'm thinking 'He doesn't like that', so I'll move on to something else. (Interview with Jack's keyworker September 28th 2015)

Music that stems from childhood and has been frequently repeated often has the power to lift or change difficult emotions (Appendix 13a: Vignette 1). Music was an important part of Jack's everyday life; it became apparent that it held strong associations for him and his family, and that the backdrop to his story was peppered with song.

### How Jack's communication is supported by the environment

In conversation with Jack's father and thinking about the kind of environment that best supports Jack's communication I summarised that Jack 'likes an atmosphere that is harmonious, congenial, happy, safe, secure, reassuring, with people who know him and he picks up on that' (Interview with Jack's father August 28<sup>th</sup> 2015). His Further Education report recorded that he 'flourishes' in activities that involve music, singing, sensory experiences and swimming. My observations during visits both to Jack's home and at the Hydrotherapy pool would reinforce those findings. On one occasion I observed Jack using all his senses to engage with his environment:

It's the first warm, Spring day of the year. As the sun is shining we decide to sit in the garden and bring some life story materials out with us. I'm sitting with Jack's parents on deck chairs. Jack's mother lays a duvet on the grass in the shade from a large tree. She puts a pillow on the duvet. Jack's father lifts him out of his wheelchair and lays him down on the

duvet. Jack rolls on to his right side and touches the grass with his left hand. He looks very relaxed. (Appendix 13a: Vignette 4)

In this example Jack touched and smelled the grass, which he pulled his fingers through rhythmically, felt the ground beneath him and listened to the natural sounds of the garden along with our conversation.

## Summary

In this section information gathered during Phase 1 about how Jack's individual communication repertoire was supported was presented. It was found that people, routines and repetition, communication tools, stories and music worked together in conducive environments to provide a structure that privileged Jack's 'voice'. In conclusion, the first phase of fieldwork with Jack, his parents, sister and day centre key worker revealed a complex and sophisticated weave of individual communication repertoire, supportive people and structures and life history materials. Through our growing understanding of these elements as they were individually interrogated we worked together to develop a range of opportunities for Jack to participate in his life story work - a process that is explained in the next section of his case study.

## 4. Phase 2: Extending opportunities for Jack to participate in life story work

The narrative described above resulted from the thematic analysis of material gathered in Phase 1 of the fieldwork. This material was drawn from both found materials, as discovered in Jack's personal archive of life history materials, and made narratives as derived from participating with him in activities and in conversational interviews with those in his circle. This information was placed on Jack's personal Rix wiki and was used as a foundation for the next phase of the research.

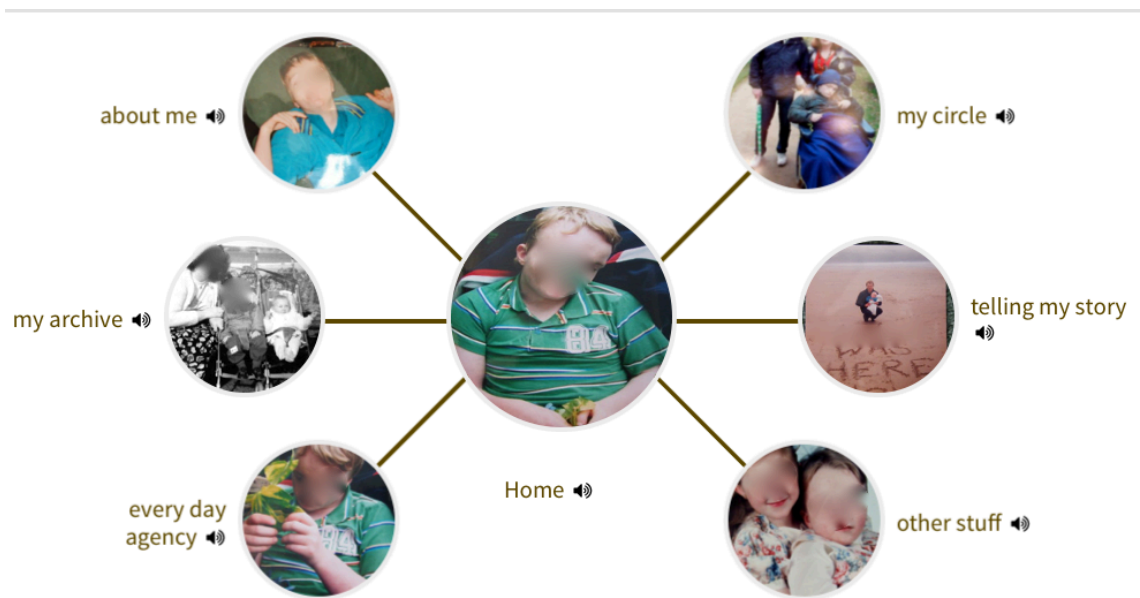


Figure 3: Jack's wiki site (Phase 1)

Through in depth discussions with my supervisors and with Jack and his family we developed a range of ways in which Jack's story was made available to him and in which he could actively participate. What follows is a detailed account of Phase 2.

### Creating opportunities for Jack to participate in life story work

The second phase of the fieldwork was planned to take place over the course of twelve afternoons. Unfortunately Jack was unwell for the first two planned sessions and both his parents were unwell for the next two. I understood that my experience as researcher was, in this instance, reflecting the day-to-day reality of the families I was researching alongside. We began working together once everyone had recovered. On our first afternoon a plan was made for the remaining eight weeks. This plan built on knowledge gathered in the first phase of the project and included a rough idea of which aspects of Jack's life story to include and how those stories would be made accessible. We knew from Jack's earlier responses and participation that he enjoyed listening repeatedly to stories and songs and that he has a great sense of humour. We also knew that he had an excellent visual and tactile memory and was able to link objects with experiences. Our hope in this second phase was that each 'life story' would be linked to a small object that Jack could hold and handle while listening. As

repeated exposure to the stories and objects went on Jack would be in a position to choose which story he would like to share or listen to by selecting the linked object. This was a low-tech solution that, given more time and an appropriate budget had potential to be developed further. To this purpose his mother bought a box and began thinking about objects to represent the stories.

We discussed the selection of stories that might be feature on Jack's 'memory site', which designed was to hold his life stories. As already observed in the first project phase, there was disagreement about the inclusion of sensitive experiences, notably Jack's back surgery and sight loss. However we came to the conclusion that we would monitor Jack's response to listening to these stories and consider removing them should they cause him distress. Jack's mother was keen to include stories about Jack's attributes, with particular reference to his emotional intelligence and his impact on those who got to know him. During the subsequent weeks we set about making short recordings that would fit with what we understood as Jack's natural attention span of up to five minutes.

The first recording session was unsuccessful for a number of reasons. Jack's parents found it difficult to tell the stories in a way that was directed to him and with him in mind as the main audience. The stories became overly detailed and lacked focus. We were sat on sofas around the outer wall of the lounge while Jack was positioned in his wheelchair in the centre. He was uncomfortable and ground his teeth. When I got home and listened back to the stories, I felt not only that they did not possess sufficiently good sound or narrative quality, but also I was concerned that the sound of Jack grinding his teeth compromised his dignity. The next week when I returned we discussed these problems and the following session was a success, as I recorded in my notes,

Good open discussion about focus and sound quality. Was reluctant to record parents away from Jack and individually, but needed to find a way to get decent sound recording quality, and keep Jack engaged in the stories. By standing around Jack we risked the audio being confused by Jack's vocalisations or self-harming behaviours. However the audio quality required us to sit/stand close together with Jack to re-record audio and he seemed to like the proximity. Much more positive, all more relaxed. Interestingly we managed to gather story after story - eight in total - in about one hour. As Jack's mother commented 'while it's going well we

might as well keep going'. Parents took turns to tell stories and responded very positively to feedback. We were all in close proximity to Jack, which meant he was included and both enjoyed and contributed vocally to the story telling. Will use audio for CD and as audio for digital stories to bring to next week's session. (FN March 2016)

This is an example of how the requirements of the recording tools can sometimes lead to a change in approach that subsequently and unintentionally alters the dynamic of a session. Throughout the recording session, which from an outside perspective may have appeared like a recording for radio, with us all huddled around the digital recorder, Jack joined in by laughing and vocalising and his voice stands out within the stories which meant he was fully present and participating in the process. The stories were burnt on to CD for review and the following week I made a note of the feedback,

Feedback on audio. Jack's mother had a quiet Saturday morning at home with Jack and put the CD on. She said that Jack was fascinated and at one point it was hard to tell whether the laughter was on record or from Jack laughing at himself laughing. (FN April 2016)

In the mean time Jack's mother continued to collect objects and we began to offer Jack the opportunity to hold one or two with specific stories.

Up until that point I was making Jack's stories available on CD format in addition to making digital stories on Jack's 'memory site', because apart from my visits to the family home when the site could be viewed via my iPad, there was limited opportunity for the family to access it. When meeting with the Rix team for the diagnostic sandpit at the end of the first project phase, I had raised this concern by sharing Jack's baseline of access to new media and digital technology, which was limited. It was not used with him at the day centre, which he attends five days a week. At home the family had a shared personal computer, located in Jack's father's study. The shared computer did not have touch screen. None of the family had tablets. They had mobile phones that were used mainly for phone calls and texts. There was, however, WIFI access in the home. Jack did have a wide range of interactive toys that make sounds when moved, pressed or otherwise played with. He demonstrated good control with touch and was able to press buttons, pull strings and manipulate sensory objects and toys.

On one occasion, earlier in the project, when Jack had returned home from the day centre in a very distressed state, Jack's parents had been surprised by his response to listening to his stories on the iPad, as they had not expected him to be interested in it. I recorded these notes at the time,

Gradually, within a 15 minute period, he had calmed right down and I suggested sharing where we've got to with his website wiki. I sat next to him and his parents sat or stood either side. I held the iPad close to his right eye and played the videos that are on his wiki - the ones of his father singing and him joining in with the conversation about his back operation saying 'Da, da, da...' which his mother had interpreted that he was strong and brave. He very gently held the iPad with his hand over my hand, and pulled it towards his face. I interpreted this as a genuine interest and enjoyment on his part. His parents both affirmed this opinion. (FN May 2015)

Having established this connection between the tablet and his story Jack continued to respond positively to listening to himself reflected back in this way during my visits to the family home. Therefore I was delighted some weeks into the second project phase when Jack's father decided to invest in a tablet computer, thus enabling Jack, his parents and sister to access his memory site anywhere in the house on a hand-held device. We continued to work together to record stories and in the days between visits Jack and his family were now in a position to listen to and engage with his developing 'memory site'. In a follow up interview at the project close, Jack's mother made the following observations:

And just the way he holds the tablet. It's just incredible. He holds it like we'd hold a book, right in front of you, like when you're first learning to read. It's like, 'I've got to hold on to this because it's telling me so much about myself'. He seems to really understand that. I think for Jack to have that kind of concentration for quite a few minutes, it's quite difficult, it's asking a lot of Jack, but he seems to know that's what he's got to do. The understanding of that, no one's told him he has to do that, he's done it of his own volition. (Feedback Interview with Jack's parents April 21<sup>st</sup> 2016)

Towards the end of our collaboration, I was invited to Sunday lunch with Jack and his family. As Jack's sister works full-time I had met her only once to interview her during the first phase of the project. The purpose of my Sunday visit was to record her story about being Jack's sister and also to record the

family singing some of Jack's favourite songs. During lunch we chatted and once we'd eaten we remained around the table together and the family took it in turns to sing to Jack. His mother sang songs that had been especially important during Jack's infancy, while his father used his theatrical voice to bring drama and humour to some of Jack's favourites. Jack's sister sang two more recent pop songs that connected her to her brother. Throughout the sing-a-long Jack joined in laughing and singing.

It was after this that the family told a story about the most difficult episode in Jack's life - when he lost his vision. They stood closely around him and explained how they had become aware that he was finding it difficult to see through his expression of anxiety about being alone. They briefly described the resulting and unsuccessful medical procedure and its aftermath, and concluded by praising Jack for the way he had dealt emotionally with this major life event and how he had taught them as a family what he needed from them to continue to support him to live a full life. Jack made no sounds or movements as he listened with rapt attention.

We were now in the closing stages of the project and the co-curated stories and songs were arranged on to Jack's wiki memory site together with a selection of films made during the previous phase. These films gave a context to the decision making process regarding the site contents and are written up as 'vignettes' (Appendix 13a), and were summarised in text. In addition I included a guide about how to navigate the site and a section about where to locate other stories and how to maximise Jack's participation as his stories were made available to him.

Because Jack enjoys being read to, I transcribed the recorded stories into a book. Each story has a picture of the related object as a reminder to continue making the connection and creating opportunities for choice. The book has a large felt 'J' stuck on to the cover. We know from experience that Jack likes to hold and feel the weight of a book before it is read to him. The intention had been to explore possibilities of raised illustrations as familiar to Jack through the 'World of Art' book series, but unfortunately we ran out of time to pursue this idea.



Figure 4: Jack's life story book and CD (Phase 2)

At the conclusion of phase two of the project, Jack's story was made available to him in a range of formats - via touch screen on his tablet by accessing the 'memory site', on CD and in book form. The content of the stories was the same in each medium and were linked to the same objects for ease of recognition.

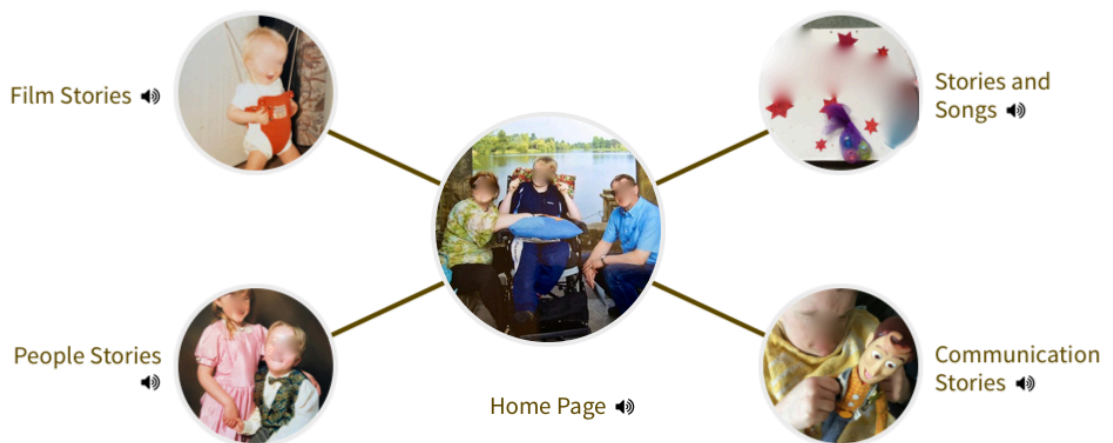


Figure 5: Jack's Memory Site (Phase 2)



## Summary

Drawing on the knowledge learnt in Phase 1 of the fieldwork about how Jack communicated and how his communication was supported a Memory Site was developed to extend his opportunities to participate in life story work. The Memory Site was formed of four sections: 'Film Stories', 'People Stories', 'Stories and Songs' and 'Communication Stories'.

We understood that Jack enjoyed listening to stories repeatedly and that repetition was a way to reduce anxiety and develop anticipation. We also knew that Jack had a good tactile sense and was capable of linking objects with events and experiences. Therefore it was agreed that one way of increasing his participation in life story work would be to link his stories with objects and in this way, after a period of repetitive exposure Jack would learn to distinguish between the object-story and be in a position to make preferences. Using a montage of materials we had jointly examined in Phase 1, a selection of short films were made. Jack and his parents added digitally recorded audio as a sound track to these films.

Because during the initial Memory Site construction stage of Phase 2 Jack's access was limited to the time I was with him at his family home and sharing the site on my iPad, the stories were also made into an audio compact disc. Understanding Jack's enjoyment of being read to and his pleasure at physically handling a book, the stories were additionally transcribed and made into a book. In all mediums the stories followed the same sequence, as this was understood to be beneficial for Jack. However it was anticipated that over time he would be in a position to express his preference for one story over another by using the linked objects.

## 5. Follow up and Feedback

In follow up interviews and correspondence his parents considered that Jack had participated in ways that they hadn't anticipated, as the following extracts describe. Firstly, according to his mother:

I wasn't sure how he was going to be, because obviously we've included Jack in all the recordings, all the stories. He's been with us all the time in the room, going through different things. And I've been amazed at how he's just homed in on what's been going on. It's just like he's got into a little routine where every Wednesday he knows you're coming - Oh it's Noelle today - and it's really, he just sits. And the expression on his face as if he's waiting for something to happen - 'OK guys, what's happening today? What are we going to be talking about today?' We've talked about all the photographs and he's looked as if he's loved all that. And I think Jack has really, as if he's looking, as if he's been waiting for someone to tell my story to, about me and my family. And it's just been amazing 'Yes, this is really happening. Someone else is going to hear about us'. And I think that has been Jack's expression. (Feedback Interview with Jack's parents April 21<sup>st</sup> 2016)

And,

And I think for me that's been the best thing about it, watching Jack's response to his life story, which I think is admirable for Jack. It shows that he's got a real good, we've talked about Jack's photographic memory and his extensive memory over thirty-one years is just incredible. The things that we were talking about when he was a baby, when he was very young, sometimes there's been real recognition in his face, 'Yes Mum, I remember that', or 'Yes Dad, I remember that'. (Feedback Interview with Jack's parents April 21<sup>st</sup> 2016)

And according to his father:

Well Jack, I mean the project has been about Jack and Jack has been fully involved in the project from the beginning. He's been hearing what's been going on, he's been laughing. He's been listening to everything we've been saying. It's prompted me to get a tablet [laughs]. We've got the tablet and we've got it all on there. It's very well organised. It's got great pictures of Jack and his stories and it's very interesting and we're going to have something that we're always going to be able to keep, which I think is great. And I think we've had fun doing this as well, haven't we? Because the time seems to have gone quickly each time you've been here. (Feedback Interview with Jack's parents April 21<sup>st</sup> 2016)

And in conclusion his father said,

Yes. He's participated in it as much as we have in his own way, without a doubt in my opinion. It's like he's been absolutely at the heart of all the storytelling, hasn't he? He's joined in, made his voice heard and really engaged with it. (Feedback Interview with Jack's parents April 21<sup>st</sup> 2016)

Several months later, I received a card from Jack's mother, who had continued to make observations between April and the end of June 2016, and reported that Jack enjoyed listening to his stories, frequently laughing and smiling and was beginning to anticipate the next story. He mirrored the vocal sounds he'd made during recording and clapped during the parts that he particularly liked. He smiled when he heard the names of friends and family and became particularly animated when listening to the story about his back operation. Jack's mother thought that the stories and songs had the potential to help Jack to feel more secure in his own company again - something that had not been possible since his sight loss.

## Case Study 2

### Amelie

#### Introduction

The journey to visit Amelie includes a bus ride along the south coast to the edge of a small town, followed by a short walk down an unmade farm road with stunning views of the rolling farm land and distant cliffs. A little cut through takes me off the farm road in to a cul-de-sac of well-maintained modern bungalows. Sometimes neighbours are chatting or gardening, but often there is no one about and it is very quiet. As I let myself in to the side gate of Amelie's back garden, her little dog runs out through the kitchen door. My arrival usually coincides with the end of lunch - Amelie's team of two or three women tidying up the kitchen, eating their own lunches and chatting and laughing together. At the centre of this activity is Amelie. She sits very still and is leaning back slightly in a moulded wheelchair, watching the women who surround her. She is a slim young woman in her late twenties with dark hair and an attractive face.

As I began to write this portrait of Amelie I wondered what direction to follow, which story to privilege. For Amelie, and other young people like her, the problems she faces on a daily basis have shaped her life story. What became apparent was the need to find a balance between her active engagement in life within the context of the many challenges she has experienced. When interviewing those in Amelie's circle of support, during the first stage of the project I asked them what they thought was essential to her story. Her mother said that Amelie's story was about demonstrating her life in a positive way, that she had had lots of opportunities and experiences. Amelie's mother's partner agreed. A family friend thought that the intensive 'patterning' programme<sup>15</sup> that Amelie had undergone was vital, as was setting up the Independent Living Trust that enabled Amelie to move back home. Her grandparents saw the

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<sup>15</sup> Amelie attended the Kerland Foundation in Bridgewater, Somerset, UK. In 1995 the charity changed its name to Brainwave. According to their current website they provide a programme based on the principle of neuroplasticity. It aims to help the brain find new pathways in the 'neural network' by providing regular repetition of newly acquired skills. For more information see: [www.brainwave.org.uk](http://www.brainwave.org.uk)

people in Amelie's life as essential to her story, the people she likes very much, the big family holidays, the 'zany nature' of Amelie's family and friends. The portrait of Amelie that follows is by no means comprehensive, but rather a snapshot of what I noticed during the time we spent together, or was told in conversation and interview, or picked up from her extensive personal archive during the research fieldwork between March 2015 and April 2016. Amelie's mother appears to be determined to seek constructive and positive approaches for how Amelie lives her life and is supported. She has no time to waste on information that doesn't progress this purpose, as she explained:

I haven't kept a lot of letters from specialists because all they say is what she isn't. So I got rid of them. I got rid of quite a lot of stuff. I kept art stuff, photos, what she did at school. (FN March 2015)

One of the threads that emerged throughout my time with Amelie, her family, friends and support team is this positive attitude, simply expressed by Amelie's grandmother when she said 'we're never going to be defeated'.

Throughout this written piece the iterative and recursive core processes of the fieldwork are referenced. The structure of this case study will replicate that of the previous one (p. 99).

## 1. Amelie's story

Born in North London during the interest rate hike in the late 1980s, Amelie was looked after in her first year by a local child minder, thus enabling her mother to return to full-time work and meet the mortgage commitment. This wasn't ideal, but was a financial necessity and put further strain on the parents' relationship, which ended at the close of that year. Although Amelie has never been given a formal written diagnosis she was described as having 'floppy baby syndrome', caused by 'Delayed Myelination' that would, according to an NHS assessor who spoke to Amelie's Grandfather, 'effect communication between the nerves and the muscles, and he had no way of knowing how long it would go on and to what extent it would manifest itself' (Interview with Amelie's grandparents October 14<sup>th</sup> 2015). Her mother and grandmother were given a bleak prognosis and told that Amelie would never walk or talk, a situation that took them a long

time to accept and required that they 'think what we were going to do because we're never going to be defeated. So how were we going to deal with it?' (Interview with Amelie's grandparents October 14<sup>th</sup> 2015).

As a result of a lack of constructive guidance from specialists, Amelie's mother and grandmother investigated the potential of alternative support in the form of 'patterning'. Her grandmother recalls their initial approach:

So that's when we decided to go to Bridgewater, to the special clinic there. And even when we went down there for an interview and they said, 'What do you want to achieve?' and we said, 'everything. We want her to walk, talk, run, ride, all the rest of it'. (Interview with Amelie's grandparents October 14<sup>th</sup> 2015)

The way they went about dealing with Amelie's difficulties was to invest time, money and commitment into a programme of intensive 'patterning' to train Amelie's brain to learn the steps that make up walking and communicating. Amelie by this time had moved from North London to live with her mother in a chalet style mobile home in her grandparent's garden. The village community and extended family environment allowed for the intensive programme to be implemented and it was successful, resulting in Amelie's ability to move independently and follow simple instructions, thus enabling her, with support, to begin school at a local nursery. In Amelie's archive of life story materials we find progress reports from Bridgewater and many photos of the patterning exercises taking place. It was a challenging few years of intensive training as Amelie's Grandma explained:

And it was very expensive to go there so we had lots of fund raising things to do it. And we used to go there regularly and through doing that we then set up this patterning thing, where Amelie would have patterning for five hours a day five days a week. And we had a team of about twenty people who came in, mostly friends of mine, some friends of Mum's and a few friends who we met through advertising and what have you. And I'm trying to remember how much Amelie's communication was at that time. She used to smile a lot. She used to cry a bit at that time, because some of it was quite testing and we had to be quite hard and stay away from that thing. We knew we weren't hurting her because we were doing it under a very structured plan, but of course, I suppose being hung by your feet and spun on a car hoist was a bit [big breath out], and some of the helpers used to find it a bit alarming, but they realised it was helping her. But we

worked on the thing they said we had to, going through the whole process; pulling to stand, crawling across the floor on her stomach, getting up and crawling on her hands and knees, then walking. We taught her to walk using an overhead ladder, so she could hold the rungs. And she was quite good then at looking where she was going. (Interview with Amelie's grandparents October 14<sup>th</sup> 2015)

Amelie's progress, understood to be a result of the intense programme, meant that she was able to attend a local nursery school with 1:1 support. The nursery was run employing the Montessori philosophy and was chosen for Amelie because of the playfully interactive exploring the world through the senses approach that fitted with how Amelie was developing and learning. The school was a half-mile walk away from home, which provided further practice in walking every day. There is a selection of photos from the nursery that show Amelie sitting at tables with her classmates and also a class group photo.

From Nursery Amelie went with support to a local mainstream infant school and had a very positive experience there until the change of class teacher who insisted that Amelie's needs were too great for the school to continue supporting her. In her archive we find a hand made leaving card that is signed by Amelie's classmates. This was a blow to Amelie's mother who had strong reservations about her attendance at a 'special school'. However, the options were now limited and when Amelie was eight she became a student at the large single site 'special school' some distance away. She was picked up by taxi every day and her mother was relieved that she was that bit older.

The records kept by the special school are a colourful and detailed account of Amelie's school life. They made up a large proportion of Amelie's personal archive and we spent many hours looking through them together. Amelie is seen through this record as an active and engaged member of her school community. Her Educational Statement (1999) describes music as one of Amelie's main motivators. There are photos of Amelie playing percussion instruments, including a big drum that she is dwarfed by. Other areas of interest include swimming and art. Her archive included artwork dating back from her school days and we spent several sessions exploring the textures, shapes and colours of this work during the first stage of the fieldwork. While examining

these records from school days Amelie's team were able to make connections between the past and the present and frequently commented on the connections between then and now. Music, swimming (in the form of hydrotherapy) and art continue to play an important role in her life in the present day.

Amelie's personal archive contained several references to different forms of augmentative and alternative communication (AAC) methods. For example a photo from school captures her choosing her name from a board. School records report that she chooses a drink 'through a choice of two enlarged symbols' and recognises signs 'more' and 'please'. Objects of reference were also been used e.g. riding hat, mixing bowl. Her Educational Statement (1999) reports that 'she really enjoys' Intensive Interaction: 'She thrives on this approach, and gives good eye contact and shows the beginnings of turn-taking' and that she is 'Able to use very simple switches to operate a cause and effect toy. She finds the touch screen computer difficult because of the angle but, with help, she gets a lot of enjoyment out of this'.

Amelie enjoyed a very active childhood in her day-to-day life and from an early age went on activity breaks during the school holidays. The holidays were adventurous and included abseiling, travelling down wires, boating and social events. As well as broadening her life experience, these early breaks provided structured, secure time away from home. The experiences feature in photo albums and diaries, all of which were available to look through and reminisce about. Amelie's mother, wishing her daughter could experience further community engagement, enrolled her in the local Brownies, evidence of which is found in photographic records and Amelie was supported at the group by an older girl who was training to be a group leader and found the experience mutually beneficial.

Structural changes to the school that Amelie attended resulted in the different age brackets being separated. Primary, secondary and further education facilities were co-located with local mainstream schools, thus avoiding the concern of ghettoization Amelie's mother had expressed about her switch from the local infant school. Amelie's mother also realised that, although not an ideal



solution, the teachers and support staff that were now working with Amelie possessed the training and skills necessary to develop her potential. However in Amelie's teenage years, as epilepsy took hold, her mobility was affected. It appeared that movement triggered epileptic drop seizures and this became increasingly difficult for Amelie and her family to cope with, as an entry from a home-school diary records was noted:

Her support worker reads out an entry from her Mum, explaining that Amelie has had a busy summer with highs and lows, but has had a lot of seizures and hurt her face a few times, so Mum doesn't like her crawling around or sitting without support. (FN April 2015)

Epilepsy has been the root cause of many of Amelie's health problems. Amelie's mother recalled the difficulties experienced as a result of these frequent and damaging drop seizures and how it gradually led to her ceasing to walk:

I felt she reached a point where she almost didn't want to walk anymore because it was just too, she just got hurt too much. I don't know, but that was always my take on it. She was having such bad seizures and falling to the floor and hitting her - even though she was wearing a helmet she was hitting her head on things, smashing herself. It must have been so distressing for her. And maybe she also felt weird when she walked, we don't know do we? It could have given her some sort of dizzy feeling, I don't know. And I felt like she just said 'that's enough. I've had enough of this, it's too dangerous'. I think she decided it was too painful and just hurt too much. It created a lot of fear in her. It was impossible to protect her. I think she chose not to move any more. (Interview with Amelie's mother September 4th 2015)

Amelie's mother was very concerned about how the loss in mobility caused by increasing numbers of drop seizures would result in her losing all the things she most loved doing:

And I always thought she'd hate being in a wheelchair because she always liked to go around and touch everything, absolutely everything. And I always felt that what she enjoyed most in life was to, um, be fiddling with everything, touching everything, putting everything in her mouth, looking at it, dropping it, moving on to the next thing. And I thought that was the thing she liked most in the world; going out in to the garden and ripping the heads off the flowers and looking at the petals and then chucking it and ripping the head off the next flower, [laughs], so I was

really worried about her going into a wheelchair because I thought for her it would shut down so much in her life, because it would take away those things that she loved to do so much. (Interview with Amelie's mother September 4th 2015)

The increase in epileptic seizures and her resulting loss of mobility led in her late teenage years, according to one of her support workers who witnessed the process, to a period of depression in which Amelie lost interest in food. Not only had Amelie lost her independence but also due to the increased levels of support required, her mother was no longer able to continue to have her at home. Amelie initially moved to a residential home in Hastings but was unhappy. Her grandmother recalls how she communicated this through her eyes:

I really hit bottom then, because I felt that, and she was looking at me, 'Don't do this, Granny', you know and it was very upsetting. Sorry. So then I said to [Amelie's] Mum, 'we have got to find somewhere else. We have got to do something else. This isn't working. It won't work'. So then, they had been building a special unit over in Canterbury, where she used to go for respite care. So we were really relieved and she went over to Canterbury and she was a changed person. (Interview with Amelie's grandparents October 14th 2015)

As the epilepsy increased it appears that Amelie's ability to process information and actively engage with her world has reduced. Amelie's progress was severely affected by the development of epilepsy, as her grandfather described, because it 'rapidly took away the cognitive processes that she had' (Interview with Amelie's grandparents October 14th 2015). Amelie's health and wellbeing and consequent ability to maintain and develop her skills has been deeply effected by epilepsy, as her mother concluded:

Because certainly, you've seen from the photos yourself, Amelie could do quite a lot of stuff that she can't do now. I think it's probably harder for her to maintain concentration, because remember with the epilepsy you only see, well you might not have seen the seizures but you probably have because you've been here quite a lot, but Amelie has that activity all the time. When you see the seizure that's the breakthrough activity, but her brain is constantly full of electricity that shouldn't be there. We've all got some electrical activity in our brain, but she's got a lot, lot more all of the time, constantly. (Interview with Amelie's mother September 4th 2015)

And so for those closest to Amelie, particularly her mother, this task of excavating and sharing her story was especially important. This was because it resulted, as her mother noted, in a 'broader picture' of Amelie's life to date, it makes her life 'more normal' and therefore easier for others to relate to. When we found for example that she had been a Brownie or that she used to ride a pony, she can be viewed in the context of a life that 'hasn't always been the same'. She is no longer defined in the needs-based context of her care-plan, but has the potential for greater social integration by being viewed as a daughter, an aunty, a schoolgirl, or an ex-Brownie or a fan of musical theatre.

When as the result of a change in management, Amelie's second residential placement in Canterbury began to deteriorate, her mother, having seen the successful set up of an Independent Living Trust by the family of one of Amelie's school peer group, went about making plans to get Amelie home. This plan took some time to implement and involved moving house to the current family home, making structural changes to the building so that it could accommodate Amelie's present mobility requirements and overnight accommodation for support staff. All of this came at a great financial cost and Amelie's mother receives ongoing support from close family to meet the household expenditure. This is yet a further example of the tenacity shown by those closest to Amelie who are determined to provide her with the best possible life she can have, in spite of the challenges encountered.

Amelie's story is also punctuated by long-lasting relationships with family members, family friends and support workers. The relationships are two-way and it is obvious in my witnessing of those around her that Amelie is someone who is both loving and loved. Amelie has a team of people who support her and a group of family and friends that extends out from her home, as described by her team leader:

We all understand her, but we work with her in different ways. She has different relationships with everyone on the team - different people, different ages, different personalities. Her mum likes extended family. She likes it when we involve our families. All of us actually adore her [Amelie]. There's something about her. People are drawn to her. (FN March 2015)

Being in her own home and with the support of a team whose sole concern is the care and well being of one person has opened up opportunities for Amelie to lead an interesting and person-centred existence. She currently enjoys the cinema and theatre, art workshops, hydrotherapy, monthly dry slope skiing trips, sensory sessions and trips out to local, community based cafes, bars and restaurants. I accompanied Amelie on many of these activities and was able to witness her participation in her day-to-day life. She has regular holidays - some with extended family and others with members of her team to explore the UK.

During the first stage of the project my weekly visits fell into a pattern and Amelie seemed to respond positively to the familiarity of us moving in to the lounge and looking through the contents of her personal archive. She appeared to demonstrate memory, which has such an integral role in life story work (Appendix 13b: Vignettes 1a and 1b). For example, Amelie began to anticipate holding photos:

Her support worker gets another photo from the album and Amelie reaches for it with her right hand, while all the time tracking the photo with her eyes. Her face appears animated. She opens the fingers of her hand to get hold of the photo. (FN April 2015)

On one occasion Amelie responded physically to the question 'Do you remember?' when being shown a photo (Appendix 13b: Vignette 2). This was interpreted as a positive sign of recognition and memory. A couple of weeks later I showed the film to another support worker who interpreted Amelie's sudden movement in the same way. Everyone close to Amelie responds positively to the idea that Amelie has memory, although her mother cautions that she may forget skills if they're not practised and this may equally apply to memory of experiences:

What I'm saying is, 'I don't know'. If there was a direct question of 'Do you think she remembers that stuff?' I would have to say, 'I don't know'. There's a lot of don't knows with Amelie's communication. You are guessing. And I think sometimes we like to interpret things, we would like to think that she remembered that, and maybe she did, but I couldn't say categorically, one hundred per cent that she did. (Interview with Amelie's mother September 4th 2015)

People who know Amelie well offered evidence of why they think Amelie remembers, for example responses to particular songs, a position reinforced by a family friend who has known Amelie since she was a little girl:

And she definitely remembers that song, and she remembers other songs too. 'The Grand Old Duke of York' we used to do with her, and that will get a reaction. Now it's not a one off reaction. Every time you sing those songs to that girl she smiles. So that is going back and back and back and back. Now I can't believe she just remembers last time I came I sang them to her. Why would she smile? It's something that is sparking something in her. (Interview with Amelie's family friend September 4th 2015)

Amelie's story is punctuated by change brought about as the result of her profound and multiple disabilities and particularly by the impact of epilepsy on her cognitive and physical abilities. Therefore the story is a narrative of a life repeatedly turned on its axis by health issues.

