

# **Exploring the potential challenges and benefits of multimedia self-advocacy tools for young people with Cerebral Palsy aged 16 – 25 years**

**Richard Lowell Westerman**

A research study submitted in partial fulfilment of the requirements of the University of East London for the Professional Doctorate in Educational and Child Psychology.

## **Declaration**

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This work has not previously been accepted for any degree and it is not currently being submitted for any other degrees. This research is being submitted in partial fulfilment of the requirement of the University of East London for the Degree of Applied Educational and Child Psychology.

The thesis is the result of my own work and investigation, except where otherwise stated. Other sources are acknowledged by explicit references in the text. A full reference list is included in the thesis.

I hereby give permission for my thesis, if accepted, to be available for reading and for inter-library loans, as well as for the title and summary to be made available to outside organisations.

Richard Westerman  
September 2017

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## **Abstract**

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This action research study aimed to improve practice by identifying the barriers of using multimedia self-advocacy tools with young people with Cerebral Palsy, and developing strategies to overcome these challenges. A literature review highlighted the limited evidence in the area of self-advocacy for young people with Cerebral Palsy, as well as demonstrating the benefits of emancipatory qualitative methodologies. The planning of the research was person-centred, and carried out with immense thought towards the Children and Families Act (2014), and other relevant codes of practice. Three young people with Cerebral Palsy were recruited in a special educational setting. The action research cycle, in conjunction with a measurement of active participation known as the ladder of participation, were utilised to provide a framework for a collaborative working partnership between researcher, facilitator and participant. Thematic analysis was employed to treat the subsequent data. The results demonstrate that multimedia self-advocacy tools can be beneficial for young people with Cerebral Palsy, and establishes adaptations that successfully increased participation. These findings have the potential to inform the researcher's own professional practice and that of the wider EP community; the strategies implemented by institutions; and policy, including legislation, at a national level.



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## List of abbreviations

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<b>AR</b>	Action Research
<b>ASD</b>	Autism Spectrum Disorder
<b>BPS</b>	British Psychological Society
<b>CAPE</b>	Children's Assessment of Participation and Enjoyment
<b>CP</b>	Cerebral Palsy
<b>CYP</b>	Children and Young People
<b>EHCP</b>	Education, Health and Care Plan
<b>EP</b>	Educational Psychologist(s)
<b>EPS</b>	Educational Psychology Service(s)
<b>HRQoL</b>	Health Related Quality of Life
<b>ICT</b>	Information and Communication Technology
<b>ID</b>	Intellectual Disability
<b>LA</b>	Local Authority
<b>MLD</b>	Moderate Learning Difficulties
<b>MMSA</b>	Multimedia Self-advocacy
<b>QoL</b>	Quality of Life
<b>SA</b>	Self-Advocacy
<b>SEN</b>	Special Educational Needs
<b>SLD</b>	Severe Learning Difficulties
<b>SPARCLE</b>	Study of Participation of Children with Cerebral Palsy Living in Europe
<b>TA</b>	Thematic Analysis
<b>UEL</b>	University of East London
<b>UK</b>	United Kingdom
<b>UNCRC</b>	United Nations Convention on the Rights of the Child
<b>UNCRPD</b>	United Nations Convention on the Rights of People with Disabilities
<b>VI</b>	Visual Impairment
<b>WHO</b>	World Health Organisation
<b>YP</b>	Young People
<b>YPCP</b>	Young People with Cerebral Palsy



## **Chapter 1: Introduction**

---

### **1.1. *Introduction to chapter***

This chapter will provide an overview of the topics and concepts that are explored in the research. It begins with definitions of key terms, before summarising the relevant legislation and current context of the chosen area of research. A brief introduction to Action Research (AR) is followed with an outline of the principles applicable to this research. Reference is made to the evolving practice of Educational Psychologists (EPs) and the relevance of practice based-evidence in this profession. There is an explanation of how AR appears to complement the researcher's ontological perspective, with an emphasis on disability rights and emancipatory-oriented research. The chapter concludes by outlining the purpose and aims of the research.