## Summary

Having introduced Amelie through the biographical information, interpretations of those who know her well and my own observations, I turn now to the main research findings from Phase 1 of the fieldwork and present a snapshot of how Amelie communicates in order to identify the key ways in which to extend her opportunities to participate in this life story work.

## 2. Phase 1: How does Amelie communicate?

This section highlights the communication capabilities that Amelie demonstrates on a daily basis and was informed through an understanding of her communication history as discovered in her personal archives of life history materials, by participating with her in a range of activities and through conversations with her friends and family. It follows the senses, and how we understand them to be used for communication purposes, and includes the body and gesture and a detailed account of what is understood as Amelie's intended communication and the extent to which she understands.

Understanding Amelie's individual repertoire of communication was an essential component in extending opportunities for her participation in her story.

### Hearing and Sounds: Listening

According to her mother Amelie's hearing is fine, although it is not clear how well she is able to process what she hears:

Whether she has a problem processing sound, I don't know. Whether she can make sense of what a sound is, make intellectual sense of a sound, I don't know. I think she can hear sound, but whether she then thinks, 'Oh, that's the kettle or the bus, or whatever', I don't know, but she certainly can hear, because she loves her music and everything. (Interview with Amelie's mother September 4th 2015)

On two occasions I observed Amelie at an art session during which the artist who was working with her used sound as a way of engaging Amelie (Appendix 13b: Vignette 5). Her response would indicate Amelie's ability to track both the sound and vibration on the canvas:

The artist is holding Amelie's left hand against the canvas while gently tapping the reverse side. She lets go of Amelie's hand and taps the reverse side of the canvas, following Amelie's hand as it moves slowly down towards the base. The artist starts to tap a different part of the canvas and Amelie moves her open hand to place it over the area. All the while she is tracking the sound and movement with her eyes. (FN June 2015)

In a sensory session, I observed Amelie tracking a ball that was being shaken by her support worker (Appendix 13b: Vignette 6). As before, Amelie's hearing was supported by what she could see:

[Support worker] shakes a small plastic toy up and down in front of Amelie's eye line. It makes a sound (does it have liquid in it?). Amelie watches the toy move up and down, her eyes wide and a smile playing on her mouth. (FN July 2015)

## Hearing and Sounds: vocalising

Amelie makes a small range of sounds, although this has reduced in recent years. While looking through her personal archives Amelie made some sounds when she had the opportunity to hold old photos and artwork:

‘Do you want to hold it? There that’s better, isn’t it?’ Amelie moves the photo closer to her face and is looking at it with her eyes wider open. She makes a small sound. They drop the photo. ‘Ooh it’s on your nose’ [Support worker] picks the photo up and holds it in front of Amelie’s face. Amelie’s face is animated. She makes a small vocalisation and moves forward, smiling. (FN April 2015)

## Vision and Sight: looking

Those close to Amelie aren’t certain of how well she sees, although her mother thinks that she can see things up close to her. Although she does sometimes watch TV ‘she likes the DVD or the iPad better, because she has them about eighteen inches away. I find it hard to believe that she enjoys them as much as she does if she can’t see any of it. So I think she must be able to see’ (Interview with Amelie’s mother September 4<sup>th</sup> 2015). When looking through family photos and artwork from school Amelie was observed having what her support worker described as ‘a really good look’. This interest in different images and materials was further reinforced at the art sessions I observed (Appendix 13b: Vignette 5):

Amelie is holding a small square sheet of transparent green plastic. She is holding it with her left hand a few inches from her face and looking at it closely. The artist reaches her hand out for it and there is some interplay of hands. Amelie pulls the plastic back towards her face and continues to study it closely. She looks up at the artist. (FN June 2015)

## Vision and Sight: eye pointing

One of the ways Amelie makes choices is by holding gaze on preferred objects, as a friend of the family described when she said that ‘If she really wants something she will really stare at it and she’ll follow it round the room’ (Interview with Amelie’s family friend September 4<sup>th</sup> 2015). Amelie’s mother explained how

eye pointing between two obviously different things can be used and then interpreted as positive choice:

We might do it with a pudding, so you've got a chocolate pudding and a lemon pudding, but you'd have to have something distinctive for her to see that there was a difference. There's no point in you asking her to choose between two things that look virtually the same. So I think it would be alright if one was brown and one was yellow. You could say 'This one's lemon and this one's chocolate'. But she can't look at both at once, so you'd have to (holds up both hands to each side), 'This is blah-blah and this is blah-blah' And then 'OK, so have a look at this one; this is the blah-blah one. Now, have a look at this one; this is the blah-blah one. Which one do you want?' And you take it probably from the one that she looks at for the longest, or the most. (Interview with Amelie's mother September 4<sup>th</sup> 2015)

Understanding how Amelie used her visual senses to identify choice was one way in which she made choices between different elements of her personal archive (Appendix 13b: Vignette 3).

### Vision and Sight: eye contact

Amelie used eye contact with her family and friends to communicate in a number of ways and this compensates for her limited vocal communication as her grandfather commented:

Even in those days she had very good eye contact, because again, we were not getting any vocal contact, that's always been her main form of communication. (Interview with Amelie's grandparents October 14th 2015)

Amelie seeks eye contact with trusted people to communicate a need (for example that she required personal care), and also to confirm when her needs have been met. She also smiles and makes eye contact to express pleasure. Because Amelie is rarely alone a friend of the family wonders if avoiding eye contact is also a way in which she communicates wishing to be left alone.

### Smell and taste

Amelie likes to explore objects with her lips and mouth, although that may be more about touch and texture rather than taste and smell. Her mother



commented that something has to have quite a strong odour to elicit a response:

Smell, again. I think if it's really a bad smell, really strong then you might see her [pulls face and laughs]. You can't see that on the tape, but she pulls a face 'Eeeughhh', but that doesn't happen very often. Where did we go, a while ago and she did that and I thought 'Oh, my goodness. You don't see her do that very often, so it must have been really bad!' [Laughs]. (Interview with Amelie's mother September 4<sup>th</sup> 2015)

## Touch

From my observations during home visits as we explored photos, objects and artworks from her personal archives I noticed that Amelie uses touch in a variety of ways. She explored different textures by opening out her fingers and demonstrated preferences by pulling her hand away from certain surfaces (e.g. polystyrene). She attempted to open flaps and cards with her fingers. She used pressure to move food and drink towards or away from her when supported hand-over-hand. She enjoys painting with her hands and opened her fingers to explore the texture of the paint on canvas. She also liked to explore surfaces with her lips, tongue and mouth as her mother described:

She likes to put things in her mouth a lot and I don't know if it's about the taste or about the texture and feeling what they are, but she's always put a lot of things in her mouth. And I think that's a bit about the senses in the early days, because that's what babies do, isn't it? Put things in their mouth to work out what they are and what they're like. (Interview with Amelie's family friend September 4<sup>th</sup> 2015)

She explored the surfaces and buttons on her musical toys and pressed with support as I observed on one of my home visits (Appendix 13b: Vignette 4). We discovered that Amelie engaged much more with photos when she was able to hold them as opposed to looking at them in an album (Appendix 13b: Vignettes 1a and 1b). Her mother questioned whether this was because Amelie hasn't had the opportunity to hold things, rather than the experience of touching the photo per se:

I think what happens a lot with people with difficulties like Amelie - and I'm including Amelie in that - is I think often they're not allowed to hold things because they mess them up and they ruin them. So it's 'OK, don't touch it, just look at it. Don't touch it'. So I wonder if it's something about, 'But I want to touch it. I want to actually hold it'. (Interview with Amelie's mother September 4<sup>th</sup> 2015)

Amelie's mother thinks that touch is important and has noticed a particular area on the palm of her hand that she likes to feel things with:

And she does that thing with her hands when she wants to feel something. I don't know what that bit's called at the front of the palm of your hand? I don't know if there's a word for it [points to area of the palm just below the fingers]. And sometimes if she wants to touch your hand herself like that, but she wants to touch that bit of your hand. She doesn't want to hold hands. She wants to touch your hand in that way. (Interview with Amelie's mother September 4<sup>th</sup> 2015)

### Body gesture and facial expression

When I began visiting Amelie and looking through her personal archives with her it was quite cold and she sometimes had a blanket over her arms and torso which restricted (or inhibited) her opportunities to express preferences using her body. However, once the blanket was folded down, Amelie reached out her arms and hand pointed to choose between albums of photos, as I recorded in my notes (Appendix 13b: Vignette 3):

I hold each album in front of Amelie, saying 'There's that album from your friend, [School support worker], and there's this album from school'. One of Amelie's team is crouching slightly to Amelie's right. Amelie looks from one album to the other. Her support worker says 'Which one would you like to look at first, Amelie?' and folds down a light blanket that had been covering Amelie's hands and arms. Amelie looks up at me and moves her left hand to her chest. I say, 'Hello' and laugh and repeat 'There's this one from school and there's this one from [School support worker]'. Amelie looks at the album her 1:1 school support worker had made when Amelie left school and reached out her left hand to touch it. (FN May 2015)

Amelie made animated body movements in response to looking at and holding family photos:

Amelie looks at the photo for a few seconds. Amelie is moving her hand around her support worker's arm and hand and is very animated. She moves to her left, bringing her body forward in her wheelchair. Her support worker laughs quietly, smiling and says 'You really like this, don't you?' Amelie sits back, her mouth slightly open, and continues to gaze at the photo. (FN April 2015)

and when invited to hold the microphone during a sensory session (Appendix 13b: Vignette 6):

I say 'Your turn' and sing a song using the initials of her name. She continues to touch the end of the amplifier. I say 'Do you want to hold it?' Amelie moves forward and to her left suddenly, stretching her arms out in front. She is smiling. (FN July 2015)

or when simply pleased to see people, as described by her mother's partner:

I know when we went down to Canterbury she was always pleased to see us. You know, she'd have a smile on her face and was all bouncy and jerky. (Interview with Amelie's stepfather October 7th 2015)

Equally people who know Amelie well can read her body to understand if something is upsetting her, as described by a friend of the family:

I would say if she becomes very agitated - so her body will go quite rigid - I would say there is something wrong. Now I haven't got the expertise that the carers have got, because I don't spend time with Amelie now like I did when she was smaller. So my expertise with Amelie has gone right down, but if she's becoming agitated, to me that says she's unhappy or she needs something. (Interview with Amelie's family friend September 4<sup>th</sup> 2015)

Amelie's movements are restricted however by her moulded wheelchair, although being more comfortable is compensation, as her mother noted:

But I think, yes she does use her whole body. I think probably her chair restricts her a little bit these days. Having said that, it's definitely a more comfortable chair for her than the other kinds of chair where she probably could move more, but overall she'd be more uncomfortable. (Interview with Amelie's mother September 4<sup>th</sup> 2015)

Amelie's face becomes very animated when she's happy or excited as I observed on many occasions:

'Ooh it's on your nose' Her support worker picks the photo up and holds it in front of Amelie's face. Amelie's face is animated. She makes a small vocalisation and moves forward, smiling. (FN April 2015)

However her mother is concerned that smiling and excitement may be connected to the electrical activity in Amelie's brain:

You see like this morning in bed she was very smiley with [her support worker] and I and we were chatting to her in the bedroom and that and I could see she was smiling. Whereas before I'd have thought 'Oh yeah, she's quite happy and pleased to see us, and that', and now quite often if she's like that she'll have a seizure. It's almost like now I think if she's too happy she has a seizure. And I don't know if it's the seizure causing the smiling and the looking like that, or whether it makes her over-excited and then she has a seizure. I'm not sure, but smiling can now be linked to seizures. (Interview with Amelie's mother September 4<sup>th</sup> 2015)

### Communication intent and comprehension

Amelie is able to indicate using small mouth movements combined with eye contact to communicate that she is thirsty, as her Grandma described:

And her eyes opened and I got a slight sideways glance. And then she went 'b, b, b' [smacking lips together], which was indicating to me that she wanted a drink. So that was like 'OK. I'm going to tell Grandma I need a drink'. (Interview with Amelie's grandparents October 14<sup>th</sup> 2015)

Her team report that Amelie closes the lid of iPad when bored or disinterested in whatever she's watching. I observed this when we were looking through scrapbooks and school folders as well. Both Amelie's grandparents think Amelie understands more than she's given credit for, as her Granddad explains:

You've always said that she's quite aware - bright-stroke-aware - of playing one person off against the other, though that's not perhaps as noticeable as it used to be. She would play Mum off against Grandma, or Grandma off against Mum. You know; if Mum says no, go and ask Granny. There were those sort of semi-normal moments, but again, it was

all through the eyes. Through the eyes, an indication of, 'Well she won't let me do it, but you might'. You'd definitely get a sense of that. (Interview with Amelie's grandparents October 14th 2015)

Amelie initiates affection with those she is close to her as I observed when at her home on more than one occasion:

She lays the saxophone on Amelie's torso and Amelie reaches out her right arm to [her support worker], who says 'Yes, of course you can give me a hug'. Amelie hugs her support worker's head to her chest. (FN May 2015)

## Summary

This section has presented an examination of how Amelie uses her body and senses to communicate. It appears that although she hears well, it is not known how much she makes sense of the sounds she hears. Amelie uses her eye gaze to express preference and also to indicate interest. She uses eye contact to develop and establish relationships with others. She is sensitive to touch and it appears to be a key route through which she can explore and make sense of the objects around her. This facility has been reduced since she lost the ability to move around independently. Facial expression and body movements are used to indicate both mood and interest. The next section of Amelie's case study introduces the ways in which her communication is supported.

### 3. Phase 1: How Amelie's communication is supported

This section includes the role of people and of communication tools and approaches that are 'outside' of Amelie, but working in tandem with her individual communication repertoire allow her 'voice' to be heard.

#### How people support Amelie's communication through relationship

Long-term relationships appeared to be vital in order to create the conditions in which to acknowledge and appreciate Amelie's communication repertoire. Amelie has a team of people who support her and a group of family and friends

that extends out from her home. I realised within a few weeks of visiting Amelie that she takes a long time to get to know. Her team leader commented that 'It takes time to see all aspects of her character. It's good that you're taking a year to spend with us' (FN March 2015). A family friend reinforced this position, adding that she had lost the ability to communicate with Amelie because she doesn't spend as much time with her as she used to:

Yes, she has changed so much, and continues to change. And because I don't see her regularly I'm not able to adjust to those changes without spending an immense amount of time with her, which I don't get the opportunity to do now. (Interview with Amelie's family friend September 4<sup>th</sup> 2015)

One of her team who has known Amelie since she was a schoolgirl has noticed how she will always look towards the person she knows and trusts most when she needs support and that person is not necessarily the one she has known for longer, but the one who she trusts to pick up on her needs at the time. Amelie shows her feelings towards the people she likes through affectionate looks, smiles and the occasional hugs. During the course of one of the interviews I reflected on the importance of our different friendships in relation to our stories:

When I read a biography, or something like that, what comes across to me is almost like a series of encounters. There are people who you meet through your life and we are different people for everybody - Amelie would be different for [her stepfather] than to me, to Mum, to yourself - so each person reflects a different aspect of us. Do you think it's important to have that in Amelie's story, because I think in the past I thought 'This is your story. This is your journey', but more and more I'm beginning to see, especially for people like Amelie - but I think it's the same for everybody I've just never been as aware of it before - it's about this facet, this impact, the way Amelie's changed you. So it's a two-way thing. (Interview with Amelie's family friend September 4<sup>th</sup> 2015)

It seems that by surrounding Amelie with a team who have different interests and are different ages, Amelie's mother has attempted to create an environment in which Amelie can develop different types of relationships. Amelie appeared to me to be at her most relaxed and happy with people who chatter and sing to her, and are naturally 'upbeat' characters.

## How people support Amelie's communication through interpretation

On one of my visits to Amelie's home I listened to two of her support workers talking about how they interpreted whether or not she is enjoying a trip out. They explained how it is not possible to build on prior experiences:

Firstly, she can like something one day and not the next. We could visit the farm and she could love it and then another time not enjoy it. It could be something like the breeze. I just know if she's not enjoying something; 'She's not enjoying that. We need to stop. (FN March 2015)

This sensitive interpretation of subtle changes in mood was a key factor in developing opportunities for Amelie to participate. While looking through photos in Amelie's archive, some of which were loose and Amelie was able to hold while others were in different styles of album, her team leader noticed that Amelie seemed more engaged when the photos were loose. This interpretation was based on small, but physically observable differences in Amelie's body language and facial expression. For example, yawning and still while looking at photos in albums, and smiling and more actively engaged physically when holding a photo. This difference was filmed and recorded as an vignette:

Her support worker attempts to take the photo, but Amelie is grasping it tightly, looking at it and her support worker comments, 'Oh, you're not ready yet'. She gently takes the photo from Amelie and turns it up the right way, holding it close to Amelie's face. Amelie looks at the photo for a few seconds. Amelie is moving her hand around her support worker's arm and hand and very animated. She moves to her left, bringing her body forward in her wheelchair. Her support worker laughs quietly, smiling and says 'You really like this, don't you?' Amelie sits back, her mouth slightly open, and continues to gaze at the photo. (Appendix 13b: Vignette 1b)

As mentioned earlier, the moulded wheelchair Amelie currently uses is comfortable and supports her posture, but also inhibits movement. Therefore, when Amelie does make a distinctive movement it is interpreted as interest, pleasure, or in this case 'remembering':

'You do remember!' Amelie moves her torso back into the chair, but her right arm remains extended. Her support worker continues 'in the buggy? She was absolutely knackered afterwards'. A couple of weeks later I showed this film to another member of Amelie's team and as Amelie made

her first sudden body movement the second support worker said 'She does remember', also interpreting this movement as a sign of recognition. (Appendix 13b: Vignette 2)

When I discuss this observation at a later date with Amelie's mother, the difficulties of interpretation are discussed in terms of what Amelie's family, friends and support workers might wish to see in her communication repertoire, rather than the reality. Amelie's body movement, facial expression and tracking of objects is, however, generally interpreted as 'interest', as I noted at a sensory session:

Her support worker shakes a small plastic toy up and down in front of Amelie's eye line. It makes a sound (does it have liquid in it?). Amelie watches the toy move up and down, her eyes wide and a smile playing on her mouth. Her support worker says 'you like this, don't you?' She places the toy in Amelie's left hand and shakes it with her. (Appendix 13b: Vignette 6)

My observations led me to conclude that an interpretation of Amelie's communication was usually based on more than one piece of information. For example, a family friend described how she combined her visual reading of Amelie's body language with confirmation from other sources:

I mean, when I came in today, the first thing I do is try to get down to her level and look at her. Well she looked pretty tired and grumpy today, so I'll do that and you'll get confirmation from somebody else. So as soon as you say 'Are you tired today?' somebody will say whether she is or she isn't. So I would probably say that I read what I think is right, verbalise it and look for confirmation from somebody that would know that information. (Interview with Amelie's family friend September 4<sup>th</sup> 2015)

Her grandfather has noticed how those who know Amelie really well are able to interpret how she's feeling by noticing her eyes:

Grandma and Mum massively, can interpret what Amelie is saying through her eyes. You know if she's frightened, you know if she's really happy. It's the little nuances - the way she looks, how open her eyes are, whether she's looking up or whether she's looking down. There are definite differences in how her eyes look and where her eyes look. Now whether that is conscious or not you can't really say. (Interview with Amelie's grandparents October 14th 2015)



Amelie's mother described how stopping certain behaviour can be indicative of correct interpretations of her needs, as for example if she has been grinding her teeth and then stops. Amelie's mother does not think that her communication is 'multi-dimensional' and that most of the time they are reasonably sure about what Amelie is trying to 'say' as 'she's probably unlikely to be making a movement with her mouth and wanting a bath, but she might be, but, [laughs], we're probably all a bit stuck in a routine' (Interview with Amelie's mother September 4<sup>th</sup> 2015).

### How people support Amelie's communication through vocalisation

Everyone supporting Amelie described and informed her verbally at all times, regardless of whether or not Amelie understood the language used, as when I recorded when her team leader looked through a scrapbook from school days:

Can you feel those? Different textures. [Supports hand over hand]. There. Shall we turn the page? [She is tracking pages of scrapbook] Ah it looks like you've done more. It looks like finger painting [Supports by pressing finger tips over painting and stroking the different textures]. They look like daisies. Look. Do you want to help me turn the page? [Supports hand over hand]. (FN April 2015)

In the first part of this section I have reported how Amelie's individual repertoire of communication is supported by the people who surround her, through the longevity and regularity of their reciprocal relationships that in turn lead to sensitive interpretations and respectful vocalisation. In the next section of Amelie's case study, attention turns to other ways in which Amelie is given opportunities to express herself.

### How Amelie's communication is supported and given agency

Amelie shows interest in the people and objects around her by looking, reaching and touching. Her opportunities to use her body have become limited since her loss of independent mobility. Her body needs to be as unrestricted as possible to permit movement. Amelie's Grandmother explains how objects of reference are used:

Well, we've always offered her choices and it's always been a strong thing with Mum that she wants Amelie to have choices. So there's always been this, you know, 'Do you want J2O or do you want Ribena?' (Grandma holding up both hands). So she's always been offered them, so she sees them and she'll do this (looks from one to the other), and her eyes will stay on the one she fancies. (Interview with Amelie's grandparents October 14<sup>th</sup> 2014)

Choices between drinks, food and clothes are offered in this way, but as her mother described, this isn't always possible for trips out, for example to the theatre. However, her mother would like to see more use of images and objects that reassure Amelie about what is happening:

I think even if she's not really interested in looking at them it's about informing her on what she's going to be doing and that kind of thing, so she's not getting in that car thinking 'Oh, I wonder what's happening today, or where am I going?' Because she might feel nervous or that kind of thing. So, yes I do think they are useful. (Interview with Amelie's mother September 4<sup>th</sup> 2014)

Amelie responded actively to hand-over-hand support, subtly resisting if the pace was too fast or she had lost interest, for example when supported to have a drink or turn the pages in a book. She prefers to move at her own pace, as demonstrated when looking at photos:

Her support worker attempts to take the photo, but Amelie is grasping it tightly, looking at it and her support worker comments, 'Oh, you're not ready yet'. She gently takes the photo from Amelie and turns it up the right way, holding it close to Amelie's face. (FN April 2015)

### How Amelie's communication is supported by routine and repetition

I was curious to find out about how routine and repetition might support Amelie's communication repertoire. Amelie has regular 'routine' activities that she goes to every week including a sensory session, an art group and a visit to the cinema. Her mother doesn't think Amelie's communication is supported by routines per se, but that she understands the pattern of her days that revolve around 'I'm at home, I get up, I go out, I come back, I'm at home again' (Interview with Amelie's mother September 4<sup>th</sup> 2014). Everyone in her team of support workers has an individual way of working with Amelie, but according to

her mother a general routine probably makes her feel safe and allows for the development of anticipation. However she doesn't think routines are a necessity for Amelie.

As discussed above, when Amelie was two years old she began an intensive programme of 'patterning'. For five hours every day for several years a team of volunteers, friends and family worked on repetitive exercises to support her development. Her mother described the principle behind it:

Well patterning is working intensively with, I would say, physio type exercises to try and create neural pathways in the brain so that people can learn to do things that perhaps they couldn't do before. (Interview with Amelie's mother September 4<sup>th</sup> 2014)

Through the practice of 'patterning' Amelie learned to walk independently and follow sets of simple instructions. However as Amelie went into her teenage years much of what she had learnt was lost and her mother doubts she has the capacity to learn in the same way, 'she can't hold on to anything in the same way as she could before' (Interview with Amelie's mother September 4<sup>th</sup> 2014) especially since the increase in epilepsy over the last decade. I did find that as the weekly visits to Amelie's house followed a similar pattern and we repeated certain activities she appeared to anticipate participating as I recorded in an interview with Amelie's Grandparents:

I found that week on week, coming here every Monday afternoon for about three months, to start with it was 'What's going on?' But then after a while it was 'Oh yeah, when you come we get the photos out'. Then from about the fifth or sixth week on, her hand was coming out to hold the photo. (Interview with Amelie's grandparents October 14th 2014)

Amelie's grandfather found this interesting:

That there is some sort of slow burn that is going on in her mind that, not quite, 'Oh Noelle's here, it must be Monday', but rather, 'Noelle's here and this is what we're going to do'. And I've never thought of that before. It might just be that you've hit on something there that's very relevant. (Interview with Amelie's grandparents October 14th 2014)

I wondered at the time if this was linked to Amelie's previous experience of patterning and how regular, repeated activities might be beneficial in terms of supporting Amelie's communication.

### How Amelie's communication is supported by augmentative and alternative communication (AAC)

It was interesting to find that Amelie's personal archive contained several references to different forms of augmentative and alternative communication (AAC) methods as previously reported. However, since leaving school there had been less use of AAC. Amelie's mother thinks that the Speech and Language therapist gave quite an accurate appraisal of Amelie's abilities when she was at school:

I think, in many respects, on a very basic level, they did assess how she communicates, which is sometimes through photos and sometimes through the actual object itself and most other things are beyond her and I think they probably got that pretty much right actually. She definitely doesn't understand symbols, like a line drawing of something. I think that other communication methods are outside her ability. (Interview with Amelie's mother September 4th 2014)

Amelie's mother thinks it's vital that any communication support is appropriate and practical:

I'd rather consolidate or learn to work with her in a way she does understand you, rather than introduce, rather than trying to 'Oh we'll do this because then the next step is she'll be able to do that', because no, she'll never be able to that. I think you can drive yourself crazy thinking 'Oh, we'll get to this level. We'll get to that level. You know, if you do enough of this she'll learn to do it'. I think it just reaches a point where she'll never learn to do it. (Interview with Amelie's mother September 4th 2014)

There is also a strong sense of resignation about both the quality of any potential assessment for use of AAC and the time it might take to test out its appropriacy and usefulness:

Yeah, it would be interesting to know if she could use an eye gaze, but because of the conversation you and I have just had Noelle, we both know that she'd probably need it for three months on loan to see if it's any good or not, see if she can learn to use it or not. She's not going to learn to use it in a day, a week, or in an hour, is she? And I think that is a challenge for services: Make an assessment. Can she use it? No she can't. (Interview with Amelie's mother September 4th 2014)

This comment reinforced my sense that Amelie's age and situation outside of educational provision was a considerable barrier to her potential communication development.

### How Amelie's communication is supported by rich media

Amelie's Educational Statement (1999) reported that she was able to use simple switches and a touch screen with support. On visits to her home I noticed that Amelie showed an interest in screens in general, on the video camera and iPad, was able to track movements and was particularly interested in seeing herself. Amelie has an iPad and one of her support team has noticed that she will close the lid if she's not enjoying a video. She seemed motivated to look at the films on her wiki site:

I sat next to her and opened her wiki on my iPad. She seemed to enjoy looking at the film of herself with the musical bus. We continued to look through the films. She followed the film sections closely and pulled the iPad towards her. (FN May 2015)

Her grandfather considered Amelie's enjoyment of watching film on her iPad and commented that if she was not interested in watching and following a story she would go to sleep, which she does not. However she does not operate her iPad or DVD independently, as a family friend observed:

Right. Well I've seen her with her video, which she's watching in bed, but that to me is more visual, she wouldn't be choosing, pushing buttons. I mean the carers may say 'Which video do you want to watch?' and she'll choose which one she wants to watch, but not operating it. I've never seen that. So, use of it, yes. Interaction with it, using it, no. (Interview with Amelie's family friend September 4th 2014)

Amelie's grandparents questioned her ability to operate any kind of communication device, except perhaps for some kind of 'touch sensitive board with very limited choices'. However, as her mother explained, when Amelie was at school and was still relatively active it would have been extremely difficult to have used new media and digital technology as a teaching tool because she wasn't still long enough for it to capture her attention:

So I think we've got more opportunity than we did have and we should see that as a positive thing and just experiment with it and try using it. I think perhaps a down side of it is that it's quite expensive, isn't it? (Interview with Amelie's mother September 4th 2014)

The cost of upgrading her iPad or investing in eye gaze technology when there is doubt about its usefulness is inhibiting. However Amelie's mother does acknowledge that eye gaze technologies have never been used and may be an effective tool to try:

Well the only thing I'd say about that is if you want to try touch screen, we've never tried eye gaze, we've never had an eye gaze system. I don't know if it's within her capacity to use an eye gaze system or not. I think maybe not, but it's not something that's been tried. (Interview with Amelie's mother September 4th 2014)

Unfortunately there was not time to explore these options further within the time-scale of this project.

### How Amelie's communication is supported by music

Music has always been important in Amelie's life, from early years singing of nursery rhymes to her current enjoyment of listening to CDs and watching music videos. A friend of the family described the impact as 'powerful'. This interest was reported in Amelie's Educational Statement (1999) as referenced earlier. Many of Amelie's team and her friends and family sing to her and she seems to get a lot of pleasure from playing with musical toys (Appendix 13b: Vignette 4). Her team are skilled at personalising the words to songs to include Amelie, as her mother's partner reported:

But she likes people to sing to her, nursery rhymes or that sort of thing. Then you change a word or put something else in and that would bring a smile to her face. It was one of those things that if you sang it, you could sing it again and she'd still smile. (Interview with Amelie's stepfather October 7th 2014)

Music has also been used to 'cheer her up' when she is feeling a bit down 'if she's looking a bit grumpy, if you sing 'The wheels on the bus', the 'knitting', she'll cheer up' (Interview with Amelie's family friend September 4th 2014).

### How Amelie's communication is supported by environment

Amelie is reported to enjoy 'immersive environments', for example the theatre, cinema, circus and live music. I observed her at Project Art Works, the weekly art session she has regularly attended for many years (Appendix 13b: Vignette 5). The sessions took place in a studio environment, artists working 1:1 with Amelie and her group. There was a very focussed atmosphere and music playing in the background. In a similar way Amelie was comfortable in the sensory room where music, light and activities exploring different sensory experiences complimented each other. One of her support workers described the value of Amelie being able to see herself reflected in her environment, both as a projected image (art sessions), and also in static and hand-held mirrors, 'She likes to look in the mirror. Straight away she looks up and you can see the enjoyment in her' (FN May 2015).

### Summary

In this section of Amelie's case study the different ways in which her communication repertoire was supported were discussed. It was found that people, routines, music and environments all played a role in providing a supportive structure within which Amelie's 'voice' could be heard. By understanding the different elements operating within this complex network we worked collaboratively to develop a range of opportunities for Amelie to participate in her life story work - a process that is explained and justified in the next section.

#### 4. Phase 2: Extending opportunities for Amelie to participate in life story work

The narrative described in the previous sections resulted from the thematic analysis gathered in Phase 1 of the fieldwork. The material was drawn from both found materials, as in Amelie's personal archive of life history materials, and in made narratives as derived from participating with her in activities and in conversational interviews with those in her circle. The information, as it was gathered, was placed on Amelie's personal Rix wiki and was used as the foundation for the second research phase.



Figure 6: Amelie's wiki (Phase 1)

At the end of Phase 1 the analysis pointed towards several clear methods for extending Amelie's participation. Through discussions with my supervisors and with Amelie, her team and her mother we made a plan for how we would maximise Amelie's opportunities for participation in her story. What follows is a detailed account of Phase 2.

#### Extending opportunities for Amelie to participate in life story work

Amelie was present at all but one of the following twelve sessions. Using the information gathered in the first project phase we listed the stories that would be



included. Amelie's mother was keen that the project outcome would be useful to two audiences (Amelie and those who support her), both directly and indirectly benefiting Amelie, by informing her team about her story. Our experience of witnessing the importance to Amelie of handling materials became key in the development of our plan. I recorded this at the time in my field notes:

One story will be most useful indirectly to Amelie by informing her team about her story. The other will be a selection of shorter stories that Amelie can choose to share, using photos, and will also include several sensory stories along the 'Bag Book' model. A BIG STORY and a series of SMALL STORIES. Amelie's mother was concerned that the task was too much for the team to complete. I reassured her that I would support them with this. (FN March 2016)

Towards the end of the project as I worked with Amelie's mother to develop a series of stories that would be accessible to Amelie, her mother was concerned that the story would be 'one dimensional' and linear. To avoid an episodic narrative we agreed to group elements of her story into themes, including for example school life, activities, holidays and important people. I printed off sheets of thumbnail photos from those I had scanned in the archive stage of the project and Amelie's mother used these sheets to develop the themed stories. The selections of photos were then used as the backdrop to audio recordings, which together formed short, five-minute digital stories. These stories formed one branch of Amelie's life story 'memory site', which she can access via touch screen on her iPad.

Amelie's mother said that she found it difficult to come up with remarkable events in Amelie's life, but commented that it was remarkable, given her disabilities, that her daughter had done so many unremarkable things like going to Brownies or swimming in the sea off Seaford Head. We talked about our own lives - what is remarkable about most people's lives?

At the close of our first meeting in Phase 2 we had agreed the following outcomes should be achievable in the remaining sessions:

- A box of approximately 30 photos, representative of Amelie’s life, laminated and enlarged to A4, with transcribed stories on the reverse.
- Up to three sensory life stories that reflected what Amelie had demonstrated interest in.
- A series of thematically arranged five minute digital stories using scanned archive photos, records and artefacts and new audio recordings from Amelie’s mother, grandmother and team.
- A ‘memory site’ wiki that would include a home or navigation page, the digital film stories, the photo life stories, the sensory life stories and the communication stories.

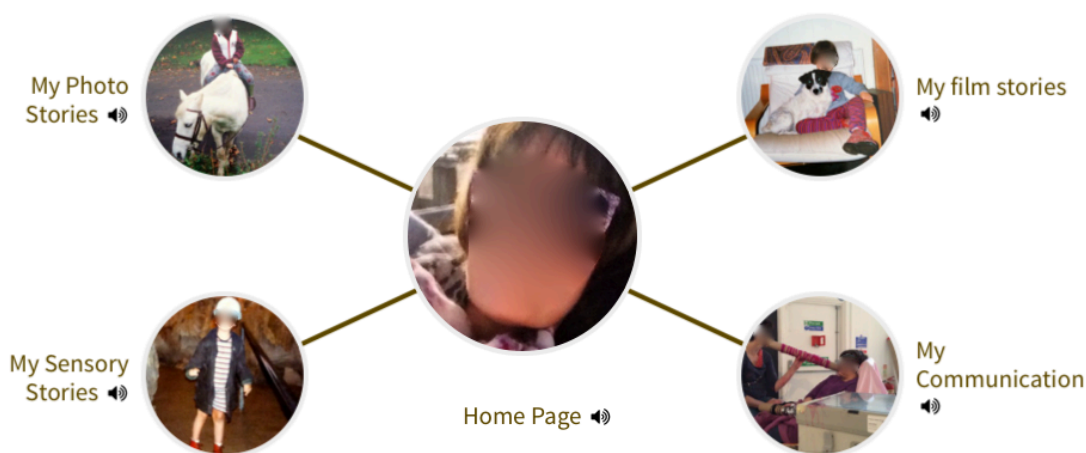


Figure 7: Amelie’s Memory Site (Phase 2)

During the following weeks we worked collaboratively to bring the plan to fruition. Each element of the Amelie’s ‘memory site’ wiki served a specific purpose and was constructed with Amelie’s capacity for participation at the forefront. The sessions included pub lunches translating Amelie’s stories in to ten-line sensory experiences, going out with Amelie and her team choosing and buying the materials required to make up the sensory stories, craft afternoons, laminating sessions and audio recording afternoons. As each element was

completed it was uploaded to the 'memory site' for review. In this way the story and Amelie's participation in 'telling' it developed iteratively.