### **1.2. *Definitions of concepts***

#### **1.2.1. *Self-advocacy***

Sutcliffe and Simons (1993) noted that it is challenging to determine the origins of self-advocacy (SA) and it is a particularly difficult concept to define. SA is commonly used as an umbrella term to refer to an individual's ability to effectively communicate, convey, negotiate or assert interests, desires, needs and rights. It involves making informed decisions and taking responsibility for those decisions (VanReusen, Bos, Schumaker & Deshler, 1994). This occurs on individual and collective levels, with and without the support of others (Goodley & Moore, 2000). Others feel that SA is a political activity that challenges disabling societies (Browning, Thorin & Rhoades, 1984). However, the researcher considers this to be a form of advocacy, which is where someone else speaks up for, or represents another person (Flynn & Ward, 1991). Overall, the following description of SA is appropriate for the current research:

*'Self-advocacy is a process of individual development through which a person comes to have the confidence and ability to express his or her own feelings and wishes.'* (Simons, 1992, P. 5).

#### **1.2.2. *Multimedia self-advocacy and wiki-pages***

The concept of multimedia self-advocacy (MMSA) was conceived and developed by researchers at The Rix Centre, based at the University of East London (UK), in collaboration with people with physical and intellectual disabilities. MMSA is described as an approach where information communication technology (ICT) is used by people with disabilities to enable or promote their ability to self-advocate (Kwiatoska, Trobinger, Back & Williams, 2012).

The ‘Klik in’ Web2.0 platform was designed to enable people with disabilities to express their views, experiences and preferences through a range of multimedia formats by utilising pictures, videos, sounds and text. It consists of an accessible, easy-to-use content management system that enables people with disabilities to upload, organise and finally publish content within a framework. They can share these items with friends, family and a range of professionals. The layout is presented in the form of a mind-map website that is suitable for presenting, publishing and consuming rich-media (*see Figure 1.2.2*). A wiki-page can therefore be summarised as a self-made multimedia website (Kwiatowska et al. 2012).



**Figure 1.2.2: Example of the wiki-page platform.**

### **1.2.3. Social model of disability**

A common misconception views disability as fixed from birth, changing little over time, and categorized within a discrete and clearly identifiable group (Prime Minister’s Strategy Unit, 2005). This is reflected in disability legislation in the United Kingdom (UK), where disability is defined, ‘*As a physical or mental impairment that has a substantial and long-term (i.e. has lasted or is likely to last for at least twelve months) adverse effect on a person’s ability to carry out normal day-to-day activities*’ (Disability Act, 1995; 2005; Equality Act, 2010). This is consistent with the medical model that views disability as a person’s inability to join in society, or being able to access the same opportunities, due to having an impairment (Imrie, 1997).

The social model of disability makes an important distinction between ‘*impairment*’ and ‘*disability*’. Impairment is interpreted as an injury, illness or congenital condition that causes

long-term effects that limits the function within the individual. Whilst, disability is outlined as the limitation of opportunities to take part in society due to social and environmental barriers (World Health Organization – WHO, 1980). The significance of such a distinction is of central importance to the research.

#### **1.2.4. Cerebral palsy**

Cerebral Palsy (CP) is the most common and well-recognized cause of severe physical disability in childhood (Kuban & Leviton, 1994). Traditional definitions of CP emphasize movement, posture and coordination in order to establish activity restriction (MacKeith, Mackenzie & Polani, 1959; Bax, 1964; Mutch et al., 1992). More recent definitions assign greater prominence to the neuro-developmental disabilities of performance and behaviours commonly accompanying CP (Rosenbaum, Paneth, Leviton, Goldstein & Bax, 2007). For this research, reference is made to Rosenbaum et al.'s (2007) description of CP:

*‘A group of permanent disorders of the development of movement and posture causing activity limitations that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication and behaviour, by epilepsy and by secondary musculoskeletal problems.’* (Rosenbaum et al., 2007, P. 9).

The inclusion criteria of CP for this research was not random, nor was its selection simply due to its relatively high prevalence rate. Rather, it relates to the nature of the disorder itself. CP is a neuro-developmental disorder widely accepted to result from brain injury occurring during the prenatal, perinatal, or postnatal period (Kriger, 2006). CP therefore does not have a single cause, nor is it a specific condition, but rather should be considered a group of complicated conditions or disorders (Rosenbaum et al. 2007). Subsequently, a notable feature of CP is its variability, *“the almost infinite variability (and the lack of a common language to describe cerebral palsy) makes learning about it very difficult indeed”* (Scrutton, 1984). Therefore, CP should not be viewed as a uniform condition as there are large ranges of functionality that varies within the domains of motor movement, cognition and perception (Benecke, 1989).