### Communication Stories

The knowledge gathered during the first phase of the project was the foundation of the new wiki. Each film found in this section reflects a vital element of the decision making that followed. The witnessed observations were written up as vignettes or 'illustrations' and can be found in the Appendix (Appendix 13b: Vignettes).

### Digital Stories

Since Amelie has lost her independent mobility she has developed an interest in film and video. On this basis we were confident that she would enjoy watching these short, five-minute, digital stories that were narrated by her mother, grandmother and team. The idea was that they would be an activity that Amelie could share with whoever was supporting her and create opportunities for Amelie to be seen in the context of her past experiences, not simply as she is perceived in the present time. With support Amelie would be able to use the touch screen of her iPad to press 'PLAY' or scroll through the range of stories and memories made available. As the stories were being made primarily with Amelie as audience, I suggested that the narrators speak directly to her. Consequently the audio typically includes phrases such as 'Amelie, do you remember when we...' and so on. Although not 'telling' her story in a conventional way, Amelie is present as the focus of each anecdote and reminiscence.

### Photo Stories

It was relatively straightforward co-curating the photographs that would be enlarged and laminated. This process was done in tandem with the audio-recordings and with reference to the people, places and experiences that were felt to be significant in Amelie's life. Decisions about which photos to use, if a

selection was available, were made by noting Amelie's assumed preference as expressed through her eye gaze. Once the selection was made and the transcribed stories attached to the photos the team began using them regularly. Two photos were taken at random from the box and held up in Amelie's eye-line. A short description of each photo was given in turn and Amelie was encouraged to look at and reach for her preferred option.



Figure 8: Amelie's Photo Stories (Phase 2)

A demonstration of this procedure was filmed and placed on Amelie's memory site in order to indicate best practise to her team and family members. In this way we were using what we had learnt during the first project phase about how Amelie expressed her preferences and made choices. The same method was used for making selections from her wardrobe, or two puddings as used with her life story photos. The team were also encouraged to read the story on the back of the photo. Should Amelie appear very animated when hearing a particular story or looking at a particular photo they were encouraged to locate the longer digital film version on her memory site and instructions about where it could be found were written on the back of the photos. This practice also reflected what we had appreciated about the value Amelie attached to the holding and handling of photos, and as they were laminated and had rounded corners she was at liberty to explore them with her hands, eyes, mouth and tongue. The team were also encouraged to tune in to Amelie's interest in each photo and resist taking it from her until she indicated that she was ready to part with it.

## Sensory Stories

Understanding the value of touch and holding was also a vital element in the decision to develop several 'sensory life stories'. We chose stories that Amelie had been particularly animated by during the first project phase. Two of these stories, the 'trip to the caves' and Amelie's 'pet dog' were collaboratively developed into ten-sentence sensory stories using the tried and tested guidelines publicly available from 'Bag Books'<sup>16</sup>.

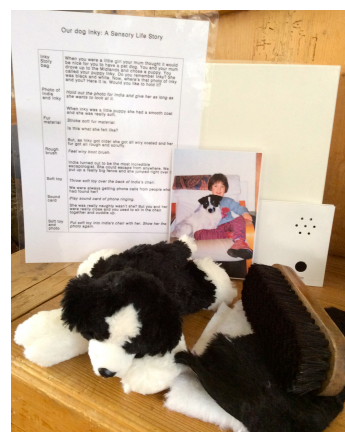
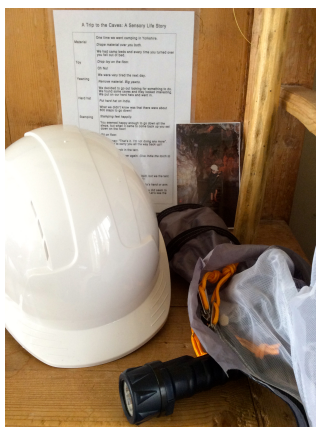


Figure 9: Life stories adapted using Sensory Story Guidelines

Amelie was with us when we shopped for the sensory items and her grandmother offered her services as bag maker. The stories were written with clear instructions about the sequential and timed introduction of sensory stimuli and demonstrated by members of Amelie's team. I filmed the demonstrations, which were then uploaded to Amelie's memory site together with a series of tips about good practice. In order to develop maximum opportunities for Amelie to participate in the stories the team were encouraged, as with the photo stories, to tune in to her responses and allow her to lead the transition from one part of the story to the next. And as the guidelines advised, the team were encouraged to stick to the written script, resist ad-libbing and be comfortable in the silence between sentences. This proved to be a challenge for the animated and empathic team that Amelie was supported by.

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<sup>16</sup> For more information about the charity Bag Books see: <http://www.bagbooks.org>

## Summary

The construction of Amelie's Memory Site in Phase 2 of the fieldwork drew on the understanding of how she communicated and how her communication was supported. Having witnessed the importance of handling and holding life story materials in Phase 1 of the fieldwork this was perceived as instrumental in extending opportunities for Amelie to participate in life story work. The Memory Site was formed of four sections; 'My Film Stories', 'My Photo Stories', 'My Sensory Stories' and 'My Communication' - each in turn providing multiple entryways for Amelie to access her story. Understanding touch to be motivating and a route to understanding Amelie's life story was made available through laminated photos and sensory stories, both of which were filmed for the Memory Site. In this way it was anticipated that the people supporting Amelie could both share the films of her accessing her story through physical routes and be trained in how to do that with her. The intention was that Amelie's Memory Site and the physical resources accompanying it would act to demonstrate the her rich and varied life experiences and provide an opportunity for those who supported her to perceive her in the context of her whole life, not simply as they saw her in the present day.

## 5. Feedback and follow up

Follow up interviews with Amelie's mother and members of her support team reinforced that we had found a number of ways to offer Amelie opportunities to participate in her life story, although one member of Amelie's team acknowledged that they hadn't really understood the purpose of the two-phase fieldwork method until the project close when they witnessed the participatory opportunities being practiced. Although appreciating the time I had spent with Amelie, she commented that 'I didn't really know what you were aiming at to be honest, and it just seemed a long way away at first', while the team leader, who had been my regular contact replied:

I think we were quite open. We didn't know what the outcomes would be, did we? We were just going to try different things and certain things that we tried worked really well, so we expanded on that. (Follow up interview with Amelie's team April 20<sup>th</sup> 2016)

The feedback revealed that making Amelie's story accessible and available enabled a number of different opportunities for shared remembering, as her team leader pointed out when she commented that, 'up until this point the only memories I could share with Amelie were the ones I'd experienced with her'. Rather than being the passive recipient of care Amelie has the potential for interaction. The team leader also felt that knowing Amelie through her story has the capacity to challenge perceptions and potentially improve the quality of care given:

The good thing about it is someone coming in and rather than seeing a young lady who's in a wheelchair - Amelie is not able to verbalise her life, her experiences and everything else - but from doing this she can. It makes her more of a person. It makes people see her differently I think and maybe be a little more compassionate with her. (Follow up interview with Amelie's team April 20<sup>th</sup> 2016)

Amelie's mother was surprised by and had not appreciated that for Amelie handling and holding objects played such a key role in both sustaining her interest and supporting her understanding. I hadn't understood why Amelie became more animated when holding photos, for example, and wondered whether it was by holding them closer to her face she could see them better. Amelie's mother thought that it was more likely that Amelie had not had the opportunity to touch photos and other artefacts because either she would damage them or it might not be safe to do so. Consequently, it's a skill that 'hasn't been well practised because she hasn't been able to do it a lot'. This already limited opportunity was further reduced when Amelie stopped being independently mobile.

Amelie's mother was satisfied that the stories included on her Memory Site showed the range of experiences that Amelie has enjoyed and felt that sharing the site with her team of support workers would demonstrate that her life hasn't always been as it is now, which leads to a broader understanding of her. This belief was reinforced when the team leader reported that Amelie was more likely to be included in conversation due to her story being known and available.

Knowing what activities Amelie had enjoyed in her past also led to ideas for the future and created opportunities for more informed decision-making.

By the project end Amelie's team had begun to use film to better inform their everyday communication practices with her. They realised how much they had been missing as a result of our shared reading and analysis of the recordings we had made together. Equally the team had absorbed the approaches that were noted to be important in Amelie's access to her past in her day-to-day life. The communication they engaged in included greater access to visual and sensory materials; retrospective reminiscence about experiences were more likely to be reinforced with sensory souvenirs. The team felt more confident about how to make a sensory story and had lots of ideas for expanding the range of stories to support both future events and past experiences. They were also enthusiastically adopting role-play as a way of supporting Amelie's communication. The team leader was not complacent about these positive developments however, and had included the review of life story work and its on going development in the agenda for the regular supervision meetings with the team.



## Case Study 3

### Marian

#### Introduction

Marian lives by the seaside. My train journey to see her passes alongside the beautiful South Downs. A thirty-minute ride takes me to the end of the line, to a Victorian seaside resort. There follows a twenty-minute walk away from the centre of town to the edge of a 1950s local authority estate. Marian has lived here since she was a young girl and has a downstairs bedroom next door to an adapted bathroom. The house is full of people - Marian's parents and grandmother live with her and members of her support team come and go. It is a brightly decorated house and the walls display Marian's artwork - large canvasses of bright acrylic. If Marian is at home she can usually be found sitting in the lounge in 'her' armchair - the one in the corner with the best view of the television and comings and goings of the household.

I find it difficult to introduce Marian. Reading through the themed fieldwork notes words like 'mercurial', 'idiosyncratic' and 'mysterious' crop up. Perhaps that is why. Over the months I've spent with her I have been struck by a sense of unexpectedness around Marian. She's unpredictable. One of her team commented that 'when you've just sussed her out she changes the rules' (Interview with Marian's support team October 15<sup>th</sup> 2015). This unpredictability is one of the characteristics that defines Marian and something that her father thinks is challenging for others to accept or understand because 'there is always this need, this natural need, to pigeonhole. These are her needs. This is what she can do. And there isn't really much of a place for this is what she can do today' (Interview with Marian's father September 1st 2015). Not only is it impossible to pigeonhole Marian because she is changeable and unpredictable, but also, as her mother reported, no one really understands how she deciphers the information around her:

So her senses, she's kind of developed them to support her in the way she experiences the world and understands it. And because we don't really

know, entirely, what that's like, the fact that she seems to inhabit the world and uses her senses as she does is her own creation. (Interview with Marian's mother July 27th 2015)

'Marian's story' is made up from a montage of biographical detail, interpretations and reflections and is drawn from a variety of sources including her personal archive, the conversations with those who know her well and my own observations. The portrait is placed at this point in the case study with the specific intention to orient the reader in preparation for the sections that follow and constitute the main body of the research. The sections of Marian's case study follow the same sequence as previously outlined (p.99). Throughout this written piece the iterative and recursive core processes of the fieldwork are referenced.

## 1. Marian's Story

Marian was born in October 1986. She has a sister who is five years older than her and a brother two years younger. She was an apparently healthy baby and ate well but her mother noticed some differences in the way she was developing, although the causes remained unidentified for several years. When she was a year old she became unwell. She had childhood eczema and her parents, in an attempt to ameliorate the condition, tried a range of dietary adjustments. By this point Marian had begun to walk. After childhood inoculations she developed a bad rash. Although she was in the top centile at birth she wasn't progressing and her head circumference didn't grow as expected. Her parents began to wonder if she was on the autistic spectrum. Her younger brother was born when Marian was two and health care professionals credited some of her differences to 'sibling rivalry'. Her behaviour was becoming difficult to cope with, she was screaming at night. The family came close to breaking point. Ever resourceful, they signed up to have trainee childcare assistants from the local college to care for Marian's younger brother. This arrangement allowed for more time to be devoted to Marian.

The family eventually got the diagnosis of Rett Syndrome<sup>17</sup> when Marian was four years old. This led to her being awarded some hours of support. The diagnosis of Rett Syndrome provided some useful information about how Marian was trying to function in the world, as her mother recalled:

The reason knowing she had Rett Syndrome helped was because it took away all the other things that we were thinking it might be and it allowed us to even take away the Rett Syndrome in the end, because that didn't offer any solutions or treatments or anything like that, it just gave us an understanding about Marian. So we could then take that away and stop getting her to do things that were just too complicated for her neurology to juggle, you know, um, and start letting her lead us in a way that achieved more for her, but without our expectations on her. (Interview with Marian's mother July 27th 2015)

It became apparent as I spent time with her family that there was a difference between what outsiders expected Marian to be capable of doing and what she can do. On a visit to Marian's home in the first stages of our research I asked her mother what she felt about the term 'PMLD'. She laughed and began a story about diagnosis, which I recorded in field notes:

Then there was a big fight to get her into a mainstream school, which delayed her start. But it was too much work, so she went to [the local Special Needs School]. And I can never forget the shock when they told me she was going into the PMLD Unit. Was it really necessary, or an insult, or did they just not know? For a number of years I was seen as 'optimistic' about her, therefore, not enough effort was made. There was a lot of wanting to wrap her up and tuck her in. At [the local Special Needs School] they learnt about her really well, but they were stuck in their realm of naming and labelling people. (FN April 2015)

This caused Marian's mother a great deal of distress. She felt that the family would hold responsibility for limiting Marian's life chances by accepting her placement in an environment that not allow her to develop in her own way 'without the pressure to prove it until it emerged in whatever way she was able to make it emerge' (Interview with Marian's mother July 27th 2015). At the time when Marian was at school, various communication aids were made available to her. Buttons and switches, although apparently understood in relation to

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<sup>17</sup> Rett syndrome is a rare genetic disorder that affects brain development, resulting in severe mental and physical disability (nhs.uk website accessed 11.1.17)

cause and effect, were however difficult for Marian to operate because of dyspraxia as well as the element of performance required. Interviewing Marian's mother it is clear that although buttons and switches weren't supportive of her communication, an activity called 'Special Time' was effective. In some ways this was a precursor to the 'whole environment' concept that became important again from Marian's teenage years to the present day:

The one intervention that happened before Marian even went to school which really worked, which really made a difference to how she interacted and responded was something called 'Special Time'. And although it isn't Intensive Interaction, it was like that. You had a period of time when you explained to Marian, 'We're going to do 'Special Time''. You'd have an environment with things in it that you might be interested in and you might not, but nobody's going to ask you to do anything, you're not going to be asked to perform, you're just going to be free to explore it in any way you want and we're going to be right beside you commenting on, saying what you're doing, giving feedback and being with you in it. And that was the one thing that really brought results up. (Interview with Marian's mother July 27th 2015)

Marian's mother was, and still is, interested in how environments detract from or support Marian's communication skills. When Marian was a teenager she became very frustrated and unhappy and her family struggled to communicate effectively with her. In 1997, when Marian was 16 years old she began working with Hastings based 'Project Art Works'. Their work together supported Marian through the transition process from school to college and it was through their approach to working in 'responsive environments' that Marian's mother says 'Project Art Works re-introduced us to our daughter'. A film recording elements of their work and creating a sense of who Marian was at this point in her life was titled 'A Portrait' and showed her in the environments that worked for her; the hydro pool, painting, in a series of cubes, yellow, red and blue. She was, according to her Mum, calmest in blue, looked beautiful in red and was 'distinctly uncomfortable' in yellow. It was this recognition of Marian in environments that 'worked' with her communication that inspired her family and team to explore further. As her mother explains:

She is a very sophisticated absorber of information. The difficulty arises when we try and work out what she makes of it all. That's why whole environments like swimming, art, music are so good, because it's focused.

Once she knows you are picking up on her communication she 'talks' to you. (Interview with Marian's mother July 27th 2015)

The opportunities created in collaboration with the artists working with Project Art Works resulted in Marian realising her creative potential. Given the performative nature of painting, and the severe dyspraxia that challenges every movement Marian initiates and intends, her artistic ability frequently surprises people, as her father explained,

I don't know if you've seen the video of her painting? When they put the paint on the surface of the board and she puts her very Rett, clenched hand on there and after a minute and a half or so her hand slowly, slowly comes undone and she starts applying the paint with her hand. That was an effort. That was something that she knew she wanted to do and it just took a minute and a half - I might be exaggerating, it was probably a little bit less than that - but for her to open her hand and start applying paint on to the board or canvas? (Interview with Marian's father September 1st 2015)

Marian's older sister, herself an accomplished contemporary dancer, has found Marian's artistic expression extraordinary and shared her personal response to the public recognition of her sister's achievements when she said, 'I still remember the time when she got video of her artwork shown at Tate Modern and I thought, [laughs], 'How did my profoundly disabled multiply disabled sister just show at Tate Modern?' (Interview with Marian's sister October 28th 2015). Marian's sister continued by explaining the depth and context of those achievements:

Oh no, that didn't happen because of a charitable organisation called Project Art Works that pushed her to the forefront, but because she's bloody good. Because she helped to make Project Art Works what it is, because of who she is and the artworks that she did and the relationships she fostered. And, yeah, most importantly the expression through art and video work that she co-created with people who would only have made that in relationship to her and would not have had a clue how to make it without her. (Interview with Marian's sister October 28th 2015)

Music, swimming and art were Marian's main interests during her school days and continue in her present life. After leaving school Marian went to an adult social care provision for a few years. Once again she was labelled and placed in a part of the day centre that catered for people with PMLD and challenging

behaviour. For a very slight and delicately built woman, Marian has an unexpectedly strong presence. She seems to have the capacity to hold her own even in challenging environments, as described by one of her team:

She joined four 'strapping' young guys there who all had some challenging behaviour. There was some concern about potential vulnerability in this environment, but she stood her ground and the guys got out of her way. (Interview with Marian's support workers October 15th 2015)

After several years, when the opportunity to set up an Independent Living Trust became available, Marian's mother went about arranging the day-to-day living opportunities that she thought best met her daughter's needs. She recalls the realisation that Marian was able to hold her own after her return from her first trip away from home when in her early teenage years:

She'd found a way and that's when we realised it wasn't just us doing it for her. She was an equal partner in how things were expressed and understood. You have to keep remembering that because sometimes she withdraws and it's harder. (FN March 2015)

Marian's sister describes the sense of relief that Marian wasn't someone they had 'made up', but who they thought she was:

I think we were afraid that she'd go there and we'd discover that she wasn't who we thought she was, that she was something we'd made up and projected on to her, because we had no proof. And I think in a funny kind of way that gave us a sense of proof. It gave us a sense of actually she really is that which we know her to be. (FN March 2015)

In a similar way, once Marian becomes familiar with an environment she is comfortable in, she is capable of asserting her personality, moving around it independently to take 'ownership of the place' (Interview with Marian's mother July 27th 2015). Being assertive and clearly expressing her preferences is one way in which Marian demonstrates who she is. Her team make this clear through one of many examples in which Marian is described as being 'very definite' about what she likes and dislikes (Interview with Marian's support workers October 15th 2015). I discussed this capacity further in conversation with Marian's sister saying:

[A] lot of what I read about and I hear is about people with profound and multiple disabilities being held in what is called 'personhood'. And it sounds from what you're saying, and from what I know of Marian, that your experience runs counter to that. She carries herself through her life and whoever encounters her experiences her, not your interpretation of her, or her mother's interpretation of her. They meet her. It's an extraordinary capacity, isn't it, for someone who is so disabled by their inability to communicate in a way we commonly accept, verbally, to arrive and be herself in such a powerful way?' Marian's sister understood this capacity as the result of her ability to keep meeting the world as it is, 'what else is she going to do? What other options do any of us have?' (My reflections - interview with Marian's sister October 28th 2015)

Marian's sister continued by comparing the capacity for Marian to be herself with what she understands as the delusion common to the rest of us, who think we can control or change ourselves:

And the problem is for the rest of us we all think we can do something about it. You know we think we can get some therapy, wear the right clothes that show us off in the right way, [laughs]. We think we can put ourselves together in a way that will make the world behave differently to us. And that's our problem. Marian doesn't have that problem. She just keeps meeting the world as she is. The problem that she has is that the world isn't always ready to listen to her, isn't ready to fall in love with her and go to that place where you have faith in how you experience a person. And the problem lies with us because we meet people and we think that by asking them what they do, asking them where they grew up, that getting to know someone means being able to write their CV or something like that [laughs]. But actually, getting to know someone means what does it feel to be with them, to hear them breathing, to smell them? (Interview with Marian's sister October 28th 2015)

I had this sense, when listening to her sister talking, of 'Planet Marian'- people orbiting around her as she sustains her central position. I'd seen very clearly when she doesn't like something, or she's cross about something. It is just so clearly communicated and everyone rushes around desperately trying to make things better. And she holds this authority from a tiny physical frame, this very delicate and easily disrupted body, but she has a tremendous power about her. I found it extraordinary. So maybe interpreting Marian is easier than I imagined interpreting someone who doesn't speak, who doesn't use language? And maybe although we use language in many ways to demonstrate how Marian is included and respected, she may well not understand any of the words we use, as her sister concludes:

And I think that's what Marian requires of you. She requires that you accept that the language you speak is incomprehensible, not valid, not useful. You might be able to write poetry, but what really counts in interacting with her is something else. And that's the bit I find really hard to explain [laughs]. There's something else that goes on. (Interview with Marian's sister October 28th 2015)

All those I interviewed in Marian's circle agreed that she could remember and evidenced this in a range of ways, but her communication is limited to the 'here and now'. I ask her mother about if Marian is able to express anything about the past or future?

Oh boy, that is really a million dollar question. If she is, then we're really rubbish, because we're not finding ways in which we're confident that we're answering that capacity. And if she isn't we're inferring a lot of things that are over-complicating it. And neither outcome is particularly great to think about. I do carry a story that this is her world, this is what she's used to, she gets on with it, she makes of it what she can. Bits that don't work she has secret ways of dealing with that that we don't understand, but that mostly she forgives us, a lot. (Interview with Marian's mother July 27th 2015)

Evidence that Marian remembers included her ability to navigate around spaces with which she is a familiar - although not a frequent visitor to, the changes in her facial expression - a smile or widening of the eyes - when hearing a loved one's voice on the phone. Marian's mother recognised how those around her make use of opportunities to reinforce memories, by for example reminiscing about shared experiences: 'we're reliving something of our time with her or our relationship with her or our understanding of her that is very inclusive to her and I think that's the bit where she can operate there' (Interview with Marian's mother July 27th 2015). Marian's sister challenged the premise of questioning whether or not she had memories and whether there was evidence for it when she said 'that feels invalidating. It's like it's questioning her ability to exist' (Interview with Marian's sister October 28th 2015).

Marian's team of support workers think that with the exception of family photos she responds more readily to moving images and that sensory information contributes to Marian's ability to remember, especially in relation to places and



that 'the sight, the sound, the smell even, of a particular place. Everything together makes her feel, 'Oh, I've been here before' (Interview with Marian's support workers October 15th 2015).

## Summary

Having introduced Marian through the biographical information, thoughts and interpretations of those who know her well and my own observations, I turn now to the main research findings from Phase 1 of the fieldwork and present a snapshot of how Marian communicates in order to understand and identify ways in which to extend her opportunities to participate in life story work.

## 2. Phase 1: How does Marion communicate?

This section highlights the communication capabilities that Marian demonstrates on a daily basis and is informed through an understanding of her communication history as discovered in her personal archives of life history materials, when participating alongside her in her day-to-day activities and in conversation with those who know her well. It follows the senses, and how we understand them to be used for communication purposes, and includes the body and gesture and a detailed account of what is understood as Marian's intended communication and the extent to which she understands.

### Hearing and Sounds: Listening

It is not clear how well Marian hears or how she processes sounds. Hearing tests have been inconclusive. Her mother described that although it appeared she could hear things from a distance, she would 'blank out precise, directed sounds that would come at her, like you calling her name or talking or even something very loud happening nearby' (Interview with Marian's mother July 27th 2015). She does however respond to sound like music and voices, but as her mother goes on to say, 'even if, or especially if, it's not directed at her'.

## Making sounds and vocalising

Marian makes a range of sounds to let you know she needs something including 'breathing sounds, vocal sounds, laughing, crying', according to her mother, and some sounds that are like words. Her vocal range changes from day to day and on one occasion when I visited her at home and she was vocalising more than usual her support worker said 'You were yesterday too. At an assessment they were asking loads of questions and you were saying "yeah, yeah". It was good wasn't it?' (FN April 2015). When Marian was very young and before the Rett Syndrome regression began she had learned a small vocabulary of words, some of which she does sometimes use, as her support workers recall: 'there are some words that you can pick out, like 'bed', but she does high-pitched noises' (Interview with Marian's support workers October 15th 2015). Sometimes when she's feeling happy and relaxed, and with people she trusts, her support workers described the following interactive vocalisations:

In the pool the other day we were mucking around and she was really happy and it was a really good swimming session and sometimes you just stand there and sometimes she burbles out these sounds as if she's trying to say something to you. It's nice, calm, burbling and it's like she's wanting that conversation with you. (Interview with Marian's support workers October 15th 2015)

## Vision and Sight: Eye pointing

Marian uses her eyes to communicate and express choice and control in her life. She uses eye pointing in conjunction with other non-verbal communication such as banging the arm of her chair, making idiosyncratic signs or touching the person near to her. However the signals can be fleeting and easily missed. On several occasions I have noticed Marian's quick glances to, for example a snack just out of her reach, which is alternated with a look towards her support worker. Sitting next to her means these furtive glances are easily missed. The team are aware that they need to 'tune in' to these fleeting moments of communication. The family are in the process of exploring the potential of eye gaze technology as Marian's mother understands that it is 'proving to be very

good at generating connections that allows girls to show who they are' (Interview with Marian's mother July 27th 2015).

Eye pointing at one of two items is used to determine preferences, for example between images, as her support worker described, 'When I have photos on the laptop, I'll ask which ones shall we choose and see what she looks at', and between food and drink, which I observed on one of my home visits (Appendix 13c: Vignette 4). Marian's eye pointing is often reinforced by her physical movement in the direction of her preference.

### Vision and Sight: Eye contact

Everyone in Marian's circle reports how powerful it is to experience her direct eye contact. There are many examples of the impact this has on those around Marian (Appendix 13c: Vignette 2). The connection that Marian reinforces through her direct gaze appears to play a strong role in cementing the relationships she has with those around her, as her father commented: 'it does happen occasionally and occasionally she'll burst in to a little laugh, which is wonderfully rewarding' (Interview with Marian's father September 1st 2015). Marian's mother relates the experience to connecting with nature:

It's the same sort of thing as when you inadvertently come across a wild animal, a fox, a deer or something and it looks at you and it's not frightened and you're not frightened and you gaze into each others souls and then you just go on your way. And there's nothing asked and there's nothing taken, but there's something given, an exchange in that way. (Interview with Marian's mother July 27th 2015)

This deep connection seems to happen when Marian is happy and relaxed and doesn't require anything, but is immensely powerful to those who are close to her, and her support workers thought it was a response from Marian to indicate friendship - a way for her to communicate that 'she's comfortable with you, that she knows you understand her and reciprocates' (Interview with Marian's support workers October 15th 2015).

## Vision and Sight: Looking

Looking at her surroundings, the TV (or other screens) and the people around her is clearly one of Marian's strongest means of communication for example, alternating her gaze between whoever is supporting her and what it is that she wants, as described by her father when he said 'she'll look at the TV, she'll look at you, she looks at the TV, saying 'Oi! Dummy! Switch the damn thing on. I'm awake' (Interview with Marian's father September 1st 2015). However it is important not to isolate 'looking' and visual communication, as her mother made clear:

I think that's a little difficult to be precise about because although it's clear for anyone who meets Marian that she has quite a visual acuity, she does look at things and seeing things is important to her, I think it would be really impossible for her to be only using that. I think there are times when you're trying to get her to look at something and she's not looking and she doesn't want to look and I think that's because she's got a much more holistic sensory intake. (Interview with Marian's mother July 27th 2015)

Marian showed a lot of interest in looking at the different items in her personal archive, looking very closely at photos in particular as well as watching film footage. She particularly sought out herself in photos, and enjoyed looking at herself in the mirror, as reported by a support worker: 'we were shopping the other day and she was giggling and very happy and I realised we'd stopped in front of a giant mirror' (Interview with Marian's support workers October 15th 2015).

## Touch

During visits to Marian's home I observed her using touch in a variety of ways. Her touch sense is complicated by the stereotypies that derive from Rett Syndrome, such as wringing or biting her hands, which according to her mother are 'self-referential and help her to know where she is in space' (Interview with Marian's mother July 27th 2015). Her support workers think that her touch is limited because she is 'hypersensitive'. Although she might initiate touch by tapping your arm or scratching a surface she 'pulls her hand away' if she is touched. They consider hand-over-hand would be stressful for Marian. Her

sister describes how her sensitivity to touch results in her missing out on physical contact. However, when Marian paints she uses her hands and opens out her fingers to touch the canvas, overcoming her discomfort, as her sister described:

I think touch is so core to her, but it's also so challenging to her. I don't think any of us do really understand how challenging it is. We can see some bits of it, but [pauses]. In painting I think the texture of the paint is inoffensive, [laughs], it doesn't cause any distress. And the people around her have learnt that supporting her in a certain way allows her to relax and find her way in to that. (Interview with Marian's sister October 28th 2015)

### Body gesture and facial expression

Marian uses her whole body to communicate how she is feeling, but again it is important, as her mother pointed out, to differentiate between physical movements that are intentional and those that are as a result of the neurological effect of Rett Syndrome. As I began to get to know Marian, I became better at judging her conflicting gestures, facial expression and movements. For example, on one occasion I arrived to find her in a very excited and apparently happy mood. It was only after ten minutes or so that I noticed that in fact she was very agitated 'wringing her hands a lot and jumping about in her chair' (FN April 2015). When Marian is bored or frustrated she bangs the arm of her chair, stamps her feet and bites her arm or hits her head. I observed this on several occasions when Marian was unhappy with whatever was on the TV (Appendix 13c: Vignette 1).

Her support workers read her body gestures and movements combined with her facial expression to ascertain her musical preferences, creating playlists from songs she responds positively to (Appendix 13c: Vignette 3). Marian is mobile and moves around independently. When she stands up suddenly and unprompted it is interpreted as a sign that she wants to go to the toilet, although sometimes she stands up and moves around for other reasons as her mother explained when she described how Marian 'just stands up and if she's very motivated she will come and sit next to you or go wandering off. Then it's quite tricky to work out what's going on. She definitely has a whole thing going on.

She has an internal world, a life of her own' (Interview with Marian's mother July 27th 2015).

### Communication intent and comprehension

Working through archive materials we came across a piece of film labelled 'Special Time' and watched it together. Marian and her mother are at home in her downstairs bedroom. There are two large communication buttons on the bed. By pressing one or other of these Marian can operate electrical devices, for example a light or DVD player. Her mother commented that 'it was really difficult to read her responses. She got that you had to hit something to get a response, but her dyspraxia made it difficult for her to do it' (FN March 2015). As a result of complex neurological conditions it was difficult to assess Marian's ability to understand the purpose of AAC tools such as these. Marian's main medium of communication intent derived from a combination of using her body and facial expressions and 'looking', as discussed earlier. Marian alternates her 'looking' from the person she is with to the object in question to demonstrate a range of intentions, which her supporter must then interpret. This object of focus might be, for example, a fleeting glance at food she would like to eat or at the TV or iPad screen to indicate she would like to watch something else. Marian also uses a range of sounds to draw attention to a need, although interpretation is required, as for example if Marian starts to laugh when alone in her room, which can mean 'her DVD has finished, has stopped working, we haven't pressed play properly, or it can mean she's had a wee and is in danger of having a wet bed' (Interview with Marian's mother July 27th 2015). Due to the generalised nature of Marian's intentional communication it requires interpretation, which is not generally straightforward, as her mother says:

But, because we don't always respond, because we don't always know what it is or we don't hear, because it's not like someone saying 'Hey, you, come here, my bed's wet now', because she doesn't say that we know that we miss quite a lot. So she lives in a world where people randomly know what she's talking about, or don't. And I think, I can't imagine what that must be like, but she does laugh when we get it right. It's like she's saying 'Oh, you're a bit switched on today are you?' whereas normally it's 'Oh you bloody lot, I can't get them to understand a single thing'. So she has her, um, her problems with us far more than we have our problems with her. (Interview with Marian's mother July 27th 2015)

In the separate interviews with Marian's parents, I noticed that they had differing opinions about her level of understanding and comprehension. Her father described her as being at the level of a ten month old because she can communicate 'I am upset, hungry, in pain in this one signal' (Interview with Marian's father September 1st 2015). He doesn't however think she is 'stupid', but is at the mercy of a range of neurological complexities that accompany Rett Syndrome:

I believe she's working away nineteen to the dozen behind the scenes, but it's the interpretation of the signals she gets that just get scrambled, that she can do little or nothing with. You get a moment of clarity, every now and then, then it's all back into, what I picture as a swirling of information that meets us all. I think we dismiss the irrelevant and she probably finds it difficult to. (Interview with Marian's father September 1st 2015)

However, Marian's mother considered that difficulties in using standard assessment tools resulted in a general underestimation of her comprehension levels:

But, you know, one of the first tests that she had when she was a year or two old was a hearing test. And the way they do hearing tests and sight tests is they use toys. And they ask children to reach for a particular thing and well, move it somewhere, or a sound behind their ear or something like that. Well her sensory responses were so fluky, you know, she would hear dogs barking but she would refuse to react to you calling her name right by her ear. And there was no test that they had that could meet her and really assess what she was capable of, because they needed her to perform in a particular way to meet their test. (Interview with Marian's mother July 27th 2015)

Being observed, for example when being assessed, seemed to inhibit Marian's ability to 'perform' on cue:

It's almost like by keeping an eye on her you were blocking her and the minute you didn't watch she got up to all kinds of things, which is not actually true, but you almost felt that. So, of course by observing her you'd mark on your thing 'She can't do this, she can't do the other, she won't do this, she won't do the other'. And you had no idea why really, just that she wouldn't at that time. (Interview with Marian's mother July 27th 2015)

Marian's mother remarked that with the arrival of affordable video equipment the family were able to record evidence of Marian's abilities in the every day home environment and counter some of the professional assessments with supportive evidence and that those who saw this 'immediately revised their estimation of her' (Interview with Marian's mother July 27th 2015).

## Summary

This section of Marian's case study has presented the multiple ways in which she uses her body and her senses to communicate. Although Marian is understood to have good hearing and enjoys listening to music, for example, it is not known how she processes sound. She makes a range of vocalisations to call attention to her needs. Marian uses her visual senses as her main means of communication; eye gaze to express choice and interest, eye contact to develop and maintain relationships and direct looking to indicate her immediate interests or needs. She is hyper sensitive to touch, but is motivated through art to use her hands when painting. Although she uses her body gestures to communicate how she is feeling, she also exhibits a range of stereotypies as a result of Rett Syndrome. She has difficulty performing on cue and her responses are often delayed as a result of dyspraxia. In the next section of this case study, the way in which Marian's communication repertoire is supported is discussed.