In addition, CP is not believed to be progressive and impairment in the brain does not deteriorate, but the nature and extent of these difficulties may change as the young person (YP) develops (Nelson & Ellenberg, 1982). The researcher's view is that many of these difficulties result from,

or are at least influenced by, cultural and societal beliefs, as well as a lack of opportunities for these individuals consistent with the social model of disability.

### **1.2.5. *Self-efficacy***

Self-efficacy can be defined as “the belief in one’s capabilities to organize and execute the courses of action required to manage prospective situations” (Bandura, 1995, p. 2). In addition to their goals, interests, and attributions, peoples’ motives are heavily influenced by specific beliefs about their personal capacities (Bandura, 2001). In self-efficacy theory, these beliefs become the primary explanation for motivation (Bandura, 1977; 1986; 1997). Self-efficacy is the belief that an individual has the capability of carrying out a specific task or of reaching a specific goal, and this can greatly impact how people feel, think, behave, and motivate themselves. Hence, it is central to personal, social and educational outcomes and is essential for promoting effort, perseverance, resilience, and optimism in the face of adversity (Bandura, 1997). Often described as task-specific self-confidence, self-efficacy is a key component in theories of motivation and learning in varied contexts (Antino, 2012).

As self-efficacy is self-constructed, meaning that it is a personally developed perception, there are often discrepancies between a person’s self-efficacy beliefs and their actual abilities. Large discrepancies between self-efficacy and ability can impact an individual’s motivation. For instance, if a person does not believe his/her efforts will result in the outcome he/she wants, they may encounter difficulties starting, applying effort, or persevering in a particular activity (Bandura, 1994). Bandura (1997) also highlights that self-efficacy should not be considered a fixed trait as it can be influenced and developed. He proposes that anyone, regardless of their past or current environment, has the ability to exercise and strengthen their self-efficacy.

There are four identifiable sources of influence that can promote the development of self-efficacy. Firstly, Mastery experiences are when an individual experiences the results of self-efficacy first hand through competency. As high self-efficacy is associated with a strong belief in one’s capacity to carry out a *specific* task successfully, past successes with a task increase students’ beliefs that they will succeed again in the future. (Erikson, 1994; Bandura, 1997). A second source of influence comes from the vicarious experience of mastery, when success is observed through social modelling (Schunk & Zimmerman, 1997). The effect is stronger when the observer lacks experience with the task, or when the task is modelled by someone who is respected by the observer (Bandura, 1994). Thirdly, social persuasion can increase self-efficacy by promoting opportunities for mastery experiences in a safe and purposeful manner,

especially if the encouragement is received from more than one person (Goddard, Hoy, & Hoy, 2004). Finally, emotions and moods also influence self-efficacy. Negative emotional states can influence an individual's interpretation of the outcomes of an activity. Furthermore, expectations of success or failure can affect motivation when people over-generalize from past experiences that they believe, rightly or wrongly, to be relevant. Introspection and education can help to ensure that such emotions do not have an adverse impact on self-efficacy (Bandura, 1997).

Bandura (1994) proposes that it is in the face of difficult circumstances that self-efficacy becomes most necessary. Experiencing failure is important so that individuals develop resiliency by perceiving these experiences as learning opportunities to achieve competence or mastery with a different approach. People who have a heightened sense of self-efficacy tend to perceive challenging problems as tasks to be mastered, rather than threats to be avoided (Bandura, 1994). Indeed, people who possess high self-efficacy tend to learn and achieve more than those with low self-efficacy "even when actual ability levels are the same" (Ormrod, 2008, p. 137). Furthermore, if a person's sense of self-efficacy is very low, he/she can develop learned helplessness (Maier & Seligman, 1993). This is a perception of complete lack of control in mastering a task and research suggests that this phenomenon may be particularly common for at risk groups of people, such as those with disabilities (Harter & Zigler, 1974; Deci, 2003; Greenspan, 2006). The importance of the concepts surrounding self-efficacy are explored further in Chapters 1.5 & 1.6.