### 3. Phase 1: How Marian's communication is supported

This section includes the role of people and of communication tools and approaches that are 'outside' of Marian, but work in tandem with her individual communication repertoire to allow her 'voice' to be heard.

#### How people support Marian's communication through relationship

Marian has a wide range of relationships with generations of family members and friends. Her key team is made up of four people: a married couple and another man and woman. When I interviewed them together they all agreed that



it takes time to develop a relationship with Marian to the point where she is comfortable enough to begin communicating with you and you have sufficiently 'tuned in' to her to notice the often fleeting moments of interaction and communication. Longstanding relationships result in an understanding of her idiosyncratic signing system and the ability to sense or predict Marian's needs and behaviours:

I think it's more like an energy when you're with her and in tune with her. Sometimes I've known before that she's wanted something because she starts fidgeting, she moves, and you think 'That's going to happen', because you can feel the different movements that she's making. She might be getting a bit stressed about something and you can tell that before it even starts. (Interview with Marian's support workers October 25th 2015)

One of the topics that came up when interviewing Marian's sister, who was five when Marian was born, was the impact that Marian has had on her friends and family, the reciprocal nature of their relationships. It's a two-way process, as her sister pointed out when she said 'It's the kind of unspoken things and the feeling I have that exists between us, the shaping she's done in me and the shaping I know I've done in her' (Interview with Marian's sister October 28th 2015). When I had the initial meeting with Marian, her parents, her support team and her nominated consultee, this was one of the discussions that emerged. Her consultee wanted Marian's story to reflect not only her life and achievements, but also to include in that the enormous impact she has had on those who have met her and got to know her. The interview with Marian's sister highlighted this as she described the way in which Marian arrived in the world as a person who wasn't able to be the little sister she had anticipated and yet:

She was still available for a relationship. And she was really cute. I mean she was this lovely, squidgy, buttony, gorgeous thing. But she was also at a distance. So I think I fell in love with her, regardless of the heartbreak that she dealt me, [laughs]. Then I think it was, [pauses], it's so foggy to think of what happened in that time, but I think she just taught us. I think she allowed us to love her, whatever that means, I mean I don't know if I can explain. (Interview with Marian's sister October 28th 2015)

Marian has a very powerful way of connecting with those she trusts. When relaxed and not in need of anything she looks long and hard into their eyes and, as previously described, everyone I've spoken to has been deeply affected by this (Appendix 13c: Vignette 2). Marian's mother thinks it creates strong bonds between Marian and her close family and friends, that Marian's direct gaze 'binds them to Marian, absolutely binds them. And they never really forget it' (Interview with Marian's mother July 27th 2015).

### How people support Marian's communication through interpretation

Interpreting Marian is a complex process. From my observations and conversations it appeared that a number of factors are taken in to consideration to arrive at a 'best guess'. For example if Marian seems unresponsive when her team go in to support her through her morning routine, it is not immediately assumed she is unwell because 'there are certain songs that nearly always get a response. If she still doesn't respond then she's either unhappy or she's ill' (Interview with Marian's support workers October 25th 2015). There are also patterns that are used in conjunction with visual clues, for example Marian's menstrual cycle which follows a regular pattern, and this time of the month combined with irritability is interpreted and responded to with the administration of pain killers. However well Marian is known, it is still difficult to accurately interpret her communication, because 'usually you have to decipher, or you have to hope that you're deciphering with reasonable accuracy what it is she's trying to say' (Interview with Marian's father September 1st 2015).

When I ask Marian's mother about the accuracy of interpreting her daughter's complex communication repertoire she opens up the idea of a different perspective. Sometimes simply making the effort creates the opportunity for Marian to be flexible in the outcome of her communication intent, especially when she trusts that more often than not a correct interpretation will be made. And, as her father said 'if you set out across the desert and you're one degree away from your course after about a thousand miles you're a thousand miles from wherever it was you were trying to get to' (Interview with Marian's father September 1st 2015).

But, as Marian's sister notes, Marian does make many of her preferences very clear, 'I mean there is great mystery around who she is much of the time - but if she likes something it's undeniable. There's just a clarity to it' (Interview with Marian's sister October 28th 2015). As well as the indications that back up interpreting Marian, her sister thinks that some credence should be afforded to deeper levels of knowing that are not measurable:

It can be all those things, but I think there is a place as well, [pauses], when you know someone, when you know someone and love someone, even if they're not giving any visual clues or vocal clues as to how they're feeling, you kind of know. Some part of you kind of knows what's going on for them. You might not know it intellectually, but there's something that lets you know that they're happy or that they're distressed. And it's so, it's so on the level that isn't - our culture pays no attention to that level of knowing. It pays no attention to that level of knowing and worse, it dismisses it and rejects it ninety per cent of the time. So it is really hard to count it and validate it in this culture, because it doesn't produce results, you can't document it or validate it easily, 'Yeah I just kind of know', [laughs]. (Interview with Marian's sister October 28th 2015)

### How people support Marian's communication through vocalisation

The family and team supporting Marian vocalise to describe what has happened, is happening and is about to happen as a way of respecting Marian and keeping her informed even though they can't be sure if it is meaningful for her as illustrated by a member of her team:

And also you talk to her about it. 'We're going to Raysted today. We're going to see the cats and the dogs', so you're generally talking about it on the way there, so you're preparing her. You don't just transfer from here to there without any communication. You're talking to her all the time about what we're doing. (Interview with Marian's support workers October 25th 2015)

In a similar way, a member of her team described and chatted through a selection of old photos we looked through together:

Now this one is [Marian's brother] and yourself. And we was [sic] asking your Dad about it this morning [Marian is looking at photo] and he was trying to get you ready and you were causing your brother chaos. Do you remember? Don't you look young there? Do you remember? (FN April 2015)

He asks this knowing that although there is a possibility that Marian doesn't understand the words he is using he will use them anyway as a sign of inclusion and respect.

In the first part of this section I have reported how Marian's individual repertoire of communication is supported by the people who surround her, through the longevity of their reciprocal relationships that in turn lead to sensitive interpretations and respectful vocalisation. Now attention turns to other ways in which Marian is given opportunities for expression.

### How Marian's communication is supported and given agency

Marian communicates both positive and negative sentiments in an assertive way. She does this by using her eyes to look alternately at the object of her dissatisfaction and her supporter, and her body to express the extent of her frustration. Her physical expression can be disturbing to witness when it develops into self-harming behaviours like arm biting, banging her chest and head. She also opens her hand to bang the arm of her chair or, if out in her wheelchair, stamping her foot. In these situations the need to decipher and remedy the cause of her distress becomes urgent and puts pressure on her supporters to act quickly (Appendix 13c: Vignette 1). When Marian is in a happier and more relaxed state it is easier to interpret her communication and also she is more likely to accept a compromise solution. Her main expression of choice is via eye pointing, and this is frequently reinforced by physically leaning in to her preferred option, generally in the form of an object (Appendix 13c: Vignette 4). Her team agreed that Marian 'doesn't really get images' and for example rather than offer her musical choices by showing her CDs, they rely more on observing her facial expressions and bodily gesture, while listening to different tunes and compile playlists from those she responds positively towards:

Well with music I used to, well still do, play her some songs and see how she responds and if she responds in a positive way I then sometimes stop it and try another one, and then over a period of a few weeks I go back and play them again and see if I get that same response and see if she

really enjoys it and likes listening to it. Because sometimes you can get a false happiness because she enjoyed the previous one and she's still on a high from the previous song. So that's what I do with her CD collection. (Interview with Marian's support workers October 25th 2015)

### How Marian's communication is supported by routine and repetition

Those in Marian's team understand that a structure at certain times of day seems to have a positive impact as 'she seems to respond quite well to doing things in a certain order' (Interview with Marian's support workers October 25th 2015). Once a routine is established, her team have noticed it can have an empowering effect for Marian:

I think, the first few times, because it's something new, she doesn't know what to expect and now it's, 'I now know where I'm going and if I don't want to go I will show you I don't want to go'. Whereas at the beginning it was new she didn't have that, I suppose, reference of 'we're going swimming'. It was literally; got changed, 'Oh, OK, now we're in the pool. Now she knows. (Interview with Marian's support workers October 25th 2015)

### How Marian's communication is supported by AAC

Different types of AAC were used with limited success in Marian's school days, as previously discussed, but are not part of her communication support at present. Marian does not use recognisable Makaton signs in her communication, however her team do use a limited range of signs on the assumption that she understands them, as recorded when I observed a swimming session (Appendix 13c: Vignette 6):

Standing together at the end of the pool, [Her support worker] speaks quietly to Marian. He holds his hands and mirrors hers. He appears to suggest 'Shall we do some swimming now?' using the Makaton sign for swimming. He then gently turns her so that she has her back against the end of the pool and points in the direction they are facing. (FN July 2015)

Marian has developed a range of signs that are meaningful to her and understood by her family and team, as they explained:

Yes. Sometimes doing this, touching the top of her thigh, means she really needs to go to the bathroom. That can be a sign that she needs to go, apart from her standing up which might be a trigger that you need to take her to the bathroom. Sometimes she stands up and she doesn't need to go, she just wants to walk around. But a combination of her standing up and the touch. (Interview with Marian's support workers October 25th 2015)

### How Marian's communication is supported by rich media

Marian is interested in digital devices like smart phones, tablets and laptop computers. This was apparent in the first stage of fieldwork on an early visit. I sat a small video camera on the arm of a chair next to where Marian was sitting in order to capture her responses to watching a film about her life and noted that Marian was 'rocking, smiling, very interested in Kodak camera. Mum said it looked like a phone' (FN March 2015). However, her interest in digital devices is not matched by an ability to operate them. As previously reported, Marian's communication strength is using her eyes to point. She loves all the digital devices, but is frustrated by pushing buttons or pointing with her finger. Her family are planning to explore opportunities with eye gaze technology after the project's end. Marian expressed pleasure on occasions when we were together and the iPad camera was reversed and she could look at herself (Appendix 13c: Vignette 5). Although Marian now has her own iPad she doesn't (yet) have the skills to operate it. It is used by her, with support from her family and team, to update her Facebook account, look up information for activities and places to visit, record appointments and watch videos on YouTube as well as Marian's favourite Thomas the Tank Engine films. Given the choice, Marian prefers to watch video on smaller devices like a mobile telephone, as opposed to the TV.

Marian's father considers her 'set in her ways' and, although he hopes he is wrong, he doubts the usefulness of introducing new technological tools like eye gaze at this point in her life. Marian's mother disagreed. She thinks that Marian has an interest in technology and a meaningful purpose for accessing it.

She now, when [her father] or I get our iPhones out, she's like 'zap!' Her eyes are right on it, that sort of glare she has. And she's trying to make it work with her glare because when we're out and wants to switch off from rest the world, she wants to concentrate on something, she wants to watch

Thomas the Tank Engine on this and this is exactly what this is about and she's trying to influence it really hard and if looks could press the button she'd have pressed it. So she understands the TV, she understands the DVD; she understands all of this kind of world that comes out of this technology. And she's got an interest in it. She's got a purpose for it in her life. (Interview with Marian's mother July 27th 2015)

Marian's mother firmly believes that Marian's communication strength as demonstrated in her ability to make choices by eye pointing has scope for development with the introduction of available technology:

And if they can affect something that captures your attention and you can engage with them, then they're participating. And this could well be something that could happen. I wouldn't want to use it just like a button you press like a good little girl when you're asked to do, but it could have a interactive capacity to it that would allow for more understanding and awareness to operate. (Interview with Marian's mother July 27th 2015)

However, Marian's fixation on 'Thomas the Tank Engine' and her understanding that it can be accessed on portable digital devices has changed from being useful to distract her during difficult environments to becoming a difficulty when it comes to exploring alternatives. The team are beginning to see Marian's fixation as problematic:

But the minute you turn it off or take it away that's when behaviours do start, because she wants it back even if she's had it for hours. For instance on the plane - she had Thomas on for four hours and the minute we turned it off she was like 'I want it on', and we were 'No, we now need to get off the plane'. It is an obsession. She won't do anything if that's what she wants. (Interview with Marian's support workers October 25th 2015)

I should explain that 'Thomas' has long standing relevance for Marian due to the original videos offering her the first significant opportunity to express choice and control. When Marian was a few years old she began to learn that she could use her eyes and gestures to indicate a preference between videos and effect outcomes. The impact of this early discovery has developed into a significant bond to 'Thomas' films and is used by Marian as a form of security when she wants to shut herself off from a difficult situation. However, it was only in the recent past that she discovered 'Thomas' could be accessed on a smart

phone or tablet. Her team are working on some strategies to introduce alternative options and phase out the fixation, because as one of the team explains, it is becoming “unhealthy” because ‘it’s got to the point now where it controls a lot of her moods and her social time’ (Interview with Marian’s support workers October 25th 2015).

When I asked Marian’s sister about the potential that rich media may have regarding opportunities for her to participate in life story work she thinks there is scope for development, but maybe not offering opportunities in the ‘telling’, but more in the ‘sharing’? More in the sense of, ‘If I tap this I can look at my picture, or I can look at a bit of film from when I was sixteen at Project Art Works’ (Interview with Marian’s sister October 28th 2015), thus able to access her own memories and share them with those sitting next to her.

I could see that, but not in the kind of [pauses], oh she’s going to switch on to it straight way and it’s going to be this marvellous thing. Just in the sense that she does have that given time and patience she will become interested in something in front of her and if she touches it and something happens and then she gets a memory or a painting that she painted years ago, or something more current - a message from a friend or her sister, or her nephew [laughs], or whoever - I could see that. (Interview with Marian’s sister October 28th 2015)

This would maybe take away this sense of us only being able to communicate in the present with Marian. Although Marian’s sister acknowledged the potential for sharing memory in this way, she was concerned that the stories could be accessed in a way that diminished Marian’s interaction with her story, which she addressed by asking some interesting questions:

Are you interested in looking at what’s someone’s put together, fragments of Marian? Which is very interesting, don’t get me wrong, there’s some really interesting stuff there. Or, are you interested in Marian interacting with her memories? Are you interested in Marian now having a relationship with these things? And if so, are you prepared to be patient and sit in the not knowing if she’s going to tap in to it. Are you prepared, if you have a strong impulse to press one and you press it, to sit in the aftermath of that and notice if she not interested? (Interview with Marian’s sister October 28th 2015)

Notwithstanding this cautionary note, Marian’s sister did see the potential for participation and consequent sharing to a wider audience.



## How Marian's communication is supported by environment

Marian's mother is interested in how environments detract from or support Marian's communication skills. As previously mentioned, when Marian was a teenager she became very frustrated and unhappy and her family struggled to communicate effectively with her. In 1997, when Marian was 16 years old she began working with Hastings based 'Project Art Works'. Environment alone does not create these opportunities however. Marian needs to be motivated by the activity itself, be it music, dance, swimming or painting. Additionally the communication happens because another person is in the environment with her, as her mother highlighted:

Well I think fundamentally when you talk of whole environments, it means you are part of the environment with her. So it's not that stand-back observer or operator environment, where you do something and you expect a performance back from Marian. (Interview with Marian's mother July 27th 2015)

When Marian was a young child this kind of playful activity was natural and reflected elements of Intensive Interaction practice, as her mother explained:

You know, if Marian was on her Dad's back and they were galloping around and he stopped she would tap him to get him going again, but if she was sat over there and he was galloping around and he stopped, she wouldn't even look, there would be no engagement in that. She might know that he'd stopped and she might quite like him to go on, but there would be no, she would have no rhythm connection to what was going on to be able to operate within it. (Interview with Marian's mother July 27th 2015)

Marian's mother recognises that a key aspect of the effectiveness of whole environments is the shared experience of both Marian and her supporter, as she explained:

But the whole environment, swimming, when you're in the water with her and you're swimming, then there was a connection, then there was engagement. I mean you didn't have to be holding on to her, you didn't have to be doing what she was doing, but it was kind of like she knew you were having the same kind of experience that she was, so it was much

easier to pass information back and forth in that environment. (Interview with Marian's mother July 27th 2015)

The same might happen when listening to music together, watching TV together, being out walking on the seafront. Being comfortable and familiar with an environment along with a personal interest therefore creates opportunities for Marian to be herself, as her mother explained:

And when she, when she really got to know a place, when the layout and the use, the purpose of it, the expectation of it all became very normal to her, she could then operate quite freely within it and she would know what she wanted to do. And she could demonstrate that. So, the capacity to perform in a way that was true to that environment would be more easily accessible to her. (Interview with Marian's mother July 27th 2015)

These observations were reflected in the life story work I did with Marian in her home. After six weekly visits and the development of a familiar routine of looking through photo albums and school records on the sofa next to Marian's armchair, I was pleasantly surprised when she got up and came to sit next to me. Although she didn't gaze continually at the album's content, she was more engaged, more relaxed and more interested from that point on. It had become a shared activity that we were part of together. I had relaxed into the task and was not expecting participation, while at the same time gently inviting it. I had tuned into the subtle nuances of Marian's nonverbal communication to have the confidence to 'feel' when she was ready for the next page, or wished to linger over a photo for a few moments longer. I think it was at this point I began to understand how the practice of immersive environments could open up opportunities for extending participatory life story work.

## Summary

In this section of Marian's case study I have shown how people, routines, AAC, rich media and environment - elements that are outside of Marian - provide the supportive structure that allows her 'voice' to be heard. Following the conclusion of the first fieldwork phase we collaborated to use the knowledge of these elements and how they worked together to develop a range of possibilities for

Marian to extend her participation in her life story work - a process that is explained in the next section of this case study.

#### 4. Phase 2: Extending opportunities for Marian to participate in life story work

The narrative described above resulted from the thematic analysis of material gathered in Phase 1 of the fieldwork. This material was drawn from both found materials, as discovered in Marian's personal archive of life history materials, and made narratives that derived through participating in activities and interviews with those in her circle.



Figure 10: Marian's wiki (Phase 1)

This was placed on Marian's personal wiki (Phase 1) and the information we had gathered was used as a foundation for the next phase. The second phase of fieldwork didn't begin smoothly. The first week was cancelled due to the impact of stormy weather on the railways. I had planned to spend some sessions with Marian and her mother initially, but this was postponed due to Marian's grandfather's death. We did however achieve several practical aims via email; the team were going to locate some digitised archive film clips, advertise on Marian's Facebook page for photos and stories from her Facebook

friends and attach the same request to the monthly newsletter emailed out to friends and family (the A4 newsletter comprised a brief visual and written record of the previous month's activities). In this way it was hoped that the project would reach a broader audience and gather stories from the wider circle. We also began to think about Marian's new site as being like an accessible digital memory museum, with sections including archive film footage, back issues of the newsletter, different people's anecdotes and memories and places where other stories might be found. There would also be a section on the site titled 'this much we know' that might include the short films gathered in the previous project phase showcasing how Marian makes choices and how to sit with her while she chooses and shares her stories, for example. We agreed that laminated screen saves of the site might support her choice-making and would also fit with the eye-gaze induction programme. Interestingly we also had a broad discussion about how Marian never used her iPad independently. She always has someone with her, both to hold the tablet and to interpret her choices about usage.

In the following few weeks I began to make short digital story films using archive footage and photographs and records from Marian's archive that we had examined together previously. Marian's mother contributed audio to these, addressing her narratives to Marian, and in this way we built up a collection of stories, including for example Marian's life as an artist. We continued the dialogue about the pros and cons of eye-gaze technology, and the team began to trial E-Trans<sup>18</sup>, to compliment the flipbook. Marian had also begun a series of visits to specialists to explore using eye-gaze and was receiving support from a speech and language therapist. A funding application to the local authority to cover the costs of speech and language support, team training and the technology itself had been submitted. The funding application was successful, but unfortunately for this purpose, it came through after the completion of fieldwork.

A familiar feeling began to emerge as the first few weeks of the second phase went by. I had experienced it while working through the different stages of the

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<sup>18</sup> E-Trans comprises a sheet of perspex a bit bigger than A4 in which letters of the alphabet, (or symbols or photographs) are grouped in each corner of the board.

first phase and I recognised it again when beginning to write about Marian here. She is mercurial and I had been trying to pin her down by linking a series of titles: 'Marian moves her body in the direction of what she wants'; 'Marian makes choices by fixing her gaze' with short films to provide evidence. I had been able to do this relatively easily and successfully with the other participants, but with Marian it felt as if I was swimming against the tide. When I spoke to Marian's mother about this she reminded me that it had never been possible to construct a communication type passport for Marian that followed the prescribed script: 'If Marian does this we think it means that'. This conversation helped us to develop a better approach, which I recorded in the following field-notes:

What we will do is film Marian sitting next to her mother who will summarise our findings and link them to the site. We will do this by using 'Because we have evidence that Marian remembers and because we understand how she expresses preferences e.g. eye gaze, facial expression etc., we can use this site to expand/extend Marian's opportunities to make new narratives. She can choose between films and while she is watching them we can notice her responses. Using our observations we can begin conversations. Was it working with [artist] that you enjoyed most? Was it being in that space with the music, the chair...Using photos? (FN March 2016)

It was at this point that I began to understand the wider potential application of the 'Memory Sites': by making the life stories available, in whatever format was most accessible, we were creating catalysts for conversations. By using the new approach of 'because we understand this about Marian' in an open and non-prescriptive way, we were allowing viewers to tune in and make their own observations rather than looking only for the specific examples I had planned to include. Rather than fixing and pigeon holing, this approach opened up opportunities for idiosyncrasy and expansiveness. The planned filming session exceeded our expectations. Marian, returning home after a few days away, was pleased to be re-united with her parents. She sat on the sofa next to her mother and we made a series of films that clearly established the way in which Marian's 'Memory Site' could be used as a tool for shared remembering and as a catalyst for conversations and creating new memories. These films acted as a reminder for those supporting Marian to be mindful of their personal agendas and to be at ease with tuning into and following Marian's interest from moment to moment.

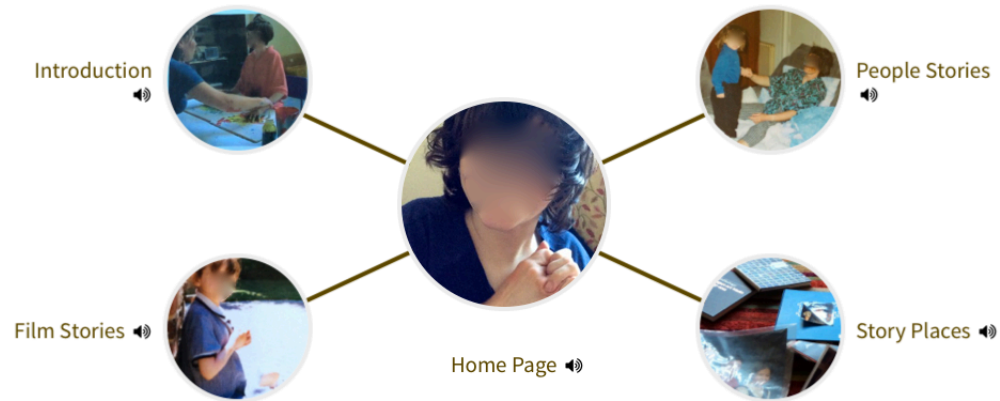


Figure 11: Marian's Memory Site (Phase 2)

The Introduction section of Marian's Memory Site is opened with 'Getting Started', which is a short description of its purpose:

In this section of Marian's site we introduce how you and Marian can make the most of her life stories. Marian, with the help of her mother, demonstrates her communication skills, shows how she makes choices and why it's important she is in control. Lastly, and perhaps most importantly, her mother suggests how to use the stories on the site to sow the seeds of new experiences and make new memories with Marian. (Marian's Memory Site)

In the series of four five-minute films Marian and her mother worked in unison, and without any observable self-consciousness of my presence, to demonstrate an organic, tuned in approach to participatory life story work. For example, during the filming session, sensing that she might be hungry, her mother offered Marian a biscuit from a large tin. Marian directed her gaze and her hand movement towards a particular biscuit perfectly demonstrating how she shows preference. There was a delay between Marian's mother offering the biscuit and Marian opening her mouth to take a bite, a clarification of both Marian's dyspraxia and suggesting how to respond with patience. Marian also vocalised during the filming, making what her mother described as a 'purring' sound, another indication that she was enjoying the activity. We were able while in the process of filming to directly relate the shared activity of choosing and eating biscuits to choosing and sharing memories from Marian's Memory Site, but with an open-ended - as opposed to prescriptive - attitude.

Marian engages in many stimulating and creative activities in her day-to-day life and one of the short films in this section examines the role of life story work within this active life and explains that 'spending time on her life story website should always be a positive choice'. This film was supported by ideas about ways in which Marian could have screen save images of different iPad based activities before the iPad is opened. The final film is titled 'What Next?' and Marian's mother opens up the different ways in which engaging Marian through her stories can create opportunities for sharing new experiences. This is possible if attention is paid to what Marian shows interest in, which may not be what is anticipated, and by following her lead.

Towards the end of the second phase of fieldwork, I was invited to join a family gathering to film Marian with her father, brother and grandmother who had all consented to participate. These short films were placed on a section dedicated to the people in Marian's life - their memories and stories and the impact Marian has had on them. Another part of the site, called 'Story Places', signposted the many physical locations which held Marian's story, including for example, paintings on the wall, photo albums and school records. The 'Memory Site' was coming together and we agreed it reflected some of the many facets of Marian's life and was a sound foundation for future growth.

## Summary

In Phase 2 of the research, Marian's Memory Site was created in response to our shared understanding of her communication repertoire and the ways in which it was supported - as an individual who was understood to be motivated by visual imagery accessed via digital platforms. The Memory Site comprised four sections including an 'introduction', 'film stories', 'people stories' and 'story places' and each section included a series of digital films, providing multiple entry ways into her site. The 'introduction' comprised a series of short films that foregrounded the various ways in which the Memory Site could be accessed and used by Marian and her team as catalysts for new conversations. The 'film stories' section included a collection of themed digital films created from a montage of materials found in Marian's personal archive that we had examined together in Phase 1. The film story soundtracks included digitally recorded

audio spoken directly to Marian by her mother. The 'people stories' section of Marian's Memory Site was an opportunity for those who were close to Marian to recall their memories of her and describe the impact she has had on their lives. In 'story places', the final section of the Memory Site, signposts were provided to direct those supporting Marian towards the location of further materials. Screen save images captured the visual imagery of the Memory Site and the different component sections and were used to support Marian's choice of access to the website prior to it being opened.

## 5. Follow up and Feedback

After the fieldwork was completed I met with Marian's mother to review the previous fourteen months and consider both Marian's participation in the research and its wider value as a piece of work. We began our reflections by returning to the first stage of the first phase - an examination of Marian's extensive personal archive of life history materials. Her mother explained how the family was not prone to collect and display family memorabilia, but with Marian they had felt impelled to do so:

A lot of time it was about having evidence of her presence, of her reality, of her being in the world, because so much of what normal living in our culture said was that someone like Marian didn't count and therefore didn't really exist and would only exist if she could co-operate in presenting herself in acceptable ways, all of which were pretty much beyond her. And so we became - us and her teachers and all the people who are involved in her world and with lots of other PMLD individuals - we became her archivists to try and maintain a level of evidence for her. (Feedback Interview with Marian's mother, April 19<sup>th</sup> 2016)

I had been surprised and fascinated by Marian's level of participation and observable interest in that process, as her mother recalled:

And then you were suddenly aware that Marian knew it was her evidence, it was hers. Kind of like we sometimes say, 'The doctor's keeping records of us', but they're not the doctor's records they are our records. Because that's a whole shift in where power lies. They're not records that allow the state to judge us and do things with us without our consent. They are ours, they're in our hands, we have a say. And Marian's response was perfectly normal and similar to every one else's in that she showed how in a way, 'this is mine. I remember this. This is something to do with me and I own it



with my interest, not with my need to have a voice in it, which was the whole reason why you wanted to do the PhD in the first place, to find out how to present that in a way that would allow the culture to start valuing it. (Feedback Interview with Marian's mother, April 19<sup>th</sup> 2016)

We went on to discuss the social and political implications of the research project, and how Marian's family's need to 'evidence' who she is can be understood in this context at a time when people's value is regularly measured and scrutinised. Marian's mother introduced the concept of 'othering' and how marginalised groups can be subject to this experience,

If you think about the values and the structures of culture as being what hold the human population, the way that it works is that it's almost snipping great holes out of the bottom of that bag and disposing of huge numbers of people who are considered as other. It's an incredibly timely re-interrogation of how we as human beings sometimes provide ourselves with reasons why we can dismiss others. For Marian and for others like her with PMLD, they are also people who have lives exactly as ours are. It's just that for some reason we have a human ability to paint that out and to make hoops through which they have to jump, which they are incapable of jumping through, in order to preserve our blindness to them. And once you are no longer blind it is perfectly obvious, but while you are blind there is nothing that you can be shown that will get past that block. (Feedback Interview with Marian's mother, April 19<sup>th</sup> 2016)

Reflecting on how people like Marian are afforded equal value and status in our culture her mother said:

And when I interrogate myself about how I feel about Marian in our lives and in the world, I always think that she is one of those people who has come into the world to, to make sure that we have to face the absolute worst of ourselves in order to remember how hard and how important it is to build the best of us. It goes a long, long way beyond making sure her pad is changed and that she's fed and kept healthy. It goes so far beyond that. Those things often stand in for the value of a person - the right for this, the right for that - but actually the real right is the right to be acknowledged as 'us'. (Feedback Interview with Marian's mother, April 19<sup>th</sup> 2016)

Finally, Marian's mother looked back across the creative, iterative and collaborative process, which we had shared throughout the fieldwork and in which we drew on 'the ability to really return to reflect again and again and again' (Feedback Interview with Marian's mother, April 19<sup>th</sup> 2016) on both the

knowledge that had been gathered and the way in which it was used to extend Marian's participation.

## Chapter 5

### Discussion of Findings

#### Introduction

Having introduced the three participants through their case studies it is useful to begin this discussion by summarising the findings in the context of the questions asked by this research enquiry. The research questions are discussed in the following order: (1) How are the three people in this study living their lives? (2) Was participatory life story work of benefit to the people in this study? (3) What were the barriers to participatory life story work? (4) How were opportunities for participatory life story work extended? The four sections in this Chapter are the result of the iterative, inductive thematic analysis, which Pink (2015:142) describes as a 'process of abstraction', which serves to connect 'complex phenomenological realities' with academic debate (2015:151). The main themes that emerged from analysis included how the key participants communicated, how their communication was supported, interpretations of their personalities and life story practice. Separating out the complex realities of the everyday made visible their interdependence. However, the untangling of the different elements identified in the thematic analysis resulted in a tidied up and somewhat reductionist picture that required rearranging and reweaving for presentation in the case studies and this chapter. Therefore the sections of this chapter synthesise a wealth of complex data into four key areas that cut across all three case studies.

#### 5.1 How are the three people in this study living their lives?

All three people who were at the heart of this research eventually received a diagnosis. Jack has a hairline crack on one of his chromosomes, Amelie has delayed myelination and Marian has Rett Syndrome. This information tells us very little about these individuals, as does the label PMLD. In all three cases the families explained how knowing there was something different about their children can be used positively and negatively. Having a diagnosis can remove doubt and blame, for example. A diagnosis that is unique, as in Jack's case,

has limited use because it provides no information about prognosis or care. However, in Marian's case, a diagnosis of Rett Syndrome, although it covers a vast range of possibilities, does help the family to understand what has happened to Marian and why it is so challenging for her to operate in the world. The main concern regarding diagnosis and labelling expressed by the families is however that it can result in low expectations and therefore limited provision and life opportunity (Simmons and Watson, 2014a).

In spite of their diagnoses and limited communication abilities all three key participants in these case studies showed evidence of reciprocal relationships and demonstrated strong characters and assertive behaviour. They utilised their communication repertoires effectively and skilfully and allowed others to see clearly who they are and this apparent vulnerability was perceived as a strength, as for example in the case of Jack, when his mother reported that he wasn't worried about expressing his emotions (p.102). And in a similar vein when Marian's sister describes how Marian is able to be herself (p.175)

All three key participants are integrated into a wide range of social networks and cultural activities and were found to be 'fully human and encultured beings' (Klotz, 2004). As such, notions of being 'held in personhood' (Lindemann, 2014) may be redundant. It would seem that the key participants in this study were capable of expressing who they were without recourse to independently telling their stories, for example as reported by Marian's sister when recalling the first time Marian was away from home and evidence was provided to confirm that 'she was who we thought she was' (Interview with Marian's sister October 28th 2015). This would support Brockmeier's (2015) position that autobiographical practices are not the only practices that define our identities. Knowing Jack, Amelie and Marian through their stories revealed their 'social and cultural engagement in the world', which in turn 'allows for their personhood to emerge' (Simmons and Watson, 2014b:16).

All three key participants in this study have significant health issues and therefore it was important to negotiate how much of this information to include while not wishing to dominate with narratives of illness, or 'fixing'. However the health issues faced by the three participants are hugely important aspects of

their lives and it became essential to consider ways to reference them. In a similar vein there was a need to consider the participants' stories of loss and how those experiences might be sensitively woven into the fabric of the memory sites in a way that supports notions of resilience and emotional well being, as for example in the case of Jack's sight loss. This brought to mind the ethical challenge of finding the balance between neither over-burdening nor over-protecting the people with PMLD at the centre of this study (Nind and Vinha, 2013:14), and recognised the key participant's impairments as important aspects of their stories and identities (Crow, 1996).

As a result of the PMLD label ascribed to the key participants in these case studies they attended 'special school' provision and, although two of the families did not want this to happen, they felt there were limited opportunities to challenge the system. The parents were concerned that their children would be socially isolated, as in the case of Amelie. However, once in the system they found that their children's teachers were highly skilled and the options for individual provision and support were on stream. But there remained concern that being in an environment that catered for people with the highest support needs would lead to a general lowering of expectation, as Marian's mother expressed (p.171).

All three key participants had access to AAC, and had limited success with cause and effect type buttons and switches, but did find approaches using the principles of II useful. The school curriculum that supported the participants' communication and wellbeing included music, sensory stimulation, swimming and art. All of these are still part of the participants' lives in the present day and could be understood as potential foundations of 'responsive environments' (Ware, 2004).

## 5.2 Is participatory life story work of benefit to people with PMLD?

Because people with PMLD have limited communication repertoires they are not able to access their pasts independently. Life story work, in all its forms - listening to stories, exploring archives, visiting places - brings the past into the present moment and makes it available and accessible to people with PMLD.

This enables the potential for 'shared acts of remembering' (Middleton and Hewitt, 2000) as a contemporaneous activity. It is this activity that leads to a number of potentially beneficial outcomes, which Brockmeier (2015:315) described as 'starting points for new narratives'. According to their circles of support, shared acts of remembering were beneficial in a number of different ways to the participants. Shared remembering led to a sense of the participants being understood in the context of their whole lives, not limited to the present moment or the recent past, and consequently perceived as more rounded human beings. This in turn created the potential for interpersonal connections and cemented relationships as support staff recognised that we are more alike than we are different. Seeing evidence of past experiences allowed for inclusion in conversations between those in circles of support that might otherwise exclude the participants. One of the 'Five good communication standards' produced by the Royal College of Speech and Language Therapists (2013) in response to the Winterbourne View crisis was that 'Services create opportunities, relationships and environments that make individuals want to communicate' and describe inclusion in every day conversation as one way in which this can be achieved.

Understanding people in the context of their pasts, seeing evidence of similarities in experience and being included in conversation resulted in better relationships and a dynamic and improving quality of care provision. One of the reasons that Grove (2014:63) offers for sharing stories with children with PMLD is that even if little change is witnessed in the children themselves 'you may find the group changes their response to them'. This was a sentiment echoed in the follow up interview with Amelie's team (p.167) and is supported by Shakespeare's (2006:55) proposal that the 'interaction between individual and structural factors' are taken into account. Shakespeare (2006:55) lists intrinsic factors as including 'the nature and severity of her impairment, her own attitudes to it, her personal qualities and abilities, and her personality, while extrinsic factors include 'the attitudes and reactions of others'. An understanding of how to extend participatory opportunities in life story work and evidence of action and interaction on the part of the participants can be generalised to become practice in other areas and vice versa e.g. sensory engagement in the every day. In this way making the past a topic of

conversation was instrumental in creating the seeds of 'new narratives' (Brockmeier, 2015:315).

The participants found pleasure in being reflected - in mirrors, in sound, in pictures, in film, reinforcing the sense that they are who they think they are. This was particularly evident when using digital media to reflect the key participants in their actions and interactions, for example when the iPad camera was turned around to film Marian and I sitting together on the sofa (Appendix 13c: Vignette 5), or when Jack listened to himself joining in with the conversation regarding his back surgery (Appendix 13a: Vignette 3). And perhaps most importantly, the process of excavating and sharing the stories with the three key participants provided them with the opportunity to 'consider who they are and how life events affect their identity', an opportunity they are, according to Hewitt (2006:7), 'often denied'.

### 5.3 What are the barriers to participatory life story work?

Utilising the ideas contained in the social model of disability (Oliver, 1990) invited a 'barriers' approach as the conceptual frame to the research. What was getting in the way of participatory life story work? As well as issues that arose prior to the beginning of the fieldwork that included researcher inhibitions derived from anxiety regarding the appropriation of another's story, completion of lengthy and complex ethical applications and getting past protective gatekeepers, the barriers identified in this study fell into two main areas, notably limitations of access and of communication.

#### 5.3.1 Barriers to access

Barriers to access to the key participants' stories stemmed from a number of issues. There was evidence in all three cases that life story materials had been deliberately omitted or destroyed. Some materials were destroyed, because it was claimed they added nothing to the narratives as a result of their language of deficit, as Amelie's mother told me (p.133). While other materials were specifically omitted to protect the participants from difficult episodes in their lives, as for example when I asked Jack's father about records evidencing

Jack's back operation (p.100). The gaps in narrative had the potential to produce edited stories. I was curious to examine how these omissions might impact the mental health of the participants, none of whom are immune to loss of one kind or another. If the losses and difficulties were shared skilfully in supportive environments would that be helpful or harmful? Ultimately the decision wasn't mine to make and I was led by those in the participants' circles about what stories to include or exclude. However the discussions were useful and thought provoking. This was illustrated in the case of Jack's sight loss, which was sensitively spoken about and recorded at the end of the second project phase. There is an argument perhaps that stories buried deeply should not be accessed easily. It is important to remember that the stories all of us tell are by necessity 'partial and selective' (Brown and Augusta-Scott, 2007:xxvi).

Physical access to life story materials was a more visibly obvious barrier to participation. The archives of personal materials that were located by families for this study were found up in the loft, in storage containers and often tucked away out of sight. However, when they were brought into close proximity for shared examination we were all surprised by the levels of engagement the key participants displayed and adjusted our expectations accordingly. When the materials were available there was frequently a concern about protecting them from damage and this had the potential to eliminate opportunities for sensory exploration. As in the case of Amelie, when the route to understanding an object is through physical engagement, then it is frequently limited by a 'look don't touch' instruction, as her mother noted (p.146). In addition, when an activity such as for example holding a photo, is extremely limited or even prohibited it isn't practiced and this could result in a lack of skilfulness.

Limited dexterity combined with other challenges such as dyspraxia and sensory sensitivities, as in Marian's case, could also limit access. It was possible for a delayed response to be misinterpreted as a lack of responsiveness or interest. Further barriers to participation included restricted mobility as the result of for example, postural chair moulds and blankets over the upper body, which prevented free movement of the limbs and torso. This was seen particularly with Amelie who, due to her immobility got cold and was routinely covered by a blanket.



### 5.3.2 Barriers of communication

However, the main barrier to participatory life story work remained the limited communication repertoires that each of the participants possessed. Limitations in verbal communication resulted in a number of barriers to participation. It was difficult for outsiders, however skilful, to penetrate the 'bubble' those in the circles of support inhabited with the key participants. In spite of the sophisticated communication that they were able to 'read' it was limited to interpretations of needs as expressed in the present time. The interpretations of those in the circles of support were therefore reduced to a narrow range of possible responses, which were routinely and systematically worked through. Although each of the key participants was understood to 'remember' people, places and objects, they were unable to communicate what their memories might include. Their support circles were fully occupied in meeting the day-to-day needs as they arose in the present time for the key participants and consequently the past and remembering was not included. Although barriers were removed wherever possible and positive support provided it was clear that the key participants' impairments 'remained problematic' (Shakespeare, 2006:63).

The three participants are outside of education and consequently have limited provision regarding SALT and communication aids. The onus is on families to push for funding to access support in this area and this is problematic because it is time-consuming and complex. Therefore, although new and digital media tools, e.g. eye gaze technology, are proving useful in facilitating communication for people with PMLD descriptions, the participants in this study, who are outside of educational provision, are less likely to benefit, an issue of discrimination highlighted by Mansell (2010). Therefore the age of the three participants further excluded them from participatory life story work and this became apparent when their communication strengths and baselines of rich media were presented to a team of technical advisors at The Rix Centre at the end of Phase 1 (Appendix: 14).

A further and significant barrier, as identified in Chapter 2, concerns the way we view personal history narrative. By questioning taken-for-granted narrative

norms (Hyden and Antelius 2011) it is possible to move away from the notion of the singular telling of a coherent story that accurately recalls past events and experiences. This alternative way of understanding personal narratives can lead to increased opportunities for participation. We found in the literature that stories are co-constructed by the teller and the listener, that there is no one true version of the self (Loots et al 2013) and that temporal coherence is used a resource to make sense of life events, not integral to the telling of them (Squire et al, 2014) - ideas that are discussed further in the remainder of this chapter.

#### 5.4 How can barriers be overcome to enable opportunities for participatory life story work to be extended?

As the fieldwork progressed it became clear that there were specific qualities to the environments that created opportunities to extend participation. The activities that took place in these environments varied e.g. swimming, art, and music, but had elements in common. I began to refer to these rich 'immersive' or 'whole' communication environments as participatory spaces. They had much in common with what Jean Ware (2004) refers to as 'responsive environments' and with the core principles of II (Nind and Hewett, 2005). The qualities found in these participatory spaces were transferable to any activity including life story work. It was found that the ways in which we could extend the participation in life story work for people with PMLD were reliant on many components that can be divided into the subject areas of (1) people; (2) time; and (3) environment. In the remainder of this Chapter these will be examined in greater depth.

##### 5.4.1 People

One of the central concepts of the participatory life story space was that the key participant was not in it on their own. Participation became a possibility when there was a supporter working with the key participant who occupied a position 'alongside' the person dependent on their support. This required an ethical/moral stance that acknowledged interdependency as a central feature of human relationships (Kittay et al, 2005). Rather than choosing to see dependency as a negative quality in a 'climate where independence is

hypervalorized' (Kittay et al, 2005:458), understanding the needs of the person supported, rather than stigmatizing that need, made way for an environment that was respectful and created opportunities for participation. This stance makes room for what Goodley (2001) described as 'distributed competence', a position reinforced by Nind (2013) who understands the value of participatory research with people with PMLD is in 'what we can do together rather than alone'; a position articulated by Marian's sister when making sense of the success of the art exhibited at Tate Modern (p.173). The unhelpful binary of dependence-independence was further blurred by the reconfiguring of the role of the life story practitioner as a participant in the storytelling event. In creating an environment that invited the co-construction of narrative (Hyden and Antelius, 2011) the roles of teller and listener merged and the focus was redirected towards joint participation with the life story materials.

The collaborative presentation of life story was observed in the voiced interpretations of the key participants' supporters. It was only through my presence alongside practiced interpreters for long periods of time, in the environments that the key participants occupied, that I began to understand the complexity of the research inquiry's main purpose. The supporter needed to feel comfortable with not always getting their interpretations of communication right, an understanding supported by Grove (2000:4) when she said that all 'communication involves interpretation and guesswork'. This is a position confirmed by Jack's mother, who regularly found words to articulate her son's range of vocal sounds, knowing that sometimes they weren't accurate (p.114). According to Nind (2011:5), the advantages of attempting interpretation, and 'thereby forging a communicative relationship preoccupy us over the dangers' of not doing so. As the fieldwork progressed I recognised that the interpretations of those in the circles of support mediated and created opportunities for inter-subjective connection. The repair work that communication partners actively engaged in and their responses to the stories and experiences of the key participants were equally important. No one shares his or her story to empty space.

Those supporting the key participants also had to be very observant and notice fleeting moments of communication and feel comfortable vocalising all

of the above. I witnessed these personal qualities in the close relatives of the key participants and in the majority of the support workers. The breakthrough in extending Amelie's participation came about as a result of this process (Appendix 13b: Vignette 1a) when her team leader spoke out loud her observations of fleeting changes in Amelie's posture and facial expression that led to the understanding that Amelie was more engaged in her life story when able to physically handle the materials. Here the embodiment of the storytelling experience (Hyden, 2013) was demonstrated and sensitively read.

The 'reading' or interpretation of the sounds and movements of the key participants was the product of relationships forged over time. As Marian's team made clear (Interview with Marian's support workers October 25th 2015), it took them time to tune in to the subtleties of her communication repertoire and for Marian to trust them sufficiently to communicate with them. However once that trust was established there was an almost telepathic 'tuning in' that happened. This was understood to be a product of not only the longevity of the relationship, but also the result of regular contact, as Jack's mother explained (p.113).

The social relationships that were apparent in the lives of the key participants were forged through the interplay of nonverbal repertoires of communication and reflected back and given value by those in the circles of support. It became evident that these relationships were reciprocal and grew as a result of shared 'participation in social and material environments' (Pink, 2015:63). However because the key participants established multiple reciprocal relationships with the individual members of their circles of support, the life story participation was represented in a 'polyphony of voices' (Bakhtin, 1982) as Amelie's team leader explained (p.139).

Additional qualities of those people supporting Marian, Amelie or Jack included adopting a stance of 'tasklessness' (Nind and Hewett, 2005). Although on many occasions during our time looking through the participants' archives we were surrounded by boxes of photos or an entire carpet covered in artwork, there was never a sense that we had to complete a set task. This

fostered an environment of openness to possibility and shared exploration and was a core practice observed at the art studio where Amelie attended Project Art Works (Appendix 13b: Vignette 5). It also enabled a non-linear approach to co-construction and participation, with 'multiple entryways and exits and its own lines of flight' (Deleuze and Guattari, 1987/2013:22) as characterised by the rhizome concept. This exploratory stance as, for example Amelie's interest in a box of loose photographs, took us on unanticipated flights to moments of temporally unconnected acts of shared remembering.

Another facet of the position occupied by the supporter was a resistance to being in charge. By standing back and deferring to the interest demonstrated by the key participant while actively supporting opportunities for action and interaction, supporters were modelling a scaffolding approach to learning (McKim, 2015). It was on the few occasions when support staff lacked some of these qualities that I became aware of how necessary they were. People with PMLD who have drastically reduced opportunities to participate in all aspects of their lives are extremely vulnerable to having opportunities shut down.

The qualities of those that extended opportunities for participation appeared to include playfulness and humour. 'Mutual pleasure' is, according to Nind and Hewett (2005:21), 'intrinsic and crucial to caregiver-infant interactions', and would appear to be essential in fostering environments that invited participation. Having fun was not an essential element of the study, but opportunities for laughter were regular and seized upon and created an atmosphere that was inviting and motivating and sent out clear signals that the key participants were 'good to be with' (Nind and Hewett, 2005:95). All three participants showed evidence of humour, which was encouraged by those in their circles of support. Grove (2014) sees the sense of humour of people with PMLD as one of their strengths. Vorhaus (2016:16) claims that the sense of humour of people with PMLD reveals their capabilities when they may not be 'entirely captured in cognitive assessments'. This certainly appeared to be my experience and was used as evidence by Jack's parents

to support their opinion: 'if someone bangs their knee or drops a plate he thinks that's hilarious' (Interview 2 with Jack's parents November 25<sup>th</sup> 2015).

In order to extend the opportunities for participation in life story work, as in all other aspects of the key participants lives, it was essential to understand how they understood and made sense of the world around them. This required an in depth knowledge about the communication repertoires of each of the participants. As with David Goode's (1994:77) findings, the participants in this study had created 'refined, intimate and unique communication systems'. The people working alongside were required to 'tune in and scan to pick up the smallest cues or signals' (Nind and Hewett, 2005:110) that might indicate interest - a skill that is, according to Hewitt (2006:32), the 'most important aspect of encouraging participation'. As with all three participants their communication repertoires do not remain the same and require constant review, as pointed out by Marian's team when they said 'when you've just sussed her out she changes the rules' (Interview with Marian's support team October 15<sup>th</sup> 2015). The case studies demonstrate that although knowledge of the key participants' impairments led to the identification of their specific needs, it was not possible to disentangle disability and impairment (Crow, 1996).

It appeared that in each of the three key participants' cases participation in their stories was dependent on the opportunity to access them using more than one sense. In Marian's case she appeared to prefer to access her story through vision and sound. In Jack's case he was reliant on confirmation from more than one sensory source to make sense of his world as his mother explained (p.108). Whereas for Amelie a combination of touch, sound and vision together extended her opportunities to participate in her story. It therefore became essential to remove the 'preciousness' of life story materials, e.g. by copying and laminating photographs, in order to enable sensory exploration. It was through the knowledge and understanding of those in the participants' circles of support that we were able to achieve this.

In summary, the person with PMLD is not alone in the participatory life story space. They are supported by someone, or a group of people, who possess certain personal qualities, knowledge and skills, including: being at ease with

issues of distributed competence and participating in co-constructed narratives; being confident enough to attempt interpretations of nonverbal behaviour knowing that sometimes they will get it wrong; being observant and tuning in to fleeting changes of behaviour; letting the person who is being supported know that others enjoy being with them; providing just enough support to enable the person being supported to lead in directions they are interested in and motivated by; enjoying opportunities to laugh and be playful; have a thorough understanding of how the person supported communicates and makes sense of their experience.

#### 5.4.2 Time

The participatory life story space contained (in no particular order) the past, the present and the future. It was a space in which to play with time. It became clear as the fieldwork progressed that the longer I spent in the company of the three participants the better I was able to 'read' their responsiveness (Hewitt, 2006), a characteristic that people in their circles of support who had long term and regular contact possessed. And so, the time shared together prior to participatory life story work was key to its success. This shared time not only meant that the supporter was 'tuned in', but also that they had some, albeit partial, knowledge about the key participants' life stories that they could contribute. The times that they had shared together in the past became pieces of the life story jigsaw in the present. Spending extended periods of time with the key participants also meant that I was able to witness a broader range of their capabilities and characteristics. Amelie, for example, was quite unwell for the first few weeks that we met and therefore her engagement in the project was very limited. Considering ways to adapt story sharing to the needs of children with chronic epilepsy Grove advises:

[T]he child's ability to attend consistently to events will be interrupted and, of course, the drug regime will affect her concentration and motivation. There is not much you can do about this other than to take full advantage of the times that you know the child will be most alert, and to use a lot of repetition. (Grove, 2014:62)

Had I not continued to meet with Amelie over the following months I would have had a very different view of how she was able to participate as the project progressed.

It was possible in the participatory life story space to pause and playback the actions and interactions of the key participants. This was both useful retrospectively, for developing skilful practice, and at the time. Reflecting the participants' participation within a short timeframe became possible using digital media. The opportunity to see or - as in Jack's case hear - the contribution soon after it was made appeared to reinforce both the motivation and enjoyment of life story work. The deliberate pausing and playing back of communicative behaviour further supported the notion of playing with time. Jack's parents noticed that he was more vocal than usual when I made the weekly visits (p.107).

Deliberately pausing in conversation was a practice that Jack's mother had developed over time to allow him to participate in conversation, as a mark of respect (p.117). Grace (2015:39) recommends slowing down and pausing in sensory story work with people with PMLD because 'someone who appears at first to not be responding may just be processing all the information they are receiving'. I found that this was an effective strategy for extending opportunities for participatory life story work. It became important to pause and open up time for the participants to respond to the various materials in their stories in whichever way they wished. It was important to be reminded that many of the materials in the personal archives may not have been seen for years, if at all.

All three key participants were vulnerable to sensory overload and it was found that repetition and routine helped to reduce this in a number of different ways. In Jack's case repetition and routine was found to reduce anxiety and was used to support his adjustment to new activities, people and environments, thus enabling him to process information more effectively. By knowing what to expect it was found that Jack's levels of stress were greatly reduced. Regular routines such as the twice weekly visits to the local swimming pool were found by Marian's team to be empowering. The first few times Marian went to the pool she wasn't able to anticipate what that experience meant. However after



several weeks she was understood to be in a position to express a preference about the activity.

Nind and Hewett (2005:133) consider repetition to be the 'engine room of forward progress' and this was evident in my experience with all three participants. I found the first stage of the fieldwork particularly reinforced this finding. Every week I arrived at the key participants' homes on specific days and times. With Amelie our move from the kitchen to the lounge, where our exploration of her archive took place, provided a clear signal. The repetitive nature of our handling of scrapbooks, photo albums and art work gave rise to anticipatory behaviour in Amelie, for example reaching out her hand for the next photo, and it became evident that the repetitive nature of our work extended opportunities for her to participate.

Routines were also understood to be useful as a communication resource. At certain times of day when, for example a meal was imminent, Jack's nonverbal behaviour was interpreted as food related. By establishing a regular routine in which to examine Jack's archive it was possible to tap into this knowledge of his preference for order. Jack's mother noticed this on our Wednesday afternoons together as recalled when reviewing the project at the end of the fourteen months of fieldwork (p.96). This finding is supported by Lacey (1996:67) who, understanding the difficulties young people with PMLD have remembering suggests that 'simple routines to encourage anticipation' as a 'useful precursor to encouraging the child to take more control over what is happening to him or her'. By providing routine and regular access to their stories it was found that participation was extended as a result of reduced anxiety, which in turn led both to the potential for anticipation and to a sense of empowerment.

Ware (2003:1) describes a 'responsive environment' as being an environment 'in which people get responses to their actions, get the opportunity to give responses to the actions of others, and have an opportunity to take the lead in interaction'. The timing of responsiveness is important here and is more effective when it happens with 'very little time delay' (Nind and Hewett, 2005:22). Additionally, physical proximity appeared to positively encourage participation. This was discussed by Marian's mother when she described the

playful interactions between Marian and her father (p.193). This was observed in my participation with Jack, Amelie and Marian in their routine activities. As long as an activity was shared and mutually enjoyable it wasn't always essential to be in physical contact, but it seemed that some kind of link object was supportive of extending opportunities for 'contingent responding' (Nind and Hewett, 2005:21). This was achieved effectively at Amelie's art session (p.142).

We found in all three case studies that the participants, in spite of evidence of memory, were viewed as being people who were living in the moment - or at least within a very short timeframe. This was a subject that was raised by a question in the conversational interviews (Appendix 2). Jack's keyworker thought that he was 'very much a what's happening at the present time person, if I'm honest.' (Interview with Jack's keyworker September 28th 2015) a position supported by Evans (2016) who believes the lives of people with PMLD 'are of the moment' (Evans, in Vorhaus, 2016:27). I wondered what had led those in the circles of support to reach this conclusion - whether it might be more to do with the functional reality of interpreting needs as they arose and the limitations of the key participants' communication, and thus a characteristic imposed on the key participants by others?

I know from my experience of working alongside people with high support needs that when, for example, deeply engaged in II practices, there is a quality of timelessness - of being in the moment. This is a subject explored by Freeman (2008:181) in his essay 'Dementia's Tragic Promise', in which he examines the complexity of losing your 'autobiographical self', an experience he witnessed with his mother. He made note of the struggle his mother experienced as her memories diminished and this led him to wonder if the 'culprit' of this apparent discomfort was the 'autobiographical self'. He imagined what it might be like to be free of the burden of telling one's story because:

It is a striking fact - and one that is well known to mystics, artists, and many others - that the experiences that move us the most, those sort of ecstatic or transcendent experiences wherein one feels truly at one with the world, generally entail what [Iris] Murdoch had referred to as 'unselfing', putting aside one's ego and thereby letting in the world, in all its profound otherness. (Freeman, 2008:182)

Marian's sister alluded to this when she described the way Marian was able to keep meeting the world as she is, unlike the rest of us who, 'think we can put ourselves together in a way that will make the world behave differently to us.' (Interview with Marian's sister October 28th 2015).

While the key participants' communication was limited to the present time, in the participatory life story space we could make their pasts available to them. The practice brought the past, in the form of tangible materials that could be handled and looked at and listened to, into the present and provided the opportunity to re-collect stories from the participants' lives. The material artefacts, as contained in the participants' personal archives, were not accessed in any chronological order, but rather randomly and in response to the participants' preferences. By letting go of the temporal axis the space extended opportunities for participation and reinforced the participants' sense of ownership of the materials. This way of operating mirrored the rhizome concept referred to earlier (Deleuze and Guattari, 1987/2013:22). There were multiple entryways to access each of the participants' stories and some of those triggered lines of flight, as for example the delight Amelie expressed when looking at a photo of her self in the caves (Appendix 13b: Vignette 2), which was later developed in to a photo, sensory and digital story. However, it was found to be supportive, particularly to Jack, to maintain temporal order when accessing individual story elements. For Jack the repeated track order of the various stories and songs found on his CD enabled him to become familiar with and to anticipate what was coming next. Although Amelie was able to demonstrate preference when choosing one of the sensory stories that had been developed, once chosen each story followed a prescribed sequence, which was always the same. The time spent with each sensory experience was variable, however, and controlled by Amelie's interest in it on the day.

In the second stage of the fieldwork, during which I joined the key participants in their various activities, the unpredictability of my being there (and not when and where I had been for the previous two months) resulted in reduced opportunities for participatory life story work. However, it was my immersion in these different activities that made visible aspects of them that opened up

avenues of participation, as well as throwing into relief those that effectively silenced the participants.

### 5.4.3 Environment

Jack, Amelie and Marian all did activities they took part in routinely. The activities mirrored those that had been highlighted as enjoyable in their school and college years and I was curious to understand what it was about them that had such an observably positive impact on their wellbeing. I found that the environments in which they took part had characteristics in common and wondered if these characteristics, which seemed to foster participation, could be replicated to extend opportunities for participatory life story work. To highlight the various characteristics of these environments I will reference Amelie's weekly visits to her art class and sensory session (Appendix 13b: Vignettes 5 & 6), Jack's trip to the hydrotherapy pool (Appendix 13a: Vignette 6) and Marian's swimming session (Appendix 13c: Vignette 3).

Art, swimming, music and sensory were regular activities that took place in environments that were familiar. As referred to in the previous section, the regularity of activities enabled the key participants to process information more easily due to a reduction of sensory overload. The familiar layouts of the places also led to a sense of empowerment. When I arrived at the health club, where Marian is a member and swims twice a week, I was taken aback by her independent navigation:

I arrived at the local health club at 9.30am in time to see Marian getting out of her car and striding purposefully towards the entrance foyer. They arrive inside and the receptionist greets Marian by name, asking her how she is. (Appendix 13c: Vignette 6)

This was a confidence that Marian's mother had described (p.194). Not only was the familiar spatial layout supportive of participation, but also what was contained within it. Arriving at the swimming pool both Jack and Marian could smell the chlorinated water and feel the heat of the room prior to stepping, or being hoisted in to the pool. Entering the art studio Amelie was able to visually scan the walls and tables for paints and materials. The sensory room was a

semi-dark space with coloured bubble tubes and mirrors and so on. These spaces were clearly sign-posted and prepared Jack, Amelie and Marian for the activity that was about to take place, as Marian's mother explained (p.172). The skilled practitioners operating within these spaces - the hydro-therapist, the artist, and the support worker - had over time accumulated knowledge of the participants' communication repertoires and understood how best to support them, building on 'strengths rather than weaknesses' (Lacey, 2015:45). We found for example that when Marian is at home and in the lounge she watches the television. This was a routine and an expectation. And although it had the potential to be a responsive environment in which to sit as a family and watch TV together, it was confusing for Marian to see it in a different context therefore there was little point in trying to engage Marian in life story work when in this space.

One characteristic of the environment appeared to be that the practitioner was sharing the experience of the activity with the key participant. The activity was a joint venture and the processes engaged in were 'co-constructed' and in 'dialogue' with each other (Loots et al, 2013; Hyden and Antelius, 2011). What seemed to be of value in this was, according to Marian's mother, 'she knew you were having the same kind of experience that she was, so it was much easier to pass information back and forth in that environment' (Interview with Marian's mother July 27th 2015).

In summary, it was found that certain environments were enabling and had an impact on reducing the communication impairments of the key participants (Shakespeare, 2006). The environments that extended opportunities for participation shared certain characteristics. The layouts were familiar due to regular visits and this familiarity reduced anxiety and had the potential to be empowering. The environments contained sensory experiences that resulted in clear signposting: in this environment this is what happens. This also contributed to a reduction of apprehension and an increase in security. The experience that was available in the specific environment was shared by the skilled practitioner and the key participants - they were in the pool together, or creating an artwork together.

## 5.5 Bringing together key research concepts with the research

This section of the chapter seeks to link the research project more concretely to some key ideas that were introduced in the literature and methodology chapters. As the shape and focus of this project developed it was influenced by several conceptual frameworks, which included the barriers approach of the social model of disability (Oliver, 1990), the deconstruction of narrative norms in personal history work (Hyden and Antelius, 2011), the rhizome as a conceptual frame for narrative (Loots et al 2013), and the personal social benefits of acts of shared remembering (Hewitt, 2006; Brockmeier, 2015). They each in turn altered the way in which I viewed the findings of this research.

As discussed in the Introduction Chapter, the social model of disability (Oliver, 1990) distinguishes between impairment and societal barriers. It is used to switch the way we look at situations and is most frequently applied to issues of physical access. Applying it in the field of learning disability is problematic due to the fluid nature of cognitive impairment (Goodley, 2001). The intention was to use the barriers approach to simplify an otherwise complex task. In order to extend opportunities for people with PMLD to participate in life story work, I found it useful to identify what it was that was preventing participation in the first place. As such it proved to be a tool that effectively made visible several areas that prevented participation. In summary, the barriers were identified as those of both access and communication. Barriers to access were found to be created by materials that were missing, destroyed, out of reach or too precious to handle and therefore not brought into the present moment to share. Barriers of communication were seen to derive from key participants' impairments, and their nonverbal communication repertoires that were difficult to accurately interpret. However, it was possible to view participation in the storytelling event as an embodied activity when the contribution of the physical body through gesture and facial expression was acknowledged (Hyden, 2013). It was found that barriers to communication were further reduced and participation extended when certain conditions were in place. These conditions included specific qualities of people, time and environment and were instrumental in extending the communication abilities of the key participants, thus demonstrating the fluidity of their cognitive impairment. However, the impairments of the key

participants remained problematic, even when barriers were removed or reduced (Shakespeare, 2006).

When culturally oriented narrative approaches were adopted, it became possible to view everyone involved in the storytelling event, including me in my role as researcher, as joint participants in life story work (Loots et al, 2013). This new perspective powerfully shifted the responsibility of 'telling' a story away from a singular voice, which in this case was problematic, towards a shared dialogue. Drawing on the conceptual notion of the rhizome (Deleuze and Guattari, 1987/2013:22) and inspired by its application in narrative research (Loots et al, 2013), this idea was further developed to understand collaborative co-construction of life story work with an individual with PMLD. Using the imagery of multiple entryways or versions of a story, whereby no one version is more true than any other, it became possible to resist the 'linear life narrative' (Fisher and Goodley, 2007:66) and extend creative opportunities for participation. This participation was evident in the different entry and exit points of the key participants' life stories - the use of film, audio, sensory and written forms. The wiki Memory Sites accommodated, via the different entry points, a large selection of small stories from different sources that together could be perceived as a life story, but privileged no single account over any other. The wiki Memory Sites both supported the development of this conceptual frame and acted as carriers for the different stories and media.

In addition to the telling of the personal story, be it through embodied or collaborative narrative, it was found that the sharing of stories was equally important. This was highlighted in the research by Brockmeier (2015) who saw the opportunities of shared remembering as a way to extend and cultivate new ways of connecting with others, a position which was supported by Middleton and Hewitt (2000), who understood the value of shared remembering in the context of participatory social interaction. The interviews conducted at the close of the fieldwork would indicate that there is value in the participatory nature of sharing life story work and that this was evidenced through changes in the way the key participants were perceived and related to.

## Conclusion

In this chapter the research questions were reintroduced and examined in the context of the research literature and the case study findings. The lives of the three main participants were discussed, as was the benefit of life story work. An understanding of the barriers to participatory activity was found to be a useful tool for establishing ways in which participation could be extended. Using the knowledge drawn from the key participants' personal archives, participatory practices and conversational interviews, I began to understand some of the ways in which Jack, Amelie and Marian were able to participate in their everyday lives. What we attempted to create throughout the fieldwork, particularly during Phase 2, was to transfer this understanding to extending opportunities for participatory life story work. It was found that the characteristics described here and explored through the lens of people, time and environment, provided an effective framework from which to achieve this. In the concluding Chapter the limitations and further applications of this work will be explored.



# Chapter 6

## Conclusion

### Introduction

In the previous chapter the findings of the fieldwork were discussed within the context of the research literature. Barriers to participation were identified as stemming from two main areas - barriers of access and communication. However, it was found that these barriers could be dismantled or in some cases significantly reduced when particular conditions were in place. Opportunities to extend participation were dependent on specific qualities of people, time and environment. It was found that participation in life story work could be extended in every aspect of the activity from the examination of personal archive materials to the choice of presentation of stories and with whom and how those stories were shared. The active participation of the key participants was found to have value both during the research process and subsequently as the life story products - whether in book, sensory story, audio CD or digital film format - acted as catalysts for social integration and reminded support workers of the full extent of the key participants' lives, rather than how they were living in the present time. The intention of this thesis was to make a concise written record that told the story of the ways in which I addressed a research enquiry from identification of gaps in the literature through to the original contribution evidenced through the findings. This short chapter recalls the departure points in this process and considers how these new findings could be applied in alternative research and practice settings or could be applied in other research areas.

### 1. Review of the research process

A practice issue drove the initial proposal that sparked this research project. I had found the limitations for engaging people with PMLD in the different aspects of life story work troubling and was concerned that because of the complexity of this endeavour the stories of those with PMLD would be missing from the planned archive of learning disability history. This project began by identifying significant gaps in the research literature regarding two areas; first

that we lack the tools to conduct participatory research with people with PMLD, and second, due to limited representation that is not deficit related we know little about how people with PMLD are engaging socially and culturally and living their lives. The fourteen-month fieldwork period was divided into two phases and structured to support the identification of the barriers, challenges and benefits of doing participatory life story work with people with PMLD using a research design that was transparent and replicable. Due to the drilled down nature of the ethnographic and life history research methodology, it was decided that a small number of people with PMLD should participate in the research. They were each supported by those in their circles of support - family members, friends and support workers - who contributed to the research findings in many ways. In the light of the research findings discussed in the previous chapter, I now turn to consider the potential for replicating this work with people with PMLD who occupy different settings, such as, for example, a day centre or residential care home.

## 6.2 Limitations of research findings

As discussed in the previous chapter, it was established that participation in life story work could be extended when certain conditions were in place. The three key participants in this research were found to have unique communication repertoires that were supported in different ways, however in other aspects of their lives they shared common ground. All three key participants lived in their family homes, which had been adapted to support their continued occupation and care needs. All three are members of loving extended families and are seen as individuals who reciprocate in social relationships. The families are articulate and driven and, although unprepared for the experience of raising a child with PMLD, have found effective ways to cope. The key participants live their lives in ways in which they can express their preferences and their life style choices are supported and respected. When I arrived at each of the three family homes in the first week of fieldwork I was greeted by extensive personal archives that had been painstakingly assembled by the families. Those in the key participants' circles of support were open to whatever my research project might reveal - there was never a sense of resistance or defensiveness, but rather the research was perceived as a shared exploration into an interesting

problem that we could tackle together. As the research relationships developed over the fourteen-month fieldwork period the confidence with which we were able to express alternative views about the research findings grew. Would this research have been possible under different circumstances, for example in a care setting without family support?

The contents of the personal archives revealed the knowledge that those with PMLD are very documented people. In some ways it could be argued that they are heavily documented people who are simultaneously without a story to call up when needed. Even when alongside experienced and sensitive support workers and looking at personal archive materials together, it was not possible to understand the context or meaning of documents by simply looking at the facts contained in the personal archive materials. To bring that information to life, the contribution of a parent, or someone who had shared that experience, was required. A chronological timeline could be written by accessing the medical, social care and educational reports commonly found in case files, but where in that information would the voice or story of an individual with PMLD be located? Even with access to family photo albums it was not possible to find contextual meaning without the contribution of those who had been there at the time, in other words family and friends.

Therefore, the findings of this research expose limitations to generalisability. I would like to have found that it is possible to extend the participation of those people with PMLD who are living without family support or access to personal archive materials, but I have come to the conclusion that although accessing factual information is not difficult, affording those facts meaning - a critical component of life story work - is more difficult to achieve. However, I consider the method design developed in response to this enquiry does offer people with PMLD the opportunity to become participants in the meaningful documentation and recording of their lives from the present moment and in the recent past (if that includes experiences shared with support staff). In this context it is possible to imagine how understanding the way in which an individual is able to engage with the life they are living through their non-verbal repertoire of communication, and being fully cognisant of the best way in which that communication is supported, could provide a foundation for the building of a story that can begin

to look backwards within a meaningful context and bring the past in to the present. This activity in itself, despite not including the whole life story, has the potential to instigate shared acts of remembering and consequently enable greater social integration - a core value to be found in participatory life story work.