### **1.3. *Context of research***

#### **1.3.1. *National context and legislation***

Revisions to the education system in the UK have resulted in national mandates that have placed an increasing emphasis on children or young people (CYP) being more involved in decision-making processes. For instance, the Children Act (1989) and the subsequent Education Acts (1993; 1996) fundamentally shifted the power structure in the education system by providing CYP with increased rights that are protected by law.

These attempts to redistribute power have been further cemented by more recent legislation – the Children and Families Act (2014) – widely regarded as the biggest reform to child legislation in over 30 years. Consequently, national policy is now arguably more in line with the United Nations Convention on the Rights of the Child (UNCRC, 1989), which empowers CYP with the basic right to have their views given due weight in all matters affecting them.

### **1.3.2. *Implications of the Children and Families Act (2014)***

As a consequence of the Children and Families Act (2014) there have been several significant reforms in relation to educational practice. Statements of special education needs (SEN) have been replaced with combined education, health and care plans (EHCP), that are intended to meet a young person's (YP) needs from birth up to the age of 25. Many YP with disabilities, and their families, face difficulties during the transition from childhood to adulthood, with increased likelihood of marginalisation during this period (Hoon & Stashinko, 2014). The resulting challenges that the inclusion of YP aged 16 – 25 presents has been recognised by some Educational Psychology Services (EPS) with the dedication of increased resources, however, there is limited existing research in this domain. This is explored in greater depth in the literature review (see *Chapter 2*).

Another consequence of the legislation has been a renewed emphasis on the participation of the CYP and their families in decision-making processes. EPS(s) are legally obliged to consider the views, wishes, feelings and needs of the CYP. This is an important shift in approach, which supports the concept of increased SA for CYP, particularly for those who face barriers in being able to do so effectively. The result is that EPs are met with the challenge of ensuring as much participation of the CYP in decision-making processes as possible and providing the relevant information or support to facilitate this. The limitations of traditional methods, time constraints, and a lack of relevant training are just some of the reasons why this is often problematic.

### **1.3.3. *Local authority approach and current provision***

The researcher's local authority (LA) has responded to legislative changes by trialling new ways of working to develop action plans known as '*One-Planning*'. This is a person-centred approach (Rogers, 1980) to ensure real involvement of CYP in decision-making processes. The principal is that planning should start with the individual, consider his/her wishes and aspirations, as well as the outcomes he/she seek, in addition to providing him/her with the support he/she need to achieve them.

As part of the One-Plan Project, '*One-Page profiles*' were developed to present a positive profile of individual CYP with SEN. They seek to highlight what others like and admire about the individual; what is important to the individual; what support the individual requires to meet his/her needs. A One-Page profile is, therefore, intended to capture all the important information about a person on a single sheet of paper. It is designed so that people working with the CYP

can either get to know him/her quickly, or ensure that they are providing support in the way that the person wants.

Whilst training, the researcher's experience of One-page profiles was that they were commonly executed in a manner that limited their potential benefits. There was a sense that this intervention was often a 'token-gesture' by school institutions that were required to complete this process prior to receiving further input from EPs. Consequently, the outcome of the process would often result in limited information, that did not always promote the views of the YP, but rather reflected the agendas of parents or teaching staff. Also, there was a lack of formalised structure or formatting guidance. Examples in the appendix illustrate the variability in presentation style, as well as the depth of information, that was frequently evident (*see Appendix A*). In addition, all too often the One-Page profiles were inaccessible to some members of staff and information was frequently 'lost'; they were not always updated regularly; failed to meet the YP's needs appropriately as he/she developed; and difficult to transfer across contexts or settings. These are some of the reasons why the researcher sought alternative methods, in this instance personal wiki-pages, to provide a more flexible and effective tool for promoting SA.

#### **1.4. *Brief history and introduction to action research***

It is widely reported that Kurt Lewin coined the term '*action research*' (AR) in the 1940s and it was first employed as a methodology in education during the 1950s (McNiff & Whitehead, 2011). AR gained more recognition as a result of the work of Stenhouse, who in education championed the benefits that it could provide for professional development during the 1970s (McNiff & Whitehead, 2011). AR was further developed by educational academics as a research methodology to evaluate the processes of professional practice. This development was connected to the idea that accountability and self-critique are essential features of good practice (McNiff, 2010). The evidence base of AR as a methodological tool is gaining momentum in the UK, as well as worldwide (Whitehead, 2012), particularly in professions related to education (McNiff & Whitehead, 2011).

According to McNiff and Whitehead (2011) the traditional view of AR is that it is a form of enquiry that enables practitioners to investigate and evaluate the impact of their work. Broadly speaking AR can be separated into two groups. The first, interpretive AR, posits that the most appropriate way to conduct research is for an external researcher to observe and report on what other practitioners are doing. The second viewpoint, highlights that AR can be formulated using ideas emanating from person-centred theory (Rogers, 1980; McNiff & Whitehead, 2011).

Person-centred theory relates specifically to an individual's potential to understand, and develop their own skills and capacities (Rogers, 1980). This assumes that practitioners should be viewed as competent professionals who have the necessary skills to act as agents of their own personal change (McNiff & Whitehead, 2011). As such, a practitioner can offer explanations for what they are doing, often referred to as self-study AR or first-person AR (McNiff & Whitehead, 2011).

Self-study AR has evolved further to incorporate a 'living-form' theory, where researchers act to understand what is happening to themselves in the context of their professional lives (Whitehead, 2014). '*Living theory*' AR therefore provides a methodological tool that enables practitioners to create their own evidence-based explanations to extend and improve their professional learning (Whitehead, 2010).

The reports produced by AR researchers seek to illustrate how they have improved their practice (McNiff & Whitehead, 2011). The result is that the knowledge cannot be directly generalised or applied to other situations, even if situations might appear to be very similar. However, the experience, acquired knowledge, and information can be shared. A key aim of AR therefore is to share the learning that led to the creation of that knowledge (McNiff & Whitehead, 2009). Consequently, researchers' accounts based upon their research experience are considered as practical theories of practice from which others can learn if they wish (McNiff and Whitehead (2011).

#### **1.4.1. *Synthesis between action research and self-reflective practice***

In many traditional research contexts 'official researchers' are perceived as those with the knowledge whilst practitioners are seen as those without it (McNiff & Whitehead, 2009). When engaging in AR however, practitioners have the ability to research their own practices. This is a markedly different approach from traditional forms of research, where a 'professional researcher' tends to 'do research on' practitioners or participants (McNiff & Whitehead, 2009).

AR should not be regarded as simply a methodology, but as an orientation toward inquiry (Bradbury & Reason, 2003), which seeks to create a quality of engagement and curiosity by posing questions through the collection of evidence and the testing of practices. A strength of AR is that, "*it begins in practice and people generate their own theories out of their practice*" (McNiff, 2010, p25). AR posits knowledge as a living and evolving process, which Lyotard (1984) describes as being in a sense, a work of art. Action researchers therefore often ask



themselves, “*What is my practice?*” or “*How do I improve what I am doing?*” (McNiff & Whitehead, 2011).

According to Fox (2011), practitioner research is a useful method of examining professional practice and developing expertise, particularly for EPs. This is primarily due to the nature of their work, where they are required to use a range of psychological problem-solving models to frame common problems (Fox, 2011). Consequently, individual EPs should systematically study their own ways of working through the rigorous process of self-reflection and appraisal (Fox, 2003). Furthermore, it is critical for EPs to strengthen their own evidence base through the process of developing their practice-based knowledge (Fox, 2011).

It is the researcher’s view, that whilst these endeavours often occur in professional practice, such as during reflections in case formulation, supervision and further professional training, they are often neglected when undertaking research. This gives further support for the use of AR, both in terms of sharing the personal learning experience and practice development with other EPs, as well as providing other EPs with an example of how practice-based development can be achieved whilst conducting research.

### **1.5. *Emancipatory action research***

The process of identifying an area of research was heavily influenced by the writings of Michael Oliver. Oliver (1992) stated that traditional research can be an alienating experience for disabled research participants and it is something that is ‘done to them’, over which they have little, or no control. Other authors have claimed that traditional research paradigms mirror and perpetuate the power relationships experienced by oppressed people in their day-to-day lives (Barnes & Sheldon, 2007). Research is therefore very powerful, in that it can either be, a significant aid in the maintenance and perpetuation of oppression, or it can be a critical tool for eradicating oppression (Vernon, 1997).