### 6.3 Applications of the research findings

During this research project I was struck by the loss experienced by the three key participants. They had each undergone tremendous challenges, for instance Jack had lost his eyesight, Amelie had lost her mobility and Marian had lost her language. And I wondered what kind of impact those experiences had had on their mental health? Given the extent of the loss it is impossible to imagine that it did not affect them in some way. As Sheehy and Nind (2005:34) remind us, having limited understanding of the emotional wellbeing of people with PMLD does not mean that mental health needs do not exist, but rather they are 'not being recognised or met'. One of the barriers to participatory life story work that was identified in this research enquiry was about limited access to life story materials. It was found that life story materials had been destroyed, were out of reach, or simply omitted. In Jack's case his parents commented that you don't keep records of difficult times. As such I was concerned that Jack's story would contain significant gaps regarding specific difficulties he had experienced during his life. One of the advantages of spending an extended period of time with the families was that they were able to witness for themselves the key participants' ownership of their stories - an ownership demonstrated, as Marian's mother reflected, in their interest. The relationships between us all became significantly more trusting as I shared personal archives, joined in with activities and became a regular visitor to the family homes. As I described in Jack's case study it was only at the very end of our time together, as we sat around the table following Sunday lunch, that Jack's parents and sister were able to share the loss he had endured when he became visually impaired. Watching Jack's face while recording the account of that particularly devastating life event, I felt an immense relief that this story was out in the open. Now that it is incorporated into Jack's wider story it can be understood in the context of a whole life and can be the subject of shared reminiscence with

greater freedom, an opportunity people with PMLD are 'often denied' (Hewitt, 2006:7). The experience of bearing witness to that particular episode in Jack's life led me to wonder if life story work had something to contribute to the wider research regarding how the mental health and emotional wellbeing of people with PMLD is addressed.

At a broader level the research design of this project may contribute towards a range of methods to support and extend the participation of people with PMLD in their everyday lives and in research projects other than life story work. By developing an in depth knowledge about how an individual engages with their experience and how that engagement is most effectively supported may open up opportunities for further research applications. If the participatory space is understood to be one where knowledge about communication and how that is supported are brought together with research materials, the opportunities for extending participatory research are limitless.

## Conclusion

There were times during the fieldwork stage of this research enquiry when I questioned the use of my time. Journeys to the key participants' homes were time consuming and sometimes I would arrive to find that the person was not well, or an urgent appointment had come up, and I would turn around and go home. At other times we might spend four hours together and, for a variety of care requirements, we might spend just twenty minutes researching together. However, as the months went by and the film footage, scanned materials and little nuggets of information built up a body of evidence, I came to fully understand that when researching alongside people with PMLD, there is no other way to engage in this kind of work. The stories that were excavated were the result of iteratively accrued understanding and were dependent on our relationships to each other and the micro communities we occupied during that time. Finally I came to the conclusion that everybody engaged in life story practice could potentially benefit from an understanding of how to extend opportunities for people with PMLD - arguably the most vulnerable population in society - to participate in life story work.

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# APPENDICES

## 1. a) UEL Notification of change of thesis title letter



Miss N McCormack  
81 HANOVER STREET  
BRIGHTON  
BN2 9SS

Date: 7<sup>th</sup> September 2016

Student number: 1346820

Dear Noelle,

### **Notification of a Change of Thesis Title:**

I am pleased to inform you that the School Research Degree Sub-Committee has approved the change of thesis title. Your new thesis title is confirmed as follows:

**Old thesis title: Words Fail Us: An exploration of the challenges of doing life story work with people who have profound and multiple learning disabilities**

**New thesis title: Making Memory Sites: Extending opportunities for people with profound and multiple learning disabilities to participate in life story work.**

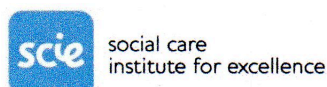
Your registration period remains unchanged. Please contact me if you have any further queries with regards to this matter.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Mayuri Jobanputra'.

Mayuri Jobanputra  
School Research Administrator  
Direct line: 020 8223 2087  
Email: [m.jobanputra@uel.ac.uk](mailto:m.jobanputra@uel.ac.uk)

## 1. b) SCREC confirmation of approval conditions met



### Social Care REC An NRES Research Ethics Committee

13 October 2014

Ms Noelle McCormack  
81 Hanover Street  
Brighton  
East Sussex  
BN2 9SS

Dear Ms McCormack

**Study title:** Words Fail Us: An exploration of the challenges of doing life story work with people with profound and multiple learning disabilities.  
**REC reference:** 14/IEC08/1014  
**IRAS project ID:** 161810

Thank you for your email of 10 October 2014. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 16 September 2014

#### Documents received

The documents received were as follows:

Document	Version	Date
Other [Declaration Sheet for Personal Consultees]	2	29 September 2014
Other [Covering Email]		10 October 2014
Other [Provisional Schedule of Research]		30 September 2014
Other [Safeguarding Information]		30 September 2014
Other [Researcher Statement]		30 September 2014
Other [Declaration Sheet for Nominated Consultees]	1	29 September 2014
Participant consent form	2	29 September 2014
Participant information sheet (PIS) [Parents]	2	29 September 2014
Participant information sheet (PIS) [Relatives and Friends]	2	29 September 2014
Participant information sheet (PIS) [Support Workers]	2	29 September 2014
Participant information sheet (PIS) [Personal Consultees]	2	29 September 2014
Participant information sheet (PIS) [Nominated Consultees]	1	29 September 2014

#### Approved documents

The final list of approved documentation for the study is therefore as follows:

206 Marylebone Road, London, NW1 6AQ  
Tel 0207 535 0900 Fax 020 7535 0901 [www.scie.org.uk](http://www.scie.org.uk)  
SCIE is a charity registered in England and Wales Reg. No. 1092778 Company Reg. No.

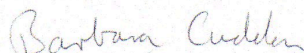
<i>Document</i>	<i>Version</i>	<i>Date</i>
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [UEL Indemnity & Insurance]		
IRAS Checklist XML [Checklist_19082014]		19 August 2014
Letters of invitation to participant [Letter of Invitation]		
Other [Bibliography]		
Other [Academic supervisor IRAS signature]		
Other [Covering Email]		10 October 2014
Other [Researcher Statement]		30 September 2014
Other [Declaration Sheet for Personal Consultees]	2	29 September 2014
Other [Academic supervisor CV - Andy Minnion]		
Other [Declaration Sheet for Nominated Consultees]	1	29 September 2014
Other [Sponsor IRAS signature]		
Other [Safeguarding Information]		30 September 2014
Other [CI IRAS signature]		
Other [Provisional Schedule of Research]		30 September 2014
Participant consent form	2	29 September 2014
Participant information sheet (PIS) [Personal Consultees]	2	29 September 2014
Participant information sheet (PIS) [Nominated Consultees]	1	29 September 2014
Participant information sheet (PIS) [Information Accessible]		
Participant information sheet (PIS) [Parents]	2	29 September 2014
Participant information sheet (PIS) [Support Workers]	2	29 September 2014
Participant information sheet (PIS) [Relatives and Friends]	2	29 September 2014
REC Application Form [SC_Form_19082014]		19 August 2014
Research protocol or project proposal [Project Proposal]		
Summary CV for Chief Investigator (CI) [CV]		

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

**14/IEC08/1014**

***Please quote this number on all correspondence***

Yours sincerely



**Barbara Cuddon**

**Social Care Research Ethics Committee Co-ordinator**

Direct Line: 020 7535 0905

[Barbara.Cuddon@scie.org.uk](mailto:Barbara.Cuddon@scie.org.uk)

Social Care REC Website: [www.screc.org.uk](http://www.screc.org.uk)

Copy to:

*Professor Neville Punchard, Dean of School of Health, Sport & Bioscience, University of East London, Stratford Campus, University House, Romford Road, London E15 4LZ*



1. c) UEL Ethical Approval sponsorship letter



21 October 2014

Dear Noelle,

<b>Project Title:</b>	<b>Words Fail Us: An exploration of the challenges of doing life story work with people who have profound and multiple learning disabilities.</b>
<b>Researcher(s):</b>	<b>Noelle McCormack</b>
<b>Principal Investigator:</b>	<b>Noelle McCormack</b>

I am writing to confirm that the application for the aforementioned Social Care research study reference **14/IEC08/1014** has received UREC ethical approval and is sponsored by the University of East London.

The lapse date for ethical approval for this study is **21 October 2018**. If you require UREC approval beyond this date you must submit satisfactory evidence from the Social Care Research Ethics Committee confirming that your study has current Social Care Research Ethics approval and provide a reason why UREC approval should be extended.

Please note as a condition of your sponsorship by the University of East London your research must be conducted in accordance with Social Care Research Ethics regulations and any requirements specified as part of your Social Care Research Ethics ethical approval.

**Please ensure you retain this approval letter, as in the future you may be asked to provide proof of ethical approval.**

With the Committee's best wishes for the success of this project.

Yours sincerely,



Catherine Fieulleateau  
Ethics Integrity Manager  
**For and on behalf of**  
Professor Neville Punchard  
University Research Ethics Committee (UREC)  
Research Ethics Office  
Email: [researchethics@uel.ac.uk](mailto:researchethics@uel.ac.uk)

## 2. Provisional Schedule of Research and Interview topic guide

[Rix Research and Media and UEL header and footer]

### **Provisional Schedule of Research**

Words Fail Us: An exploration of the challenges of doing life story work with people who have profound and multiple learning disabilities.

#### Personal archived materials

I will be examining a range of life history materials including for example, family photos, memorabilia, school reports and personal objects. The purpose of this is to establish a communication and life event timeline. I will be looking for evidence of augmentative and alternative communication tools, use of different media, key relationships and locations.

As discussed at the SCREC meeting attended on September 5<sup>th</sup> 2014, the observation schedule and interview guide will be developed from information obtained through personal archive materials. However it is anticipated that the following will be examined:

#### Ethnographic observation

I will be video recording evidence of communication with specific reference to the following contexts: activity, environment, motivation, relationship and time. I will be noting whether communication behavior is elicited or spontaneous and how it is interpreted and responded to. I will be noting the type and detail of communication behavior, for example if it involves a physical movement or vocalization. I will design charts to record the details of observations.

#### Interview topic guide

The interviews with members of the circles of support will vary depending on who is being interviewed, their relationship with the participant and how long they have known them. The interviews will provide an opportunity to examine further information identified from the previous two stages of fieldwork and to clarify any inconsistencies. All the interviews will focus on communication and will be different for each of the participants. However, it is likely that

the following areas will be examined:

What is your relationship to the participant and how long have you known them?

In broad terms, do you notice differences in how the participant communicates as a result of what they are doing, where they are, if they are more or less motivated, the person they are with and the time of day?

Can you tell me more about each of the above?

How does the participant use his/her senses in communication behavior? Is one particular sense more prevalent? For example, touch or sight? Expand.

Does the participant use any augmentative or alternative forms of communication?

If so, when were they introduced and how are they of use?

Are they able to recognize people, places or objects from photos, sounds or objects of reference?

How does the participant communicate choice and control in their life? Give some examples.

Is the participant's communication limited to the present moment or are they able to express choices about future events? If so, how?

Do you think the participant has memories of people, places or objects? If so, what is the evidence for this?

Do you think that the SALT assessments have under or over estimated the participant's communication abilities? Expand.

Do you think that the participant can 'tell' you information? If so, do you have any examples?

Do you think that you infer/project what the participant may be communicating? If so, are you aware this is the case and how do you know if you are getting it right?

Is a familiar structure important for the interpretation of the participant's communication?

How do you explain/teach new people about communicating with the participant?

How do you imagine they might tell their story? What would be the essential elements- people, places, objects and experiences?

Noelle McCormack 14/IEC08/1014

30.09.14

### 3. Researcher Statement

[Rix Research and Media and UEL header and footer]

Words Fail Us: An exploration of the challenges of doing life story work with people who have profound and multiple learning disabilities.

#### Researcher Statement

I will make every effort to ensure that the project participant's rights are respected at all stages.

This means that:

- I will tell the individual what I am doing and why.
- I will not video record the participant in private situations, for example when they are unwell or during personal care.
- I will be sensitive to any signs that the participant is no longer pleased to participate in the research and should I judge this be the case will withdraw them and their families from the project immediately and permanently.

Noelle McCormack 14/IEC08/1014

30.09.14

#### 4. Safeguarding Information

[Rix Research and Media and UEL header and footer]

#### Safeguarding Information

Words Fail Us: An exploration of the challenges of doing life story work with people who have profound and multiple learning disabilities.

The catchment area for my research is likely to be in Sussex. I will contact the appropriate services should I be concerned about safeguarding issues. If participants are from another location I will find out the relevant contact details of safeguarding services in that area.

East Sussex County Council Adult Social Care: 0345 60 80 191.

Brighton and Hove Council Adult Social Care:

To report abuse of vulnerable adult, use our [online adult abuse reporting form](#) or call Brighton & Hove City Council Adult Social Care on 01273 295555.

To report a crime call Sussex Police on 0845 60 70 999.

In emergencies: phone the police on 999.

I have included the following 'breaching confidentiality' statement in all PIS's as instructed by the SCREC:

*Please note: Everything you say or report is confidential, unless you tell me something that indicates that you or someone else is at risk of harm. I would discuss this with you before telling anyone else.*

Noelle McCormack 14/IEC08/1014

30.09.14

## 5. Recruitment Letter

[Rix Research and Media and UEL header and footer]

### Invitation to Participate

#### Words Fail Us: An exploration of the challenges of doing life story work with people who have profound and multiple learning disabilities

Date

Dear Sir or Madam

I am a PhD student at the Rix Centre at the University of East London, currently undertaking a three-year project examining the challenges of doing life story work with people who have profound and multiple learning disabilities. This is part of a larger project that is funded by the Arts and Humanities Research Council and led by the Open University.

The study I am planning to do will be divided in to three phases. During the first phase I will use a range of methods including analysis of life history materials, interviews and observation, to record the communication abilities of your son or daughter. The second phase will match their abilities and skills with new media technologies and communication tools to provide meaningful opportunities for them to participate in life story work.

The story they participate in producing will be theirs and can be used by them to help explain themselves and to increase opportunities for choice and control in their lives. I will write up a report about the project in the third phase.

The project will involve me working in the family home for an average of three hours a week between March 2015 and April 2016. I will work closely with you and your son or daughter's support staff to fit in with day-to-day routines. There will be time in the project for planned (and unplanned) breaks as the need arises.

If you are interested in taking part and would like more information please contact me on 07791957093 to arrange a time to discuss the project.

Many thanks for your interest,  
Yours sincerely,

Noelle McCormack



## 6. Accessible Information sheet

[Rix Research and Media and UEL header and footer]

### Accessible information sheet<sup>19</sup>

#### How can you take part in life story work?

[IMAGE] My name is Noelle McCormack.  
I am a researcher.

[IMAGE] I want to find ways for you to take part in telling your story.

[IMAGE] I will do this by working with you and your support circle for a year and a half.

[IMAGE] I will ask questions like:  
'How do you communicate?'  
'What helps you communicate?'

[IMAGE] To find out the answers I will follow these steps:

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<sup>19</sup> Version 1. 6.08.14

[IMAGE] I will read reports that people have written and look at records that your family kept.

[IMAGE] I will ask the people who know you well what they think.

[IMAGE] I will video how you are communicating day-to-day.

[IMAGE] Then I will work with you to find ways for you to take part in your life story.

[IMAGE] I will record what we do in a way that everyone can understand.

[IMAGE] It's OK to change your mind if you do not want to take part.

[IMAGE]

Everyone has a story to tell and your story matters.

[IMAGE]

If you have any questions please contact me  
[phone number]

## 6. a) Information Sheet for Personal Consultees

[Rix Research and Media and UEL header and footer]

### **Information Sheet for Personal Consultees**<sup>20</sup>

**Project title:** Words Fail Us: An exploration of the challenges of doing life story work with people who have profound and multiple learning disabilities.

I would like to invite your son or daughter ..... to take part in this research project. I would like your support to decide whether or not they would be happy to take part. I will go through the information sheet with you and answer any questions you have. Please ask if anything is not clear.

#### **Purpose of the study**

The purpose of the study is to identify the nonverbal communication repertoires of people with profound and multiple learning disabilities for use in the development of meaningful opportunities to include and engage them in different aspects of life story work. The research project will employ a range of qualitative methods and will be divided in to three distinct phases and will last for approximately 18 months in total.

#### **Phase One**

The main purpose of Phase One is to identify the individual nonverbal repertoire of communication of your son or daughter. This will be done in the following ways:

##### **1. Life Story Material: March-April 2015**

This first part of the project will take place in your family home. Life history materials including photos, videos and written records from a range of sources including school, college, adult services, projects, and family memorabilia will be analyzed. The life history materials will be used to chart lifelines of your son or daughter with specific reference to communication. It is anticipated that this first stage will take an average of 3 hours a week and will last for up to 8 weeks in total. I will be guided by your wishes regarding how best to arrange these weekly visits. My aim is to fit in to the rhythm of family life and minimise disruption.

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<sup>20</sup> Version 2. 29.09.14

## **2. Observation: May-July 2015**

The second stage of Phase 1 will include direct observations of the every day lived experiences of son or daughter. Video recording, observation and field notes will be used in this stage. The use of video recording will provide the opportunity to observe the communication repertoire of your son or daughter. It is anticipated that an average of 3 hours each week will be spent with them and their support worker, at their convenience.

*Please Note: video recording will not take place under any circumstances that compromise the dignity of ..... For example during personal care or if they are unwell.*

## **3. Interviews: August-November 2015**

Findings from Stages 1 and 2 will form the basis of semi-structured interviews with people who know your son or daughter well. The circles of support will vary, but may include one or both parents, up to two relatives, up to two support workers and up to two family friends. The focus of the interviews will be on developing a further understanding of the personal communication repertoires and life stories of your son or daughter. Questions will build on the analysis of the archived material, clarify any inconsistencies and will focus on specific qualities of relationships, environments, purposes, motivations, structures and routines which offer the best conditions for them to communicate. Each of those in the circles of support will be interviewed for between 1 and 3 hours. More than one interview may take place if necessary. The interviews will take place in your home at the convenience of all involved. It is anticipated that one interview will take place on average each week and that this stage of the study will last for up to 4 months.

## **Phase Two**

### **Preparation December 2015-January 2016**

I will spend this time investigating possible media and communication tools that have the potential to provide opportunities to engage and include .....in the different stages of life story work.

### **Life Story Work: February-April 2016**

The purpose of Phase 2 is to explore creative and meaningful opportunities for your son or daughter to use their individual repertoires of communication, as identified in Phase One of the research process and to engage in the research, production and sharing of their personal life histories. This will involve using a range of appropriate multimedia and communication

tools. This phase of the project will be based in your home and will involve working with ..... and their support worker for an average of 3 hours a week for up to 3 months. By the end of Phase Two your son or daughter will have taken part in creating an accessible story that can be used to tell people about themselves and their life.

### **Phase Three**

I will regularly update you so that you are involved and informed as the project progresses. I will write a final report within three months of completing Phase 2 of the project. The research methods and findings will form part of the final write up of my PhD thesis.

### **Your son or daughter's participation**

If you decide that your son or daughter would like to take part in the project they will be invited to participate by:

- Reflecting on their life history materials March –April 2015
- Being filmed in day-to-day interaction with people they are in contact with May-July 2015
- Participating in using a range of new media and communication tools in various stages of life story work February-April 2016

### **Confidentiality**

All the information collected will be kept securely and only used for the purpose of the project. Your son or daughter's personal details, as contained in the Consultee Declaration form, will be kept in a secure location at the University of East London and not disclosed to anyone except academic staff supervising the project. Your son or daughter's details will be anonymised for analysis and they will be given a pseudonym in publications. All project data will be kept for three years on a password protected computer and then deleted. Hard copy print outs will be kept securely and shredded after 3 years. I will abide by the principles of the Data Protection Act 1998. *Please note: Everything you say or report is confidential, unless you tell me something that indicates that you or someone else is at risk of harm. I would discuss this with you before telling anyone else.*

### **Risks and Benefits**

The research will last for up to 18 months and will be taking place in the family home and could be intrusive. I will work with all involved to minimize any disruption to family life and be guided by you in all arrangements. I have allowed extra time for planned and unplanned breaks. The purpose of the study is to look closely at all the ways in

which your son or daughter is communicating and to make detailed records.

This will be of potential benefit to them by increasing opportunities for choice and control. The records may be of use for training and development purposes. The life story work and final story will be owned by your son or daughter and has the potential to help them explain themselves to everyone they come in to contact with.

*Please note: Your son or daughter will be free to withdraw from the project at any time. I will take responsibility for judging whether any distress has been caused by the research or for another reason. If they show signs of distress due to the research, they will be withdrawn from the project immediately and permanently and I will discontinue work with your family.*

### **Research funding**

This study is part of a larger project. The Arts and Humanities Research Council has awarded a grant to develop an accessible archive of learning disability history. The project is led by the Open University in partnership with Leeds University and the Rix Centre at the University of East London. The findings of this project will contribute to an increased understanding of the barriers and challenges faced by profoundly disabled people and identify some creative opportunities for representation.

### **Ethical review**

This study has been reviewed and given a favourable opinion by the Social Care Research Ethics Committee. A Research Ethics Committee is a group of independent people who review research to protect the dignity, rights, safety and wellbeing of participants and researchers.

### **Contact details**

If you think that your son or daughter would like to take part in the project please contact me to arrange a time to complete the Consultee Declaration form. If you have any questions please do not hesitate to contact me. Your son or daughter's .....participation is voluntary and if you feel that they would like to withdraw from the project they may do so at any time.

Noelle McCormack  
Lead Researcher  
c/o Rix Centre  
University of East London  
Docklands Campus  
4-6 University Way  
London E16 2RD  
0779 1957 093  
[u1346820@uel.ac.uk](mailto:u1346820@uel.ac.uk)

If you have any concerns or queries about the research or the researcher, please contact:

Andy Minnion  
Director of Studies  
The Rix Centre  
University of East London  
Docklands Campus  
4-6 University Way  
London E16 2RD  
023 8223 2447  
[A.T.Minnion@uel.ac.uk](mailto:A.T.Minnion@uel.ac.uk)



6. b) Declaration Sheet for Personal Consultees

[Rix Research and Media and UEL header and footer]

**Declaration Sheet for Personal Consultees<sup>21</sup>**

Project title: Words Fail Us: An exploration of the challenges of doing life story work with people who have profound and multiple learning disabilities.

Please tick box  
Yes No

	Yes	No
I have read the information sheet for consultees, dated .....version.....		
I have had the opportunity to ask questions and have had my questions answered satisfactorily.		
I understand that the supervisory team may review data collected during the project.		
I think that ..... will be happy to be filmed during the project.		
I understand that the participation of ..... is voluntary and that they are free to withdraw at any time, without giving reasons and without their rights being affected.		
I understand that if ..... withdraws from the study, data collected up to that point would be destroyed.		
I think that ..... would like to take part in the study.		

Name of participant on whose behalf you are being consulted:

.....

Relationship to participant:.....

Name of Personal Consultee (please print).....

Signed.....Date.....

Name of researcher (please print).....

Signed.....Date.....

<sup>21</sup> Version 2. 29.09.14

## 7. a) Information Sheet for Nominated Consultees

[Rix Research and Media and UEL header and footer]

### **Information Sheet for Nominated Consultees**<sup>22</sup>

**Project title:** Words Fail Us: An exploration of the challenges of doing life story work with people who have profound and multiple learning disabilities.

I would like to invite ..... to take part in this research project. I would like your support to decide whether or not they would be happy to take part. I will go through the information sheet with you and answer any questions you have. Please ask if anything is not clear.

#### **Purpose of the study**

The purpose of the study is to identify the nonverbal communication repertoires of people with profound and multiple learning disabilities for use in the development of meaningful opportunities to include and engage them in different aspects of life story work. The research project will employ a range of qualitative methods and will be divided in to three distinct phases and will last for approximately 18 months in total.

#### **Phase One**

The main purpose of Phase One is to identify the individual nonverbal repertoire of communication of ..... This will be done in the following ways:

##### **1. Life Story Material: March-April 2015**

This first part of the project will take place in their family home. Life history materials including photos, videos and written records from a range of sources including school, college, adult services, projects, and family memorabilia will be analyzed. The life history materials will be used to chart lifelines of ..... with specific reference to communication. It is anticipated that this first stage will take an average of 3 hours a week and will last for up to 8 weeks in total. I will be guided by the family's wishes regarding how best to arrange these weekly visits. My aim is to fit in to the rhythm of family life and minimise disruption.

##### **2. Observation: May-July 2015**

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<sup>22</sup> Version 1. 29.09.14

The second stage of Phase 1 will include direct observations of the every day lived experiences of ..... Video recording, observation and field notes will be used in this stage. The use of video recording will provide the opportunity to observe the communication repertoire of ..... It is anticipated that an average of 3 hours each week will be spent with them and their support worker, at their convenience. *Please Note: video recording will not take place under any circumstances that compromise the dignity of ....., for example during personal care or if they are unwell.*

### **3. Interviews: August-November 2015**

Findings from Stages 1 and 2 will form the basis of semi-structured interviews with people who know ..... well. The circles of support will vary, but may include one or both parents, up to two relatives, up to two support workers and up to two family friends. The focus of the interviews will be on developing a further understanding of the personal communication repertoires and life stories of ..... Questions will build on the analysis of the archived material, clarify any inconsistencies and will focus on specific qualities of relationships, environments, purposes, motivations, structures and routines which offer the best conditions for them to communicate. Each of those in the circles of support will be interviewed for between 1 and 3 hours. More than one interview may take place if necessary. The interviews will take place in the family home at the convenience of all involved. It is anticipated that one interview will take place on average each week and that this stage of the study will last for up to 4 months.

## **Phase Two**

### **Preparation December 2015-January 2016**

I will spend this time investigating possible media and communication tools that have the potential to provide opportunities to engage and include ..... in the different stages of life story work.

### **Life Story Work: February-April 2016**

The purpose of Phase 2 is to explore creative and meaningful opportunities for ..... to use their individual repertoires of communication, as identified in Phase One of the research process and to engage in the research, production and sharing of their personal life histories. This will involve using a range of appropriate multimedia and communication tools. This phase of the project will be based in the family home and

will involve working with ..... and their support worker for an average of 3 hours a week for up to 3 months. By the end of Phase Two ..... will have taken part in creating an accessible story that can be used to tell people about themselves and their life.

### **Phase Three**

I will write a final report within three months of completing Phase 2 of the project. The research methods and findings will form part of the final write up of my PhD thesis.

### **(Name's) participation**

If you decide that ..... would like to take part in the project they will be invited to participate by:

- Reflecting on their life history materials March –April 2015
- Being filmed in day-to-day interaction with people they are in contact with May-July 2015
- Participating in using a range of new media and communication tools in various stages of life story work February-April 2016

### **Confidentiality**

All the information collected will be kept securely and only used for the purpose of the project. .... personal details, as contained in the Consultee Declaration form, will be kept in a secure location at the University of East London and not disclosed to anyone except academic staff supervising the project. Their details will be anonymised for analysis and they will be given a pseudonym in publications. All project data will be kept for three years on a password protected computer and then deleted. Hard copy print outs will be kept securely and shredded after 3 years. I will abide by the principles of the Data Protection Act 1998.

*Please note: Everything you say or report is confidential, unless you tell me something that indicates that you or someone else is at risk of harm. I would discuss this with you before telling anyone else.*

### **Risks and Benefits**

The research will last for up to 18 months and will be taking place in the family home and could be intrusive. I will work with all involved to minimize any disruption to family life. I have allowed extra time for planned and unplanned breaks. The purpose of the study is to look closely at all the ways in which ..... is communicating and to make detailed records. This will be of potential benefit to them by increasing opportunities for choice and control. The records may be of use for training and development purposes. The life story work and final story will be owned by .....and has the potential to

help them explain themselves to everyone they come in to contact with.

*Please note: ..... will be free to withdraw from the project at any time. I will take responsibility for judging whether any distress has been caused by the research or for another reason. If they show signs of distress due to the research, they will be withdrawn from the project immediately and permanently and I will discontinue work with the family.*

### **Research funding**

This study is part of a larger project. The Arts and Humanities Research Council has awarded a grant to develop an accessible archive of learning disability history. The project is led by the Open University in partnership with Leeds University and the Rix Centre at the University of East London. The findings of this project will contribute to an increased understanding of the barriers and challenges faced by profoundly disabled people and identify some creative opportunities for representation.

### **Ethical review**

This study has been reviewed and given a favourable opinion by the Social Care Research Ethics Committee. A Research Ethics Committee is a group of independent people who review research to protect the dignity, rights, safety and wellbeing of participants and researchers.

### **Contact details**

If you think that ..... would like to take part in the project please contact me to arrange a time to complete the Consultee Declaration form. If you have any questions please do not hesitate to contact me. .... participation is voluntary and if you feel that they would like to withdraw from the project they may do so at any time.

Noelle McCormack  
Lead Researcher  
c/o Rix Centre  
University of East London  
Docklands Campus  
4-6 University Way  
London E16 2RD  
0779 1957 093  
[u1346820@uel.ac.uk](mailto:u1346820@uel.ac.uk)

If you have any concerns or queries about the research or the researcher, please contact:

Andy Minnion  
Director of Studies  
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023 8223 2447  
A.T.Minnion@uel.ac.uk

7. b) Declaration Sheet for Nominated Consultees

[Rix Research and Media and UEL header and footer]

Declaration Sheet for Nominated Consultees<sup>23</sup>

Project title: Words Fail Us: An exploration of the challenges of doing life story work with people who have profound and multiple learning disabilities.

Please tick box  
Yes No

I have read the information sheet for nominated consultees, dated .....version.....		
I have had the opportunity to ask questions and have had my questions answered satisfactorily.		
I understand that the supervisory team may review data collected during the project.		
I think that ..... will be happy to be filmed during the project.		
I understand that the participation of ..... is voluntary and that they are free to withdraw at any time, without giving reasons and without their rights being affected.		
I understand that if ..... withdraws from the study, data collected up to that point would be destroyed.		
I think that ..... would like to take part in the study.		

Name of participant on whose behalf you are being consulted:

.....

Relationship to participant:.....

Name of Nominated Consultee:.....

Signed.....Date.....

Name of researcher:.....

Signed.....Date.....

---

<sup>23</sup> Version 1. 29.09.14

## 8. Information Sheet for Parents

[Rix Research and Media and UEL header and footer]

### **Information Sheet for parents**<sup>24</sup>

#### **Words Fail Us: An exploration of the challenges of doing life story work with people who have profound and multiple learning disabilities.**

I would like to invite you to take part in this research project. Before you decide I would like you to understand why the research is being done and what it would involve for you. I will go through the information sheet with you and answer any questions you have. Please ask if anything is not clear.

#### **Purpose of the study**

The purpose of the study is to identify the nonverbal communication repertoires of people with profound and multiple learning disabilities for use in the development of meaningful opportunities to include and engage them in different aspects of life story work. The research project will employ a range of qualitative methods and will be divided in to three distinct phases and will last for approximately 18 months in total.

#### **Phase One**

The main purpose of Phase One is to identify the individual nonverbal repertoire of communication of your son or daughter. This will be done in the following ways:

##### **1. Life Story Material: March-April 2015**

This first part of the project will take place in your family home. Life history materials including photos, videos and written records from a range of sources including school, college, adult services, projects, and family memorabilia will be analyzed. The life history materials will be used to chart lifelines of your son or daughter with specific reference to communication. It is anticipated that this first stage will take an average of 3 hours a week and will last for up to 8 weeks in total. I will be guided by your wishes regarding how best to arrange these weekly visits. My aim is to fit in to the rhythm of family life and minimise disruption.

##### **2. Observation: May-July 2015**

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<sup>24</sup> Version 2 29.09.14



The second stage of Phase 1 will include direct observations of the every day lived experiences of son or daughter. Video recording, observation and field notes will be used in this stage. The use of video recording will provide the opportunity to observe the communication repertoire of your son or daughter. It is anticipated that an average of 3 hours each week will be spent with them and their support worker, at their convenience.

*Please Note: video recording will not take place under any circumstances that compromise the dignity of your son or daughter, for example during personal care or if they are unwell.*

### **3. Interviews: August-November 2015**

Findings from Stages 1 and 2 will form the basis of semi-structured interviews with people who know your son or daughter well. The circles of support will vary, but may include one or both parents, up to two relatives, up to two support workers and up to two family friends. The focus of the interviews will be on developing a further understanding of the personal communication repertoires and life stories of your son or daughter. Questions will build on the analysis of the archived material, clarify any inconsistencies and will focus on specific qualities of relationships, environments, purposes, motivations, structures and routines which offer the best conditions for them to communicate. Each of those in the circles of support will be interviewed for between 1 and 3 hours. More than one interview may take place if necessary. The interviews will take place in your home at the convenience of all involved. It is anticipated that one interview will take place on average each week and that this stage of the study will last for up to 4 months.

### **Phase Two**

#### **Preparation December 2015-January 2016**

I will spend this time investigating possible media and communication tools that have the potential to provide opportunities to engage and include your son or daughter in the different stages of life story work.

#### **Life Story Work: February-April 2016**

The purpose of Phase 2 is to explore creative and meaningful opportunities for your son or daughter to use their individual repertoires of communication, as identified in Phase One of the research process and to engage in the research, production and sharing of their personal life histories. This will involve using a range of appropriate multimedia and communication tools. This phase of the project will be based in your home and will involve working with your son or daughter and their support worker

for an average of 3 hours a week for up to 3 months. By the end of Phase Two they will have taken part in creating an accessible story that can be used to tell people about themselves and their life.

### **Phase Three**

I will regularly update you so that you are involved and informed as the project progresses. I will write a final report within three months of completing Phase 2 of the project. The research methods and findings will form part of the final write up of my PhD thesis.

### **Your participation**

I have invited you to take part in this study because of your importance in the life of your son or daughter and because you are in a position to tell me about how, why, where and with whom they communicate.

*Please note: In order for your son or daughter to be involved in this project it will be necessary for his or her circle of support to freely consent to participate. The circle of support can include up to six people including for example, one or both parents, up to two relatives, a support worker and a family friend. I will arrange the research times to coincide with those of your son or daughter's support workers who freely consent to participate. It will be their decision whether or not to take part in the project.*

It is up to you to decide to take part. I will describe the study and go through this information sheet with you. If you agree to take part then I will ask you to sign a consent form.

*Please note: You may wish to take part, but to opt-out of specific aspects of the project, for example having your interview recorded or being filmed. This is a yearlong project and I will ensure that we meet regularly (at least once a month) to update you, to check that everything is going well and make changes to arrangements as requested. However, it is important for you to understand that you are free to withdraw at any time without giving a reason. Should you choose to withdraw your son or daughter and their circle of support will no longer be part of the project. I will support you in this decision.*

If you decide to take part you will be participating in the following:

- Invite me in to your home to work for an average of 3 hours a week for up to 12 months (including breaks) between March 2015 and March 2016.
- Make available life history materials for analysis. March 2015

- Take part in a recorded interview for between one and three hours. August-November 2015
- Check the interview transcript for accuracy.

*Please note: There are separate information sheets for you as personal consultee about the participation of your son or daughter in the project.*

### **Confidentiality**

All the information collected will be kept securely and only used for the purpose of the project. Your personal details, as contained in the consent form, will be kept in a secure location at the University of East London and not disclosed to anyone except academic staff supervising the project. Your details will be anonymised for analysis and you will be given pseudonyms in publications. All project data will be kept for three years on a password protected computer and then deleted. Hard copy print outs will be kept securely and shredded after 3 years. I will abide by the principles of the Data Protection Act 1998.