An interest in disability rights, and the social model of disability, led the researcher to adopt an emancipatory worldview to inform the values of the research design. This position arose during the 1980s and 1990s from individuals who felt that post-positivist assumptions imposed structural laws, and theories, that did not fit marginalized individuals or issues of social justice (Oliver 1992). Whilst some authors have identified a preference for disabled, over non-disabled researchers (Vernon, 1997), others accept that non-disabled researchers can produce emancipatory disability research within the emancipatory model (Barnes, 1992). The core

message seems to be that disability researchers should devote more attention to methodological issues, such as power relations and inequalities, as well as critical reflections on how the knowledge is produced (Mertens, 1998).

Consequently, the researcher believes that AR methodology can be elegantly synthesized with emancipatory principles. McNiff and Whitehead (2011) note that AR can be a powerfully liberating form of enquiry because it means that practitioners themselves investigate their practices as they find ways to live more fully in the direction of their educational values. Furthermore, they also state that there is an importance in the researcher taking action for personal, professional and wider social benefit (McNiff & Whitehead, 2011). AR has also been described as a participatory, democratic process concerned with developing practical knowledge in the pursuit of worthwhile human endeavours that aim to improve participants' lives (Reason & Bradbury, 2006). Therefore, a wider purpose of AR methodology is the creation of practical knowledge for the increased well-being of the people involved in the research. AR in this context can clearly be deemed as emancipatory, as it leads not just to new practical knowledge, but to new abilities to create knowledge (Bradbury & Reason, 2003). It seeks practical outcomes, creates new forms of understanding, as well as providing guidance or inspiration for practice.

#### **1.6. *Purpose of research***

An emancipatory worldview stipulates that research inquiry ought to be intertwined with politics. Kemmis and Wilkinson (1998) provide a useful summary, highlighting four key features that typify emancipatory AR:

- 1). They adopt dialectical approaches that focus on bringing about change in practices or advancing an action agenda for change.
- 2). They focus on helping individuals free themselves from constraints found in the media, in language, in institutional procedures, and in the relationships of power in educational settings.
- 3). They should seek to follow emancipatory values in order to unshackle people from the constraints of irrational, or unjust structures, which limit self-development and self-determination.
- 4). They should be practical and collaborative, where inquiry is conducted and completed with others, rather than on or to others (Kemmis & Wilkinson, 1998).

This research contains an action agenda for reform by seeking to address important social issues such as empowerment, inequality, and suppression. It is the researcher's intention that the adaptations and improvements of practice will have a direct, and beneficial, impact upon the lives of the participants, as well as the institutions in which the individuals are located.

Given the key features of the Children and Families Act (2014), as previously outlined in *Chapter 1.3.2*, the researcher identified three factors in relation to the role of EPs that he felt was essential to incorporate as central aspects of the research:

- 1). The research will involve young people aged 16 – 25.
- 2). The research will focus on exploring the concept of self-advocacy.
- 3). The research will seek to empower and emancipate young people who are at high risk of potential marginalisation.

This research aims to specifically focus on promoting the ability of young people with cerebral palsy (YPCP) aged 16 – 25 to have increased opportunities to self-advocate using a MMSA tool. By focussing on the needs of a particular group in society that are at high risk of marginalisation, attempts will be made to construct a picture of the necessary changes to practice that are required to address these issues. Therefore, the researcher's philosophical worldview, and the principles underpinning the research, appear to meet the criteria for emancipatory AR.

The first purpose of this research is to improve professional practice by developing knowledge and skills in identifying potential challenges that may limit an individual's ability to use MMSA tools. This will be achieved by exploring and assessing different approaches, techniques or adaptations to practice through the consideration of feedback provided by participants, educational staff and parent(s)/carer(s). Although this research will involve only a small number of participants, it is hoped that the rich data of, skills, knowledge and insight will improve professional practice in future situations, both with YPCP, as well as with the wider population of people with disabilities.