*Please note: Everything you say or report is confidential, unless you tell me something that indicates that you or someone else is at risk of harm. I would discuss this with you before telling anyone else.*

### **Risks and Benefits**

The research will be taking place in the family home and could be intrusive. I will work with all involved to minimize any disruption to family life and be guided by you in all arrangements. I have allowed extra time for planned and unplanned breaks. The purpose of the study is to look closely at all the ways in which your son or daughter is communicating and to make detailed records. This will be of potential benefit to them by increasing opportunities for choice and control. The records may be of use for training and development purposes. The life story work and final story will be owned by your son or daughter and has the potential to help them explain themselves to everyone they come in to contact with.

### **Research funding**

This study is part of a larger project. The Arts and Humanities Research Council have awarded a grant to develop an accessible archive of learning disability history.

The project is led by the Open University in partnership with Leeds University and the Rix Centre at the University of East London. The findings of this project will contribute to an increased understanding of the barriers and challenges faced by profoundly disabled people and identify some creative opportunities for representation.

### **Ethical review**

This study has been reviewed and given a favourable opinion by the Social Care Research Ethics Committee. A Research Ethics Committee is a group of independent people who review research to protect the dignity, rights, safety and wellbeing of participants and researchers.

### **Contact details**

If you would like to take part in the project please contact me to arrange a time to sign the consent form. If you have any questions please do not hesitate to contact me. Your participation is voluntary and if you decide that you would like to withdraw from the project you may do so at any time.

### **My contact details are:**

Noelle McCormack  
Lead Researcher  
c/o Rix Centre  
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### **If you have any concerns or queries about the research or the researcher, please contact:**

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## 9. Information Sheet for Relatives and Friends

[Rix Research and Media and UEL header and footer]

### **Information Sheet for relatives and friends**<sup>25</sup>

#### **Words Fail Us: An exploration of the challenges of doing life story work with people who have profound and multiple learning disabilities.**

I would like to invite you to take part in this research project. Before you decide I would like you to understand why the research is being done and what it would involve for you. I will go through the information sheet with you and answer any questions you have. Please ask if anything is not clear.

#### **Purpose of the study**

The purpose of the study is to identify the nonverbal communication repertoires of people with profound and multiple learning disabilities for use in the development of meaningful opportunities to include and engage them in different aspects of life story work. The research project will employ a range of qualitative methods and will be divided in to three distinct phases and will last for approximately 18 months in total.

#### **Phase One**

The main purpose of Phase One is to identify the individual nonverbal repertoire of communication of ..... This will be done in the following ways:

##### **1. Life Story Material: March-April 2015**

This first part of the project will take place in their family home. Life history materials including photos, videos and written records from a range of sources including school, college, adult services, projects, and family memorabilia will be analyzed. The life history materials will be used to chart lifelines of ..... with specific reference to communication. It is anticipated that this first stage will take an average of 3 hours a week and will last for up to 8 weeks in total.

##### **2. Observation: May-July 2015**

The second stage of Phase 1 will include direct observations of the every day lived experiences of ..... Video recording, observation and field notes will be used in this stage. The use of

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<sup>25</sup> Version 2 29.09.14

video recording will provide the opportunity to observe the communication repertoire of ..... It is anticipated that an average of 3 hours each week will be spent with them and their support worker, at their convenience.

*Please Note: video recording will not take place under any circumstances that compromise the dignity of ....., for example during personal care or if they are unwell.*

### **3. Interviews: August-November 2015**

Findings from Stages 1 and 2 will form the basis of semi-structured interviews with people who know ..... well. The circles of support will vary, but may include one or both parents, up to two relatives, up to two support workers and up to two family friends. The focus of the interviews will be on developing a further understanding of the personal communication repertoires and life stories of ..... Questions will build on the analysis of the archived material, clarify any inconsistencies and will focus on specific qualities of relationships, environments, purposes, motivations, structures and routines which offer the best conditions for them to communicate. Each of those in the circles of support will be interviewed for between 1 and 3 hours. More than one interview may take place if necessary. The interviews will take place in your home at the convenience of all involved. It is anticipated that one interview will take place on average each week and that this stage of the study will last for up to 4 months.

### **Phase Two**

#### **Preparation December 2015-January 2016**

I will spend this time investigating possible media and communication tools that have the potential to provide opportunities to engage and include ..... in the different stages of life story work.

#### **Life Story Work: February-April 2016**

The purpose of Phase 2 is to explore creative and meaningful opportunities for ..... to use their individual repertoires of communication, as identified in Phase One of the research process and to engage in the research, production and sharing of their personal life histories. This will involve using a range of appropriate multimedia and communication tools. This phase of the project will be based in their home and will involve working with..... and their support worker for an average of 3 hours a week for up to 3 months. By the end of Phase Two ..... will have taken part in creating an accessible story that can be used to tell people about themselves and their life.

### **Phase Three**

I will write a final report within three months of completing Phase 2 of the project. The research methods and findings will form part of the final write up of my PhD thesis.

### **Your participation**

I have invited you to take part in this study because of your importance in the life of ..... and because you are in a position to tell me about how, why, where and with whom they communicate.

*Please note: In order for your ..... to be involved in this project it will be necessary for his or her circle of support to freely consent to participate. The circle of support can include up to six people including for example, one or both parents, up to two relatives, a support worker and a family friend. I will arrange the research times to coincide with those of their support workers who freely consent to participate.*

It is up to you to decide to take part. I will describe the study and go through this information sheet with you. If you agree to take part then I will ask you to sign a consent form.

*Please note: You may wish to take part, but to opt-out of specific aspects of the project, for example having your interview recorded. However, it is important for you to understand that you are free to withdraw at any time without giving a reason. Should you choose to withdraw I will support you in this decision.*

If you decide to take part you will be participating in the following:

- Take part in a recorded interview for between one and three hours. August-November 2015
- Check the interview transcript for accuracy.

### **Confidentiality**

All the information collected will be kept securely and only used for the purpose of the project. Your personal details, as contained in the consent form, will be kept in a secure location at the University of East London and not disclosed to anyone except academic staff supervising the project. Your details will be anonymised for analysis and you will be given pseudonyms in publications. All project data will be kept for three years on a password protected computer and then deleted. Hard copy print outs will be kept securely and shredded after 3 years. I will abide by the principles of the Data

Protection Act 1998.

*Please note: Everything you say or report is confidential, unless you tell me something that indicates that you or someone else is at risk of harm. I would discuss this with you before telling anyone else.*

### **Risks and Benefits**

The research will be taking place in the family home and could be intrusive. I will work with all involved to minimize any disruption to family life. I have allowed extra time for planned and unplanned breaks. The purpose of the study is to look closely at all the ways in which ..... is communicating and to make detailed records. This will be of potential benefit to them by increasing opportunities for choice and control. The records may be of use for training and development purposes. The life story work and final story will be owned by them and has the potential to help them explain themselves to everyone they come in to contact with.

### **Research funding**

This study is part of a larger project. The Arts and Humanities Research Council have awarded a grant to develop an accessible archive of learning disability history.

The project is led by the Open University in partnership with Leeds University and the Rix Centre at the University of East London. The findings of this project will contribute to an increased understanding of the barriers and challenges faced by profoundly disabled people and identify some creative opportunities for representation.

### **Ethical review**

This study has been reviewed and given a favourable opinion by the Social Care Research Ethics Committee. A Research Ethics Committee is a group of independent people who review research to protect the dignity, rights, safety and wellbeing of participants and researchers.

### **Contact details**

If you would like to take part in the project please contact me to arrange a time to sign the consent form. If you have any questions please do not hesitate to contact me. Your participation is voluntary and if you decide that you would like to withdraw from the project you may do so at any time.



**My contact details are:**

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Docklands Campus  
4-6 University Way  
London E16 2RD  
023 8223 2447  
A.T.Minnion@uel.ac.uk

## **Information Sheet for support workers<sup>26</sup>**

### **Project Title: Words Fail Us: An exploration of the challenges of doing life story work with people who have profound and multiple learning disabilities.**

I would like to invite you to take part in this research project. Before you decide I would like you to understand why the research is being done and what it would involve for you. I will go through the information sheet with you and answer any questions you have. Please ask if anything is not clear.

#### **Purpose of the study**

The purpose of the study is to identify the nonverbal communication repertoires of people with profound and multiple learning disabilities for use in the development of meaningful opportunities to include and engage them in different aspects of life story work. The research project will employ a range of qualitative methods and will be divided in to three distinct phases and will last for approximately 18 months in total.

#### **Phase One**

The main purpose of Phase One is to identify the individual nonverbal repertoire of communication of the person you support. This will be done in the following ways:

##### **1. Life Story Material: March-April 2015**

This first part of the project will take place in the family home of the person you support. Life history materials including photos, videos and written records from a range of sources including school, college, adult services, projects, and family memorabilia will be analyzed. The life history materials will be used to chart lifelines of the person you support with specific reference to communication. It is anticipated that this first stage will take an average of 3 hours a week and will last for up to 8 weeks in total. I will be work with all involved to arrange these weekly visits. My aim is to fit in to the rhythm of family life and minimise disruption.

##### **2. Observation: May-July 2015**

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<sup>26</sup> Version 2 29.09.14

The second stage of Phase 1 will include direct observations of the every day lived experiences of the person you support. Video recording, observation and field notes will be used in this stage. The use of video recording will provide the opportunity to observe the communication repertoire of the person you support. It is anticipated that an average of 3 hours each week will be spent with them and you, their support worker, at your convenience.

*Please Note: video recording will not take place under any circumstances that compromise the dignity of the person you support, for example during personal care or if they are unwell.*

### **3. Interviews: August-November 2015**

Findings from Stages 1 and 2 will form the basis of semi-structured interviews with people who know the person you support well. The circles of support will vary, but may include one or both parents, up to two relatives, up to two support workers and up to two family friends. The focus of the interviews will be on developing a further understanding of the personal communication repertoires and life stories of the person you support. Questions will build on the analysis of the archived material, clarify any inconsistencies and will focus on specific qualities of relationships, environments, purposes, motivations, structures and routines which offer the best conditions for them to communicate. Each of those in the circles of support will be interviewed for between 1 and 3 hours. More than one interview may take place if necessary. The interviews will take place at the convenience of all involved. It is anticipated that one interview will take place on average each week and that this stage of the study will last for up to 4 months.

### **Phase Two**

#### **Preparation December 2015-January 2016**

I will spend this time investigating possible media and communication tools that have the potential to provide opportunities to engage and include the person you support in the different stages of life story work.

#### **Life Story Work: February-April 2016**

The purpose of Phase 2 is to explore creative and meaningful opportunities for the person you support to use their individual repertoires of communication, as identified in Phase One of the research process and to engage in the research, production and sharing of their personal life histories. This will involve using a range of appropriate multimedia and communication tools. This phase of the project will be based in the family home and will involve working with you and the person you support for an average of 3 hours a

week for up to 3 months. By the end of Phase Two they will have taken part in creating an accessible story that can be used to tell people about themselves and their life.

### **Phase Three**

I will regularly update you so that you are involved and informed as the project progresses. I will write a final report within three months of completing Phase 2 of the project. The research methods and findings will form part of the final write up of my PhD thesis.

### **Your participation**

I have invited you to take part in this study because of your importance in the life of the person you support and because you are in a position to tell me about how, why, where and with whom they communicate.

*Please note: In order for the person you support to be involved in this project it will be necessary for his or her circle of support to freely consent to participate. The circle of support can include up to six people including for example, one or both parents, up to two relatives, up to two support workers and family friends. I will arrange the research times to coincide with those of support workers who are happy to participate. It will be your decision whether or not to take part in the project.*

I will describe the study and go through this information sheet with you. If you agree to take part then I will ask you to sign a consent form.

*Please note: You may wish to take part, but to opt-out of specific aspects of the project, for example having your interview recorded or being filmed. This is a yearlong project and I will ensure that we meet regularly (at least once a month) to update you, to check that everything is going well and make changes to arrangements as requested. However, it is important for you to understand that you are free to withdraw at any time without giving a reason. Should you choose to withdraw you will no longer be part of the project. I will support you in this decision.*

If you decide to take part you will be participating in the following:

- Working alongside the person you support in the material analysis stage of the project for an average of 3 hours a week. March-April 2015
- Working with the person you support while I observe and film communication behaviour for an average of 3 hours per week. May-July 2015

- Take part in a recorded interview for between one and three hours. August-November 2015
- Check the interview transcript for accuracy
- Working alongside the person you support during the life story work in Phase 2 for an average of 3 hours a week. February-April 2016

### **Confidentiality**

All the information collected will be kept securely and only used for the purpose of the project. Your personal details, as contained in the consent form, will be kept in a secure location at the University of East London and not disclosed to anyone except academic staff supervising the project. Your details will be anonymised for analysis and you will be given pseudonyms in publications. All project data will be kept for three years on a password protected computer and then deleted. Hard copy print outs will be kept securely and shredded after 3 years. I will abide by the principles of the Data Protection Act 1998.

*Please note: Everything you say or report is confidential, unless you tell me something that indicates that you or someone else is at risk of harm. I would discuss this with you before telling anyone else.*

### **Risks and Benefits**

The research will last for up to 18 months and will be taking place in the family home and could be intrusive. I will work with all involved to minimize any disruption to family life and be guided by you in arrangements. I have allowed extra time for planned and unplanned breaks. The purpose of the study is to look closely at all the ways in which the person you support is communicating and to make detailed records. This will be of potential benefit to them by increasing opportunities for choice and control. The records may be of use for training and development purposes. The life story work and final story will be owned by the person you support and has the potential to help them explain themselves to everyone they come in to contact with.

### **Research funding**

This study is part of a larger project. The Arts and Humanities Research Council have awarded a grant to develop an accessible archive of learning disability history.

The project is led by the Open University in partnership with Leeds University and the Rix Centre at the University of East London. The findings of this project will contribute to an increased understanding of the barriers and challenges faced by profoundly disabled people and identify some creative opportunities for representation.

### **Ethical review**

This study has been reviewed and given a favourable opinion by the Social Care Research Ethics Committee. A Research Ethics Committee is a group of independent people who review research to protect the dignity, rights, safety and wellbeing of participants and researchers.

### **Contact details**

If you would like to take part in the project please contact me to arrange a time to sign the consent form. If you have any questions please do not hesitate to contact me. Your participation is voluntary and if you decide that you would like to withdraw from the project you may do so at any time.

### **My contact details are:**

Noelle McCormack  
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11. Participant Consent Form

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**Participant Consent Form<sup>27</sup>**

Thank you for taking part in this research. You will be given a copy of this consent form to keep and refer to at any time.

Project title: Words Fail Us: An exploration of the challenges of doing life story work with people who have profound and multiple learning disabilities.

Please tick box  
Yes No

I have read the information sheet dated ..... version .....		
I have had the opportunity to ask questions and they have been answered satisfactorily.		
I understand that the supervisory team may review data collected during the project.		
I give permission for my interview to be audio recorded *		
I give permission to be filmed *		
I understand that my participation voluntary and that I am free to withdraw at any time, without giving reasons and without my rights being affected.		
I understand that if I withdraw from the study, data collected up to that point would be destroyed.		
I agree to take part in the study.		

\*Please note: your interview will be recorded and you will be filmed with permission. You may opt out of either or both audio and video recording and still participate in the research.

Name of participant: (please print).....

Signed.....Date.....

Name of researcher: (please print).....

Signed.....Date.....

<sup>27</sup> Version 2. 29.09.14

## 12: Fieldwork Records

### Research Participants

The participants in this research were anonymised to protect their identities. The key participants were given different names (Jack, Amelie and Marian) chosen by their families. All other participants are identified through their relationship to the key participant.

KP= Key Participant (Jack, Amelie and Marian)

M= Key Participant's mother

F= Key participant's father

SF= Key Participant's stepfather

GP= Key Participant's grandparent

S= Key Participant's sister

FF= Key Participants family friend

KW= Key Participant's key worker

SW= Key Participant's support worker

TL= Key Participant's team leader

### Fieldwork Locations

The fieldwork took place in a variety of locations, all of which are described.

### Research activities

The activities undertaken in the fieldwork included:

A= examination of personal archive materials

P= participating in everyday activities

I= interviewing those in the key participants' circles of support

F= facilitating participatory life story work

### Fieldwork recording

The fieldwork visits were recorded in the following ways:

FN= handwritten field notes

V= filming using portable video camera or iPad

A= audio recording using digital audio recorder

P= photographing using digital camera or iPad

S= scanning of documents using iPad application



## 12.a) Case Study 1: Jack

Date	Present	Location	Activity	Record
4/3/15	KP, M, F	KP's home	A	FN, P
11/3/15	KP, M, F	KP's home	A	FN, V, P
18/3/15	KP, M, F	KP's home	A	FN, V, P, S
25/3/15	KP, M, F	KP's home	A, P	FN, V, P
1/4/15	KP, M, F	KP's home	A	FN, V, P
14/4/15	KP, M, F	KP's home	A	FN, V, P
22/4/15	KP, M, F	KP's home	A	FN, V, P, S
6/5/15	KP, M, F	KP's home	A	FN, V, P
20/5/15	KP, M, F	KP's home	A	FN, V, P
24/6/15	KP, M, F, KW	Hydrotherapy	P	FN, V, P
29/6/15	KP, M, F	Gardens	P	FN, V, P
9/8/15	KP, M, F, S	Day Out	P	FN, V, P
24/8/15	M, F	KP's home	I x 2 (1st)	A
28/9/15	KW	Day Centre	I	A
21/10/15	S	Cafe	I	A

25/11/15	KP, M, F	KP's home	I (2nd)	A
2/3/16	KP, M, F	KP's home	F	FN, V, P, A
9/3/16	KP, M, F	KP's home	F	FN, V, P, A
16/3/16	KP, M, F	KP's home	F	FN, V, P, A
30/3/16	KP, M, F	KP's home	F	FN, V, P, A
3/4/16	KP, M, F, S	KP's home	F	FN, V, P, A
6/4/16	KP, M, F	KP's home	F	FN, V, P, A
20/4/16	KP, M, F	KP's home	F	FN, V, P, A
21/4/16	M, F	KP's home	I	FN, A

12.b) Case Study 2: Amelie

Date	Present	Location	Activity	Record
6/3/15	KP, M, TL,	KP's home	A	FN, P
9/3/15	KP, TL, SW	KP's home	A	FN, P
16/3/15	KP, TL, SW	KP's home	A	FN, V, P
23/3/15	KP, TL, SW	KP's home	A	FN, V, P
30/3/15	KP, TL, SW	KP's home	A	FN, V, P

16/4/15	KP, TL, SW	KP's home	A	FN, V, P
20/4/15	KP, TL, SW	KP's home	A	FN, V, P
27/4/15	KP, TL, SW	KP's home	A	FN, V, P
1/5/15	KP, M, TL	KP's home	P	FN, V, P
18/5/15	KP, TL, SW	KP's home	P	FN, V, P
9/6/15	KP, TL, Artist	Art Group	P	FN, V, P
23/6/15	KP, SW, Artist	Art Group	P	FN, V
1/7/15	KP, SW	Café/Park	P	FN, V
23/7/15	KP, SW	Sensory	P	FN, V
4/9/15	M	KP's home	I	A
4/9/15	FF	KP's home	I	A
7/10/15	SF	SF's home	I	A
14/10/15	GPs	KP's home	I	A
11/2/16	KP, TL, SW	KP's home	F	FN, V, P
15/2/16	M	KP's home	F	FN
22/2/16	KP, M, TL, GM	KP's home	F	FN, V, P, A
25/2/16	KP, SW, SW	KP's home	F	A

7/3/16	KP, M, SW	KP's home	F	FN, A
20/3/16	KP, TL, SW	KP's home/town	F	FN, A
4/4/16	KP, TL, SW	KP's home	F	FN, A
17/4/16	KP, TL, SW	KP's home	F	FN, V, P
20/4/16	M, TL	KP's home	I	FN, A

### 12.c) Case Study 3: Marian

Date	Present	Location	Activity	Record
3/3/15	KP, SW	KP's home	A	FN, P, V
10/3/15	KP, SW, SW	KP's home	A	FN, V
17/3/15	KP, M, KW	KP's home	A	FN, V, P
24/3/15	KP, SW, SW	Café	A	FN, V, P
31/3/15	KP, SW, SW	SW's home	A	FN, V, P
14/3/15	KP, SW, SW	SW's garden	A	FN, V, P
21/4/15	KP, SW, SW	Marina	A, P	FN, V, P
12/5/15	KP, M	KP's home	A	FN, V, P
19/5/15	KP, SW, SW	Café	A, P	FN, V, P

26/5/15	KP, SW, SW	SW's home	A, P	FN, V, P
26/6/15	KP, SW, SW	Day Trip	P	FN, V, P
30/6/15	KP, SW, SW	Café	P	FN, V
22/7/15	KP, SW, SW	Pool	P	FN, V
27/7/15	M	KP's home	I	A
1/9/15	F	KP's home	I	A
15/10/15	SW x 4	KP's home	I	A
22/10/15	KP, M, F	Gallery	P	FN, V, P
28/10/15	S	SKYPE	I	A
16/2/16	KP, SW, SW	Café	F	FN
28/2/16	M	KP's home	F	FN, A
15/3/16	KP, SW	KP's home	F	FN, A
22/3/16	KP, M	KP's home	F	FN, V
26/3/16	KP, M, F, GM	KP's home	F	FN, V
12/4/16	KP, M, SW	KP's home	F	FN, A
19/4/16	M	KP's home	I	FN, A

## 13: Vignettes

### 13.a) Vignettes: Jack

#### Jack Vignette1: Songs from Childhood (1:33) March 26<sup>th</sup> 2015

I'm at Jack's home talking about the stories and songs he still enjoys from his childhood days. His mum and dad are reminiscing about how he's always loved being sung to. His father is explaining how he encourages Jack's support workers to sing but they are sometimes reluctant.

'They say, but I can't sing and I say that's alright, neither can I'. Jack's mum laughs and his dad stands up on his Jack's right side and puts his left arm around the back of Jack's wheelchair. He crouches slightly and begins to sing into Jack's right ear.

'Old MacDonald had a farm, e I e I o'. Jack becomes more alert, lifts his head and opens his right eye slightly. 'And on that farm he had a (pause) little piggy, with a (snorts like a pig) here and a (snorts like a pig) there, here a (snort), there a (snort)'

Jack begins to giggle, shaking his head from side to side, 'Everywhere a (Snort, snort). Old MacDonald had a farm. E I, e, I, o'. As Jack's dad pauses for the next verse, Jack moves his head closer to his dad and appears to be waiting, anticipating. 'And on that farm he had a little (pause) cow. E, I, e, I, o' Jack is laughing, holding his head to his left. 'With a' (pause) Jack is now holding his arms up slightly. 'With a moo moo here, and a moo, moo there. Here a moo, there a moo, everywhere a moo moo'. Jack leans his head towards his Dad and laughs. 'Old MacDonald had a farm. E, I, e, I, o.'

Jack's mum and dad explain that they use songs and singing to Jack for fun and to soothe and distract him if he is unhappy.

#### Jack Vignette 2: Tactile Information (4:18) March 26<sup>th</sup> 2015

I'm sitting in Jack's lounge with Jack and his mum and dad. Jack's mum is sitting to his right looking through a scrapbook from 2005. It has a pink felt star attached to the side. His mum says 'Do you remember this book that you did? Look, do you want to feel? There's a big star on the side. Do you want to touch the star? You sometimes feel the star'. Jack is holding on to one of his toys, Woody, but drops it in to his lap as his mum puts the star into his hands. 'They've put a special star on the side so you know what book it is. Can you feel it? Do you remember? It's all tactilely'. Jack is holding the star in both hands. I say 'Oh that's good. So they made it almost like a code for the book'. Mum laughs 'Yes. It's got wool on it as well, Jack, that's good because you love wool'.

Jack continues to hold the star as his mum opens the scrapbook. 'And on the first page there is a lovely picture and it says 'me and my mum', and you were only four months old Jack' Jack repeats a vocalisation 'Da, da'. Mum continues 'And it says, I love you, at the bottom'.

Jack's mum opens the scrapbook at a picture of Jack with a pony (also called Jack). 'There's a big one of you with Jack's head right close to you, right there'; she holds the palm of her left hand a few inches in front of Jack's face. Jack is being very vocal, repeating 'Da da'. He's let go of the star and has his hands at chest height. 'And you're putting your fingers right up his nostrils' and she touches Jack's nose. Jack is making longer sounds 'Daaaa, daaaa'. I say 'Blimey, that horse must have been very trusting'. Jack laughs. Mum says 'The trust. And also if you were to do that to a horse it would be quite difficult, so the trust for Jack and the horse to do that is quite remarkable really.' Jack makes more assertive, 'Da, da, da' sounds.

'And then we've got some pictures, Jack, of you with your sensory things, your feely, tactile things', Jack's mum plays her fingers over his right arm, 'Like your ribbons and your bows and your string. Looking very chilled'. She turns the page. Jack is now holding the page open by both corners. As his mum turns the pages he accommodates them under the fingers of both hands. 'It looks like you're in the sensory room here. I can see the tubes that light up'. Jack continues to vocalise 'Da, da. Da, da.'

'Sweet dreams. In the car having a nap' And they've put little pictures here of cars. Can you feel them?' As Jack's mum reads the photo caption she takes his hand and places his fingers on the small felt cars that are placed at each corner of the photo. He traces the shapes. 'And they've put a picture in here of you having a sleep in the car'.

'This is something tactilely' Jack's mum takes a paper flower with the middle filled by felt and scrunched up tissue on each side. 'Can you feel it? On this side it's rough and the other side it's all velvety and soft.' Jack opens his fingers and feels the different textures. He continues to hold the flower. 'You probably made that in craft'.

Jack's mum continues to look through and describe the pages of the scrapbook. 'And on the last page we've got your weekly programme as it was then.' Jack is grinding his teeth and holding a small blue card. 'So, Hydro on a Monday morning. Pottery on a Tuesday morning, Jack. You had relaxation and sensory in the afternoon. On Wednesday morning you had tactile art and craft and in the afternoon you did a sing-along session. On Thursday morning you did 3D craft, which is probably where you made something like your lovely flower. And Thursday, they call it a mixed bag day, which meant they could do anything, maybe go out. And on Friday morning is paper craft and in the afternoon you'd have a feedback meeting', Jack laughs and shakes his head from side to side. 'And I think that was to talk about the week. His targets and his plans for the following week. So that was all about reflecting on the week for the next week, what you needed to work on. So your programme's a bit different now. He's doing some of those things and a few extra bits added in there as well, that he wasn't doing, but he now is. Was

that good?' Jack moves the blue card around in his hands and continues to grind his teeth. I say 'Oh thank you, thanks for showing that to us'.

### Jack Vignette 3: Joining the Conversation (2:08) March 2015

We are sitting in the lounge in Jack's home. He has returned from his day centre. We're sitting with his mum and dad who have been talking about the serious back surgery that Jack had to correct severe curvature of the spine. Jack is becoming more and more vocal, as if he is joining in with the conversation. I ask if I can film him talking. He is holding a string of beads, which he plays through his fingers.

I say 'You're probably not going to say anything now'. Jack laughs and turns his face towards me. I continue 'We've been talking all about your back surgery' His dad says 'He is very good. I have to say, I mean we were told that that he would be in intensive care and he was in high dependency. And high dependency was going to be a week and it was a day and a bit. The way he recovered from the operation was', Jack vocalises over his dad 'Da, da, da, da', his voice becoming louder and more assertive. His dad continues 'He never moaned once and he must have been in quite a bit of pain'. Jack slows down 'Dah, dah, dah'. I say 'It's really nice you're joining in the conversation'. Jack appears to listen and raises his eyebrows and opens his right eye slightly, looking in my direction, vocalising more strongly again, 'Da, Da, Da,' His mum touches his right shoulder and says 'You're telling everybody you're strong. You're so strong and brave, Jack'. Jack laughs. His dad continues 'In the hospital he was laughing and joking. Jack was chuckling and stuff, so he was quite happy. I mean obviously he couldn't watch TV or anything like that, so we were reading stories', 'Da, da, da' Mum says 'Lots of singing', Dad continues 'He was stuck in bed all day so you've got to try and find ways to keep him amused'. Jack is half smiling with his eyes closed and says 'Dah (pause), dah'. Dad continues 'Hospitals are very boring places'. I say to Jack, 'Shall I stop now?' He turns his face towards me, smiles 'Da, da, mmm, mmm' I say what do you think?' His mum says 'What do you think, tiger?' and he turns his face towards her, laughing. 'Shall I stop' Jack laughs. 'Shall I stop now?' Jack laughs. 'Would you like to hear it back?

### Jack Vignette 4: Feeling the grass (0:46) April 2015

It's the first warm, Spring day of the year. As the sun is shining we decide to sit in the garden and bring some life story material out with us. I'm sitting with Jack's parents on deck chairs. Jack's mother lays a duvet on the grass in the shade from a large tree. She puts a pillow on the duvet. Jack's father lifts him out of his wheelchair and lays him down on the duvet. Jack rolls on to his right side and touches the grass with his left hand. He looks very relaxed. I get down onto the grass facing him and film for a few minutes.

Jack stretches his hand and fingers out, pulls his fingers towards him through the grass and pulls a small handful of grass up. He repeats this movement



rhythmically for twenty minutes or so.

This is described by his parents as one of the things Jack loves to do.

#### Jack Vignette 5: Making his voice heard (1:46) May 20<sup>th</sup> 2015

I am sitting in the lounge at Jack's home with him and his parents. Jack has a large green soft crocodile on his lap. I have been visiting Jack and his parents every Wednesday afternoon since the beginning of March and Jack has become more and more vocal. His father notices this and says that Jack always seems happy and vocal on my visits. He appears to enjoy being recorded and listening back to his voice. On this occasion Jack is making a range of sounds that are from his repertoire, but are new to me. He is sitting with his arms bent, his hands up, smiling broadly and making laughing, high-pitched sounds.

I say 'Are you ready?' His mum laughs. Jack opens and closes his fingers and opens his right eye slightly. I say 'A range of sounds'. Jack begins to vocalise 'Ber, ber, ber, berby, ah'. We are listening. I say 'We've all gone quiet, haven't we?' Jack continues to make a series of high-pitched, expressive sounds. His father says 'Also, don't forget, we were talking before, so he talks, doesn't he?' Jack makes louder sounds, drowning out the sound of his dad. He pulls the crocodile to his face with his left hand. His father says, 'It's a bit like the church syndrome, isn't it? It's all quiet and you let loose'. Jack lowers the crocodile, appears to be listening. I say 'Do you really?' His mum says 'Giggle pants'. Jack pulls the crocodile to his face with his right hand. His father continues, 'The last time he did it I said we're sorry and he said, Oh no, it had cheered up his situation'. He scratches his nose and his mother says 'Jack, have you got an itch?' I say 'Would you like to listen to you talking?' When I speak Jack stops scratching his nose, as though concentrating on my voice. I say 'Yeah? Yeah? Shall I stop this so you can listen back?' Jack laughs. His dad says 'Then you can hear what you sound like Jack'. I stop filming and play the film back to Jack. He holds the iPad and pulls it towards his right ear, apparently listening closely and concentrating on the sounds.

#### Jack Vignette 6: Hydrotherapy (3:55) June 24<sup>th</sup> 2015

I have travelled with Jack's parents to the hydrotherapy pool where he has a 30-minute physiotherapy session every week. We meet him there as he arrives with two staff from his day centre. We go through and sit poolside and watch his physiotherapist, S, as she puts Jack through his exercises. The film is a series of extracts that capture the different elements of his weekly programme. They have been working together for three years and built up a routine and a trusting relationship. S talks quietly to Jack throughout, but is too far away for me to catch what she is saying.

S begins by holding Jack around his chest and moving him backwards through the water. His legs are floating at the surface. She slows and Jack

puts his feet down on the floor of the pool.

Between every five-minute exercise S swirls Jack around, to indicate the end of one exercise and the beginning of the next. He enjoys the repetition of this and anticipates the swirl as S counts in, 'One, two, three and weeee'. Jack laughs. The routines include balancing, leaning back, walking forwards, swaying from side to side, walking holding a long float, standing and balancing with a float and an improvised wave machine. S reassures and praises Jack throughout 'Very good'. Jack's expression alternates between concentration and delight. Overall the session seems like a dance between S and Jack, which includes a sensitive responsiveness on S's part to how long or how far Jack can move independently.

### 13.b) Vignettes: Amelie

#### Amelie Vignette 1a: First Year (2:59) April 16<sup>th</sup> 2005

We are sitting in Amelie's lounge and her team leader is looking through an album of photos of Amelie's first year. She is standing to Amelie's right and is holding an album of photos in Amelie's eye-line. She is upbeat and smiling. Turning from photo to photo.

'Look there you are again. You're on your mum's back' Amelie is looking at the photo and has a serious (bored?) expression on her face.

'Look, there you are. You can just see your face'.

The team leader holds the album a little closer to Amelie's face. She turns to the next photo. Amelie continues to look.

'Whoops', the photos drop down in the album.

'I think I've noticed, with Amelie, I might start taking them out, because I think she's actually better at holding on to them'

I say to Amelie, 'You like holding them?'

The team leader takes a photo from the album. Amelie is tracking the photo with her eyes. She holds it in front of Amelie. 'Right, Amelie, this is you at four months old. When you're just sitting up'

She supports Amelie to hold the photo with her right hand and continues to hold it herself. The photo is moved closer to Amelie's face.

'Do you want to hold it? There that's better, isn't it?'

Amelie moves the photo closer to her face and is looking at it with her eyes wider open. She makes a small sound. They drop the photo.

'Ooh it's on your nose' The team leader picks the photo up and holds it in front of Amelie's face. Amelie's face is animated. She makes a small vocalisation and moves forward, smiling.

'There. That's much better, isn't it? See you've got little stripy leggings on. They're quite funky, aren't they?'

Amelie looks down and back to the photo. She moves her right arm and hand. The team leader gets another photo from the album and laughs softly.

'Oh, there you are again'. Amelie reaches for the photo with her right hand making small vocalisations. The team leader supports her hand over hand, holding the photo steady in front of Amelie's face. 'Look. That's you. Sorry Amelie, let's sort your mouth for you'. She wipes Amelie's mouth and Amelie

is looking down smiling. Her team leader laughs. I say, 'This has made a huge difference. Well spotted. Just having that physical contact.'

The team leader gets another photo from the album and Amelie reaches for it with her right hand, while all the time tracking the photo with her eyes. Her face appears animated. She opens the fingers of her hand to get hold of the photo. The team leader is smiling, 'Yeah. There you are. Seems like she's enjoying it, doesn't she? Having a little look'.

Amelie makes a louder vocalisation and holds the photo while the team leader supports her wrist. Amelie smiles at her. She continues to gaze at her team leader who says, 'Look at you! Looking all lovely in pink socks. Yeah, yeah. You want to hold it again?'

Amelie opens her fingers and holds the photo. She drops it.

'Ooh. Shall we find another one?' Amelie is watching the team leader with interest as she gets another photo from the album. 'I remember your Mum saying that your Grandma had a black Labrador'. Amelie has her hand ready for the photo and her team leader is holding her right wrist. While she is getting the next photo out Amelie looks at me, filming.

'Do you see?' The team leader holds the photo up to Amelie's eyes and she looks at it with a serious expression for a number of seconds. The team leader moves the photo up and down in front of Amelie's face and she tracks the photo.

'Do you remember?' Amelie continues to look, although she's not holding the photo. 'She's really, really having a good look'.

#### Amelie Vignette 1b: Handling photos (3:10) April 20<sup>th</sup> 2015

I have arrived at Amelie's home after lunch and as in previous weeks we move into the lounge to continue looking through her personal archive of material. The team leader is supporting Amelie and has been throughout the project so far. We've spent ten minutes looking at photos in albums. The team leader holds the album so that Amelie can see the photos and describes who is in them, but Amelie, though glancing at them, does not appear engaged. The team leader noticed the previous weeks that Amelie enjoyed holding photos and looking at them very close to her face. We decide to take individual photos out of the album and give them to Amelie. I am sitting a few feet away and filming with a small mobile Kodak film camera. I am interacting with them both.

The team leader gives Amelie a photo to hold and it flips out of her hand. The team leader says 'oop!' and picks it up. 'And there's a little Amelie. Look at you there. You are very young'. The team leader supports Amelie hand over hand to hold the photo a few inches from her face. As she lets go Amelie moves the photo to her mouth and the team leader supports her again, moving the photo away a few inches, saying, 'Not in your mouth' quietly. The team leader says 'This is you looking beautiful' as Amelie independently manipulates the photo for a few minutes, looking closely at it. The team leader turns to me and says, 'She's really' and indicates Amelie's concentration with a look. I say 'Oh, careful, you might poke your eye out. Sharp corners'. The team leader attempts to take the photo, but Amelie is

grasping it tightly, looking at it and the team leader comments, 'Oh, you're not ready yet'. She gently takes the photo from Amelie and turns it up the right way, holding it close to Amelie's face. Amelie looks at the photo for a few seconds. Amelie is moving her hand around the team leader's arm and hand and is very animated. She moves to her left, bringing her body forward in her wheelchair. The team leader laughs quietly, smiling and says 'You really like this, don't you?' Amelie sits back, her mouth slightly open, and continues to gaze at the photo.

### Amelie Vignette 2: Memories (1:28) April 20<sup>th</sup> 2015

We are in the lounge at Amelie's home looking through photos from Amelie's childhood. The team leader is taking photos out of an album and holding them about a foot from Amelie's face. I am sitting slightly to their right, a few feet away and filming with the small portable Kodak film camera. The team leader holds up a photo of Amelie and her mother in some caves. She says, 'Do you remember when you're mum thought it was a really good idea to take you down in the caves?' Amelie is looking down at her lap and after a few seconds, she repeats, 'Do you remember that?' I ask, 'Was that at Hastings?' and Amelie makes a sudden movement, raising both arms out in front and moving her torso to the left.

The team leader says 'You do remember!' Amelie moves her torso back into the chair, but her right arm remains extended. The team leader continues 'In the buggy? She was absolutely knackered afterwards'. Amelie attempts to hold the photo and the team leader says 'Do you want to see the picture?' and Amelie holds the corner tightly and her hand is supported at her wrist.

Amelie accidentally knocks the photo to the floor and the team leader laughs saying, 'Oi!' Amelie moves forward again to her left and the team leader picks the photo up and holds it in front of Amelie saying, 'There you are again'. Amelie focuses on the photo with her arms stretched out in front of her. She moves her right hand towards the photo to hold it and the team leader says, 'Do you remember your mum had to carry you all the way up the steps?' Amelie holds the photo by gripping the top edge with her right hand and looks from the team leader to the photo.

A couple of weeks later I showed this film to another member of Amelie's team and as Amelie made her first sudden movement the support worker said 'She does remember', also interpreting this movement as a sign of recognition.

### Amelie Vignette 3: Making Choices (0:47) April 27<sup>th</sup> 2015

It's early afternoon and we are in the lounge at Amelie's home looking through her personal archive. We start the afternoon thinking about what we should look at next. I suggest we ask Amelie to choose between two albums of photos.

I hold each album in front of Amelie, saying 'There's that album from your

friend, and there's this album from school. One of Amelie's team is crouching slightly to Amelie's right. Amelie looks from one album to the other. Her support worker says 'Which one would you like to look at first, Amelie?' and folds down a light blanket that had been covering Amelie's hands and arms, saying 'Shall we have a little bit of co-operation?' Amelie looks up at me and moves her left hand to her chest. I say, 'Hello' and laugh and repeat 'There's this one from school and there's this one from your [1:1 support worker]'. Amelie looks at the album her 1:1 school support worker made for her when she left school and reached out her left hand to touch it. I say 'Well done. Good choosing'.

We spend the afternoon looking at this album of pictures.

#### Amelie Vignette 4: Musical Toys (2:44) May 18<sup>th</sup> 2015

We have spent the afternoon in Amelie's lounge sorting through and making a selection of photos that can be laminated. We've finished our work for the afternoon and the team leader has gone into Amelie's bedroom and returned with a yellow toy saxophone and musical toy bus. She lays the saxophone on Amelie's torso and Amelie reaches out her right arm to the team leader, who says 'Yes, of course you can give me a hug'. Amelie hugs the team leader's head to her chest who afterwards supports Amelie to place the fingers of her right hand on to the buttons on the musical toy.

Amelie is looking at her fingers as they are pressed down on the buttons and make a musical note. The team leader moves the saxophone up slightly, continues pressing the buttons herself and Amelie holds the toy with her right hand. Amelie watches the team leader's fingers on the toy and opens out her fingers. The team leader has pressed one of the buttons that plays a tune on the toy and is moving the saxophone in time with the beat.

Amelie is holding the toy and looking at the team leader who lifts the toy up slightly and Amelie follows with her eyes, moving her right hand up to hold it. She explores the open end of the toy with her fingers as the tune ends and the team leader says 'Yeah!', turns the toy over, takes Amelie's right hand in hers and says, 'If you press one of those it makes more music. Look one of the stars, that's it, press one of the stars'. Amelie's fingers are over the stars and the team leader presses them down. Amelie's attention is focussed on her fingers. 'There you go'. The team leader is moving the toy around and Amelie is holding it, feeling all the buttons and looking at her hand. She drops her hands down into her lap, glances up at me, down and then looks at me, making eye contact. She smiles and looks down suddenly, continuing to smile. The team leader says 'You've got her on a really good day today', places the toy more centrally on Amelie's torso and takes both her hands towards the toy saying 'Both hands'. Amelie looks at her toy and her hands and glances up at me.

Amelie Vignette 5: Project Art Works (5:49) June 23<sup>rd</sup> 2015

Amelie first went to art sessions with artists at Project Art Works when she was a teenager. She now attends a weekly at their studio, working 1:1 with an artist. She is in a group of up to six other people with learning disabilities. She is well known in the group and the artists alternate within the group. This session, which I was permitted to film, lasted for two hours, is represented by a series of scenes that demonstrate the way artists and people with learning disabilities work together to create their pieces.

Amelie is in the far corner of the studio, facing away from the rest of the group. The artist is sitting on a high stool in front of her, to her right. She is balancing an A2 light box on Amelie's lap and holding Amelie's hand flat against the surface. Amelie is looking at her hand. The artist lets go of Amelie's hand, which drops to her lap and moves her own hand across the middle of the light box. Amelie follows with her gaze. Amelie moves to her left and looks away, at the same time stretching the fingers of her right hand out against the base of the light box. The artist places some cling film in

Amelie's left hand, stretching it out against her arm. She reaches over Amelie for a roll of cling film and stretches the film over the light box. Amelie follows her movements closely.

The light box is now covered with Clingfilm and has a red square of transparent plastic placed in its centre. The artist has filled a pipette with red ink and is dropping it from the top right of the light box. Amelie watches as it rolls down the box. The fingers of her right hand are open and placed on the red plastic square. The artist gently lifts Amelie's right hand to the top right corner and Amelie opens her fingers wide as her hand moves down through the red ink. The artist lifts the side of the Clingfilm under Amelie's right hand and places her left hand on to the red plastic square. She lifts the corner of the plastic several times and Amelie follows closely with her eyes. She lifts the plastic again and Amelie grasps the corner, lifts it off the light box towards her.

Amelie is holding a small square sheet of transparent green plastic. She is holding it with her left hand a few inches from her face and looking at it closely. The artist reaches her hand out for it and there is some interplay of hands. Amelie pulls the plastic back towards her face and continues to study it closely. She looks up at the artist.

Amelie's hands are covered in red ink. The artist holds a 12" square of clear yellow plastic at Amelie's head level, several feet away from her. Amelie is trying to hold the plastic square and as the artist holds it in position Amelie moves the bottom edge back and forth.

The artist has placed a large canvas that is about three feet square at right angles on Amelie's lap. Amelie is holding a piece of scrunched up Clingfilm in her right hand. Her left hand is touching the base of the canvas. She moves the Clingfilm towards her mouth and the artist says 'It's like a snake' and pulls the end, moving it towards the canvas. Amelie is looking at it. The artist pulls

the end up against the canvas, extending it to about 18” and pulls it across. Amelie is firmly holding the other end.

The artist is holding Amelie’s left hand against the canvas while gently tapping the reverse side. She lets go of Amelie’s hand and taps the reverse side of the canvas, following Amelie’s hand as it moves slowly down towards the base. The artist starts to tap a different part of the canvas and Amelie moves her open hand to place it over the area. All the while she is tracking the sound and movement with her eyes.

The artist has stuck the end of a roll of red and white striped tape to the top of the middle of the canvas. She pulls it down towards Amelie. The artist lifts the top of Amelie’s right hand to the sticky side of the tape and gently lifts the tape off. She tears the tape, scrunches it up and gives it to Amelie to hold. Amelie looks at her hands as she moves the sticky tape around. The tape makes a crinkly sound as Amelie slowly manipulates it. The artist holds it with Amelie’s right hand. As Amelie moves it to her mouth it sticks lightly and she smiles. The artist takes the roll of tape and attaches one end to the top of the canvas, pulls down about 18” and scrunches up the end, leaving it dangling. Amelie moves her right hand backwards and forwards over the canvas, while holding the first ball of scrunched up tape in her left hand. Amelie now has placed both hands on the canvas and is manipulating the dangling tape with her right hand.

The artist has wound strips of silver foil and black wool around a long cardboard tube. Amelie is looking at the tube and has her right hand curled around it, holding it against her chest. The artist holds the tube at each end and slowly turns it up and away slightly. Amelie watches the tube and moves her right hand up and down against the different textures and materials.

The artist holds the tube against Amelie’s right ear and sings nursery rhymes quietly into the other end. Amelie gazes at the artist and holds another tube that is wrapped in wool, on her lap.

#### Amelie Vignette 6: Sensory Session (3:12) July 24<sup>th</sup> 2015

Every week during school term time Amelie goes with a member of her team to a local children’s centre for a booked one hour sensory session. The following is a series of short extracts demonstrating the interactions that took place when I went along. I was roped in to singing because the team member didn’t wish to be filmed singing.

Amelie is positioned under some spotlights in an otherwise darkened room. Mirrors reflect the coloured lights from a bubble tube in one corner. The support worker has opened a cabinet and taken out a small, mirrored ball. She holds this in her hand and Amelie manipulates it by rolling it around. This is repeated with a range of different types of balls all of which can fit in the hand. The support worker places a large piece of aluminium on Amelie’s lap and another around her feet. Amelie plays her hands around these, watching and listening.

An ultraviolet light is turned on and Amelie is given a 6” long tube of plastic, which is bright in the light. She holds it in her right hand and moves it her mouth. The support worker puts some white gloves on and moves her hands around in the light. All the time Amelie tracks the sounds and movements.

The support worker shakes a small plastic toy up and down in front of Amelie’s eye line. It makes a sound (does it have liquid in it?). Amelie watches the toy move up and down, her eyes wide and a smile playing on her mouth. The support worker says ‘You like this, don’t you?’ She places the toy in Amelie’s left hand and shakes it with her.

Amelie gazes at her support worker.

Amelie has been moved towards the other end of the room. The support worker picks up the fibre optic tubing and holds it in front of Amelie who reaches out both hands to touch and hold it. The support worker supports Amelie’s right hand to touch the fibre optics and Amelie follows with her eyes. The support worker says ‘It’s really good to get those arms going’. Amelie holds on to the end of one rope of fibre optics.

The support worker introduces a small metallic amplifier/microphone and asks me if I’d like to sing to Amelie. The support worker takes over filming with the iPad. Amelie looks at me and I lean in to her right side and sing ‘Row, row, row the boat’. Amelie looks at me as I sing and moves the fingers of her right hand over the end of the amplifier. I say ‘Your turn’ and sing a song using the initials of her name. She continues to touch the end of the amplifier. I say ‘Do you want to hold it?’ Amelie moves forward and to her left suddenly, stretching her arms out in front. She is smiling.

I repeat ‘Do you want to hold it?’ as I support her right hand around the toy and ‘Have you got it?’ She is smiling. The support worker says, ‘You like that, don’t you sweetheart’. I support Amelie to hold both hands around the amplifier saying, ‘Amelie’s got it. Well done’. Amelie is smiling and looking in to the distance.

### 13.c) Vignettes: Marian

#### Marian Vignette 1: Choice and Control (1:09) March 17<sup>th</sup> 2015

Marian is sitting in her armchair, which is in the corner of the lounge. She has been watching a film from school days and has become agitated. We decide that it would be a good idea to stop watching the film and put on a ‘Thomas the Tank Engine’ episode. ‘Thomas’ is significant for Marian and is used to comfort her. Her mother describes how ‘Thomas’ represents choice and control for her daughter. The first time Marian was able to make a choice and experience the result was with a ‘Thomas’ video when she was a few years old. It is now used as a default, a comfort, when Marian becomes agitated or distressed.

She is looking straight ahead at the TV. She opens her right hand and hits the arm of the leather chair twice. She is rocking back and forth. She looks



serious. Her mother says 'What's going to happen now?' Marian grasps her hands together at neck height and continues to rock and look directly at the TV. Her mother says 'Where is it? Where's the?' Her support worker says 'I've has got it', Marian's mother says 'Come on' to which her support worker replies 'Oh, silly me. My fault, Marian'. She continues to rock backwards and forwards, grasping her hands together. She hits the right arm of the chair once with her open right hand. She begins to hit the base of her neck, just above chest level, several times and looks from her mother to the TV. Her mother sings 'Ta da!' and her support worker says 'Do you want to watch Thomas?' Marian looks at her briefly and then looks down. She brings her head and clasped hands together and looks to her right, towards me, with a softer look on her face. Mother says 'I said I wanted to watch Thomas. Please. Put the damn thing on'. I say 'Here it comes, here it comes'. Mother says 'Oh, Marian. Any minute now. Any minute now' Marian looks back to the TV, lowering her clasped hands and rocking gently back and forth. Her hands are now clasped at the base of her neck and rhythmically rocking back and forth. She stops rocking her body as the 'Thomas the Tank Engine' theme music begins.

#### Marian Vignette 2: Eye Contact (1:39) March 24<sup>th</sup> 2015

It's a cool Spring day. We are sitting on the seafront having a drink and talking about a monthly newsletter that one of Marian's team compiles every month. I am sitting opposite Marian and her two support workers are sitting on her right and left. I am filming with a small Kodak film camera. Marian is relaxed and looking around her and responding when her support workers draw her attention to one of the newsletter photos. She is included in the conversation. At one point she looks directly at one of her support workers, for several seconds, which triggers the following exchange.

'When Marian gives you that eye contact it's actually quite an amazing feeling. It doesn't happen all the time, but when it does you kind of feel that's she's looking in to your soul. It a real kind of, you can't pull your eyes away. It's beautiful really, it's beautiful'. She looks at Marian and holds her hands together, palm to palm, to her lips as if in prayer, thinking.

'It's hard to explain, it's hard to put it in to words really, you just feel, not choked up, that's not the word about it. It's just, you don't have that very often with people. When I say staring, it's not an uncomfortable stare, but you're kind of, you're kind of captured in Marian. And it feels to me like she's looking in to me, but I can't, I don't know, I don't know, it's bizarre. Because when you have those moments with Marian she's not stressed, she's not. It's just quite calm. It's just one of those things. You just catch Marian's eyes, because obviously you're looking at Marian for prompts all the time and it's just that, it's very difficult to explain. You just can't look away, because she's caught you. And it's kind of like [pauses, smiling]. It's very beautiful, isn't it Marian? And then she usually laughs after it. So it's kind of like whatever you're seeing must be funny' [laughs].

I return the camera to Marian who is smiling broadly, her hands clasped and resting on the edge of the table.

### Marian Vignette 3: Music Playlist (1:31) March 31<sup>st</sup> 2015

A married couple who are part of Marian's team have her stay overnight at their house every week. Today they pick me up from the station and we drive back to their house. Marian appears very much at home, walking in and sitting in 'her' chair. They make tea and suggest I might be interested in finding out about the music playlists that they have compiled for Marian.

I am sitting on the sofa next to Marian and set up the Kodak portable film camera on the arm of the sofa. Marian is leaning over on to the right arm of the chair, away from me. She has her hands clasped and held up to her eyes and forehead. They have put on one of her favourite Take That songs. She is listening and making some sounds and smiling. She sits up suddenly, rocking, and puts her head and clasped hands on to the right arm of the armchair. She sits up again, rocking and hitting her clasped hands on to the arm of the chair in time with the music. She is making small, excited grunting sounds. During the verse she sits up and knocks her clasped hands gently against the base of her throat, rocking slightly and making small high-pitched sounds. As the chorus begins she moves in big rocking movements towards the right arm of her chair, hitting the arm of the chair with her clasped hands. She is smiling broadly. She sits back up and listens for a couple of seconds, make a small laugh and rocks backwards and forwards with her hands clasped in front at chest level. She resumes rocking to the right and banging the arm of the chair in time.

Her support workers comment that Marian's response to her favourite songs is a good indicator of how she is feeling. For example if she is slow to respond in the morning, hearing a song usually wakes her up and gets her going. However, if one of her favourite songs isn't responded to it is generally accepted that there is something the matter.

### Marian Vignette 4: Choice (0:57) April 2015

It's a sunny and warm April day. I am spending the afternoon looking through photo albums with Marian at the home of the married members of her team who she stays overnight with each week. They have picked me up from the station and we head straight out in to their back garden. We sit around a large table. I am opposite Marian and set up the Kodak mobile film camera.

We have drinks and Marian also has a plate of savoury snacks. We chat as we look through the photos. One support worker sits to Marian's left, holds the photos and talks about them; who is in the photos, what they are doing, and the probable dates. I notice Marian looking fleetingly at the snacks that are on the table, out of her reach. Marian is sitting upright, her hands clasped at chest height. She appears relaxed and is looking down at the photo in front of her.

The support worker who is sitting alongside Marian says, 'it's definitely, with her vision, that's what she uses to communicate. But it's so hard sometimes,

because you do miss. I mean I could be looking over here, and I miss the fact that she's looked'. While she is saying this Marian has glanced over to the snacks again and up looks at the support worker sitting opposite, who says 'She is now'

The support worker sitting alongside Marian says 'What do you want, Marian?' She moves the photos out of the way, places a glass of orange and the savoury snacks in front of Marian and says, 'Look. Which one do you want? You choose. Which one Marian?' The word 'which' is backed up with the Makaton sign. Marian looks away and puts her left hand up to her face. The support worker gently pulls her hand down and repeats 'Marian, which one?' once again signing. Marian looks towards the snacks and rocks in the same direction. Her support worker says, 'This one' and picks up a snack, which she places in Marian's open mouth.

This is repeated throughout the afternoon. If the support worker sitting at her side misses Marian's fleeting eye pointing, Marian will engage the other one, who is sitting opposite, by looking at him and then the food or drink that she wants.

#### Marian Vignette 5: Looking at herself (4:16) May 19<sup>th</sup> 2015

I am sitting on the sofa in the lounge at Marian's home. Marian has been watching a Disney movie on TV. I have been looking through two big lever arch folders of school records and making some notes about different types of AAC (augmentative and alternative communication) devices, environments and activities. These are the last two pieces in Marian's personal archive. I've noticed that Marian has been looking over at me every minute or so. I'm not asking her to look at anything. She stands up and her mother interprets this as a cue to go to the bathroom. When Marian returns she stands in front of the empty space next to me on the sofa. I invite her to sit down next to me and continue going through the folders. Marian looks from the TV to the folder each time I turn over a page. She looks at me frequently. She seems very relaxed and content. I finish looking through the folder and put it down on the floor. I get out my iPad and turn the camera around so that it captures Marian and myself and film for a few minutes.

Marian is smiling. She holds her hands to the side of her neck and looks at the screen. Her mother looks over the top and laughs. Marian looks up at her, smiling. I whisper 'What's going on?' She continues to look at herself on screen intently, swaying her head slightly from side to side. I say 'There. What do you think?' I move the iPad slightly so that I am included in the frame and say 'Oh look, that's me'. She looks away, smiling. I look at her and laugh and comment 'That's us on the sofa, watching the telly'. She smiles and sways her head, unclasps and claps her hands several times. I say 'That's very good'. She looks away for a second and I say 'It's a bit like looking in the mirror isn't it?' Marian looks back, frowning slightly. She lifts her clasped hands to her mouth, looks up towards her mother, licks her lips slightly, looks back at the screen and unclasping her hands gently slaps the sides of her head.

She clasps her hands together and holds them high enough so that she can see through them to the screen. She is smiling. I ask 'Now what does that mean?' She knocks the top of her head several times with her hands and looks at me. I turn to look at her. She scratches her head, frowns and looks away towards her left. She then turns back and hits the iPad with both hands four times in a rhythmic movement. She smiles and rubs her left eye with her clasped hands. She bites the side of her left arm through her cardigan, pulls at her hair and grinds her teeth momentarily. She raises her arms again and looks through them, but not at the screen. She has a much more serious expression now. She looks through her arms at the TV, then at me, repeating this sequence several times. She pulls at her hair, claps her palms together and rocks back and forth. She seems to have re-engaged with the Disney film on TV. I say 'Shall I switch it off now? What do you think?' I laugh and Marian looks at me smiling. I say 'I can't decide if you want me to switch it off or not'. I close the iPad cover and Marian taps it, so we repeat this several times. I think that she was probably hoping I'd put on one of her favourite films or songs, although she may have had other motivations for sitting next to me.

#### Marian Vignette 6: Swimming (3:23) July 22<sup>nd</sup> 2015

Marian is a member of the local health club and goes swimming twice a week.

I arrived at the local health club at 9.30am in time to see Marian getting out of her car and striding purposefully towards the entrance foyer. Three members of her team are with her (although only two of them are working). They arrive inside and the receptionist greets Marian by name, asking her how she is. The team and receptionist chat for a few minutes, explaining that Marian didn't go off to sleep until 5.30 am, so they're all feeling a bit tired. I'm signed in as a visitor and arrange to see them all in the pool.

They walk in together and get into the pool via some shallow steps. I move around to their side of the pool and film for a few minutes.

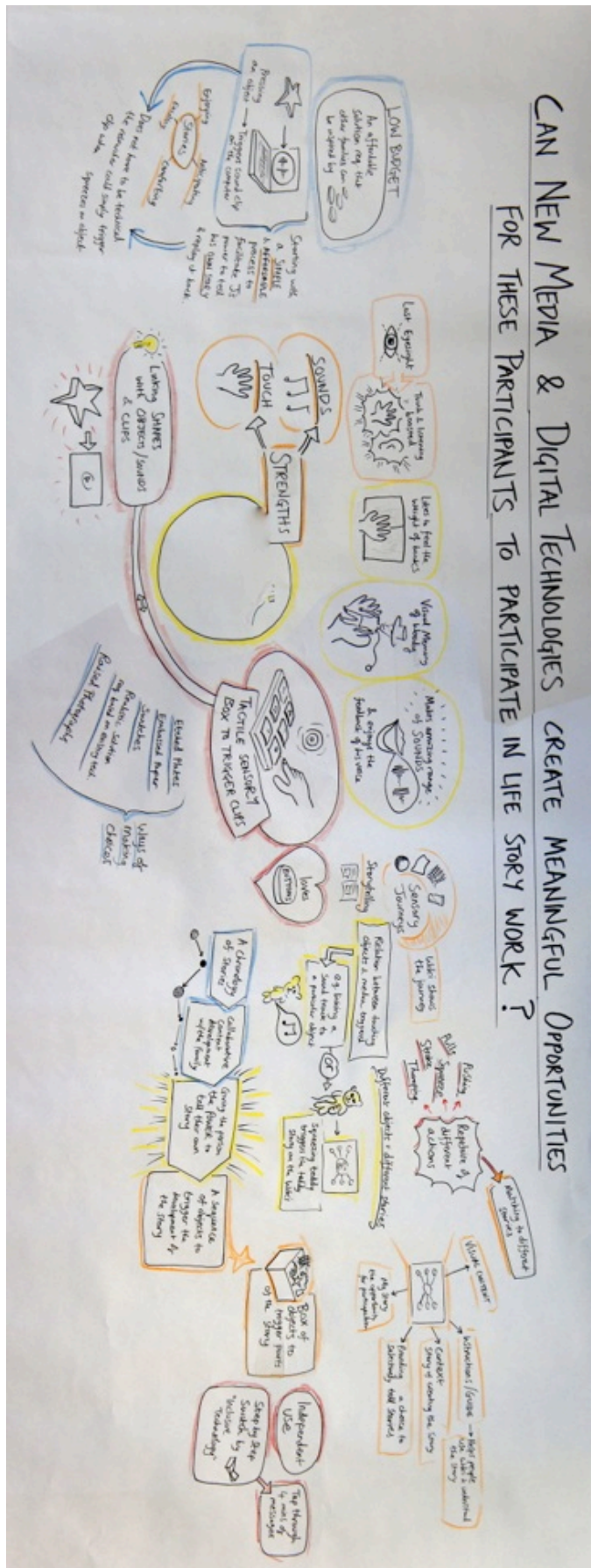
One support worker is holding Marian around her shoulders and waist and moving her backwards through the water. Her feet are floating at the surface. She is clasping her hands just below her chin and looking towards her feet. They reach the end of the pool. She looks out of the window and her support worker swings Marian round and continues to walk backwards. She lowers her hands then raises them back up to her chin. The other support worker swims along following them. Marian spots me crouched down on the side of the pool and immediately moves to stop and stand, which her support worker supports her to do. I say 'I'm going to fall in' and we laugh.

Marian walks to the side of the pool unaided. She briefly holds her support worker's arm then lets go, clasping her hands together at chest height. She looks up at me briefly and then swims forwards as her support worker steps backwards.

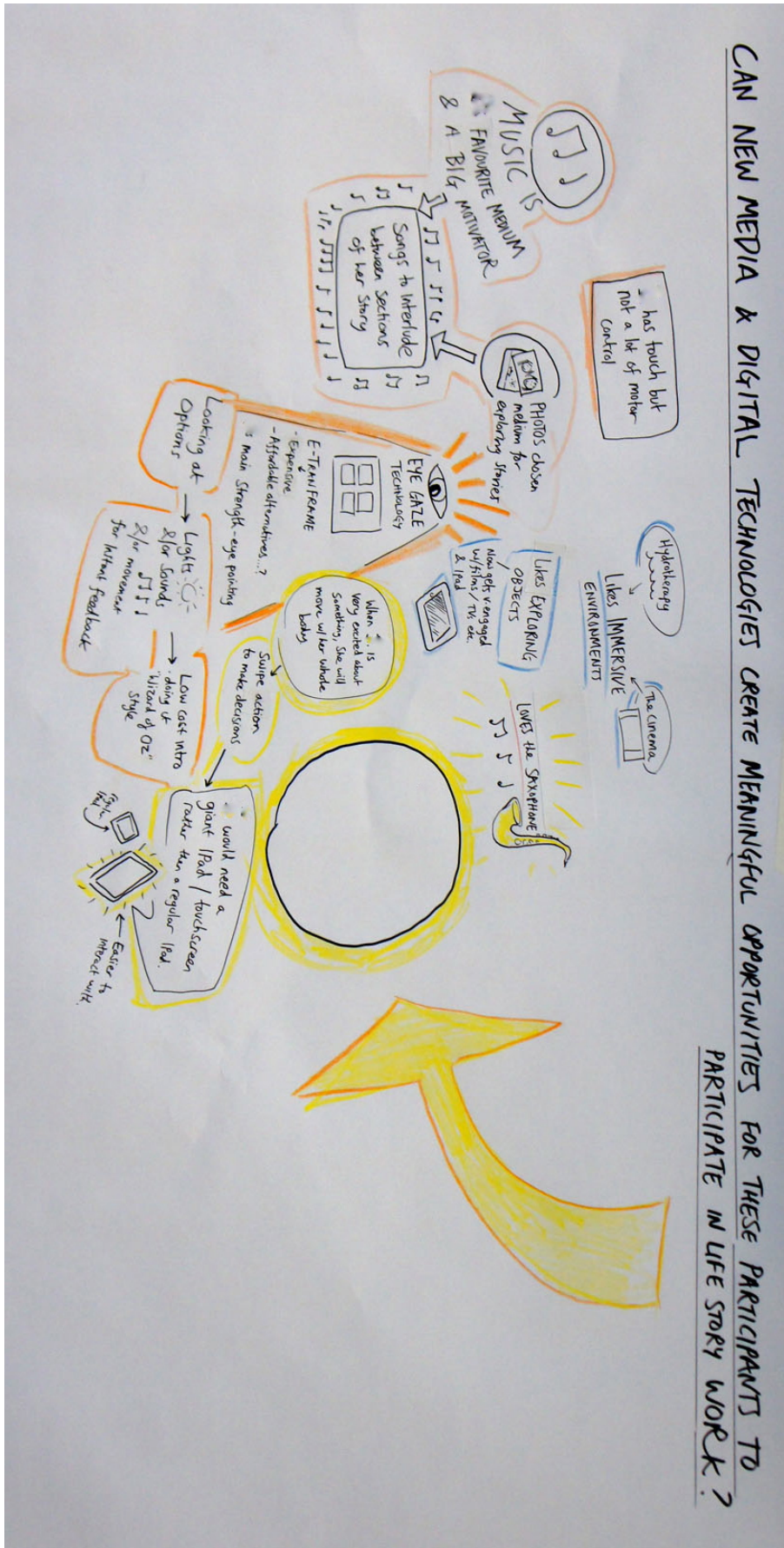
Standing together when they reach the end of the pool, one of her support workers speaks quietly to Marian. He holds up his hands and mirrors hers. He appears to suggest 'Shall we do some swimming now?' using the Makaton sign for swimming. He then gently turns her so that she has her back against the end of the pool and point in the direction they are facing. Marian swims with her support worker holding her around her waist. She does about eight strokes of doggy paddle then stands up. He points to the far end of the pool and they repeat the exercise.

A short while later the other team member takes over supporting Marian and does some physiotherapy exercises with her. Walking backwards and supporting Marian at both hips, she turns her gently from side to side. Marian has her hands clasped at her chin and watches the other team member who is walking a metre behind them and making big, wide arcs with his arms on the water's surface. They turn and repeat the movement to the end of the pool. They both then stand with Marian and bounce up and down slowly in the water together.

14: Diagnostic Sandpit Illustrations  
 14.a) Diagnostic Sandpit: Jack



14.b) Diagnostic Sandpit: Amelie



14.c) Diagnostic Sandpit: Marian





## 15: Thematic Analysis

### Phase 1: Familiarising self with data

*'Transcribing data, reading and re-reading, noting down initial ideas.'*

### Phase 2: Noting Down Initial Codes

*'Coding interesting features of the data in a systematic fashion across the data set, collating data relevant to each code.'*

1. Communication: repetition
2. Communication: routine
3. Communication: motivation
4. Communication: eye pointing
5. Communication: touch
6. Communication: vocalisation
7. Communication: sound
8. Communication: anticipation
9. Communication: new or digital media
10. Communication: environment
11. Communication: relationships
12. Communication: use of AAC
13. Communication: the body
14. Personhood: being held in
15. Personhood: holding own
16. Personhood: holding others
17. Idiosyncratic behaviour
18. Unexpectedness
19. Ascertaining views
20. How information is shared or told

21. Barriers and challenges of LSW
22. Value of LSW
23. Loss
24. Interpretation and inference
25. A sense of humour or mischief
26. Eye contact
27. Things for the tool box
28. Choice and control
29. Communication and music/songs
30. Communication intent
31. Capture of fleeting moments
32. Communication: Looking
33. How decisions are made
34. Life story in objects and docs
35. Capability versus deficit
36. Colour, texture, sound
37. Evidence of Memory
38. Communication: emotions
39. Communication: smell
40. Life story materials; missing
41. Health and illness
42. Attitudes of others
43. Mystery and beyond explanation
44. Understanding/comprehension
45. Listening
46. How to communicate

- 47. Essential elements
- 48. Specific PhD ideas re: structure
- 49. Fieldwork analysis
- 50. Methodological challenges

### Phase 3: Searching for themes

*'A grouping of codes together under the following emerging four themes.'*

### Theme 1: INSIDE - Individual repertoires of communication

#### VISION

- 4. Eye pointing
- 26. Eye contact
- 32. Looking

#### TOUCH

- 5. Touch

#### BODY GESTURE/MOVEMENT

- 13. Embodied communication

#### SOUND

- 6. Vocalisation (from the person)
- 7. Sound
- 45. Listening

#### SMELL/TASTE

- 39. Smell

#### AGENCY

- 3. Motivating factors
- 19. Ascertaining views
- 28. Choice and control

- 30. Communication intent
- 44. Understanding/comprehension

### MEMORY

- 8. Anticipation
- 37. Evidence of Memory

### Theme 2: OUTSIDE - what supports repertoires of communication

- 1. Repetition
- 2. Routine
- 3. Motivating factors
- 6. Vocalisation (to the person)
- 9. New or digital media
- 10. Environment
- 11. Relationships
- 12. AAC
- 23. Loss
- 24. Interpretation and inference
- 29. Music/songs/stories
- 36. Colour, texture, sound
- 41. Health and illness
- 46. How to communicate

### Theme 3: THE PERSON - the kind of people they are

- 11. Relationships
- 14. Personhood: being held in
- 15. Personhood: holding own
- 16. Personhood: holding others

- 17. Idiosyncratic behaviour
- 18. Unexpectedness
- 23. Loss
- 25. A sense of humour or mischief
- 38. Emotions
- 41. Health and illness
- 43. Mystery and beyond explanation

#### Theme 4: LIFE STORY WORK - practice and project issues

- 20. How information is shared or told
- 21. Barriers and challenges of LSW
- 22. Value of LSW
- 27. Things for the toolbox
- 31. Capture of fleeting moments
- 33. How decisions are made
- 34. Life story materials in archives
- 35. Capability versus deficit
- 40. Life story materials- missing
- 42. Attitudes of others
- 47. Essential elements
- 48. Specific PhD ideas re: structure
- 49. Fieldwork analysis
- 50. Methodological challenges

#### Phase 4: Reviewing Themes

*'Checking the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis.'*

#### Phase 5: Defining and Naming Themes

*'On-going analysis to refine the specifics of each theme, and the overall story the analysis tells; generating clear definitions and names for each theme.'*

#### Phase 6: Producing the Report

*'Final analysis and write up, including data extracts.'* (See case studies in main text)

From Braun and Clarke's Phases of Thematic Analysis. In Braun, V. and Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3 (2) pp. 77-101