The second purpose of the research is the empowerment of the participants involved. By simply participating in the research, the participants will have access to a MMSA tool that may promote increased opportunities for them to self-advocate. The hope is that the YP will be empowered to be a central part of the research process by helping to shape adaptations that increase their

ability to access the wiki-page. The researcher will explore which strategies, techniques and approaches can be used with the YP and how these can be adapted. The researcher intends to do this through a collaborative process which utilises the YPs' behavioural responses and feedback, as well as the expertise of a facilitator. There is also the possibility of additional benefits for the individuals, such as developing their skills in information and communication technology (ICT), increasing their self-confidence, and fostering positive emotional states. All the participants will have the opportunity to keep the wiki-pages that they create beyond the scheduled period of the research project.

A third purpose is to create new ways of working for the profession. It is hoped that other EPs can learn from the techniques and strategies, so that they can support YP to self-advocate more effectively. It also seeks to inspire EPs to attempt novel approaches, or unfamiliar techniques, as well as to develop the confidence to use their skills alongside emerging technologies that can potentially promote SA. By learning from the creative adaptations to practice, as well as the limitations of this research, other EPs can apply similar adaptations to provide increased opportunities for CYP to self-advocate. By learning from the adaptations that are developed through the research, it is hoped that other EPs can increase the range of YP who they work with using MMSA tools or other emerging technologies.

### **1.7. *Aims of research***

Rather than adopt a traditional method of research, the researcher is seeking to identify potential barriers, or challenges, that may limit or restrict YPCP ability to self-advocate. By adopting an active role, and adapting professional practice to meet the participants' needs, it is hoped that this can assist the individuals to overcome challenges through a recorded process of identification, action, and reflection. By explaining the process of what happened, why it happened, and what it achieved, it is hoped that this research provides insight by outlining the novel techniques or improved practice for the researcher in the context of educational psychology (McNiff & Whitehead, 2011).

The researcher is also seeking to explore the techniques, approaches, and strategies that are necessary to meet the individuals' needs, so that professional practice can be adapted to provide the YP with increased opportunities to self-advocate. This research adopts a living theory AR approach, whereby the researcher will reflect upon his own practice, as well as the practice of the facilitator who will be working alongside the researcher, and the YP, during the creation of the wiki-pages. The researcher will become a 'knowledge-creator' (McNiff & Whitehead,

2011). In this scenario, a theory is about what I am doing and the theories that are generated can be explained as taking on a 'living form'. The personal theories generated are known as '*living theories*' because they develop and change as the researcher changes and develops.

The decision to write parts of this thesis from a first-person perspective reflects the position as a 'practice-based' researcher. The researcher therefore writes from an 'I', where the object of enquiry is himself, or 'we', when working in collaboration with others. This provides authenticity and McNiff and Whitehead (2011) provide support for this stylistic choice stating:

*"Perhaps the main 'do' is to write in the first person; to use 'I' with conviction and celebrate your capacity and to write high quality texts that will withstand the most rigorous critique. Previously the use of 'I' was avoided; today, in action research and most study research, the use of 'I' is expected."* (McNiff & Whitehead, 2011, p.118).

### **1.8. Summary of chapter**

This chapter has provided definitions of key terms including; SA, MMSA tools, the social model of disability, and CP. The relevant legislation and current context in the UK related to the area of research was then explored. Legislative changes, and the impact of professional practice for EPs was considered. The researcher then provided an introduction, and brief history to AR, in addition to the importance of practice based-evidence. The researcher briefly proposed his ontological perspective, highlighting disability rights, and emancipatory-oriented research, as central influences. The chapter concluded by outlining the purpose of the research, in addition to the orientation, and the aims of the proposed inquiry. The next chapter provides details of the literature review.

## **Chapter 2: Literature Review**

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### **2.1. *Introduction to literature review***

This chapter outlines the process of how relevant literature was located and gathered in a systematic manner. It provides a comprehensive list of the databases accessed, in addition to the primary and alternative search terms utilised. Results of the search and the number of articles obtained from each database are provided. Explanations of additional search criteria, and the inclusion/exclusion criteria adopted demonstrate how the search was refined. The relevant articles are critiqued using a thematic review, and this informs the research questions.

### **2.2. *Details of the systematic literature search***

A systematic literature review was carried out on 30/07/15 to identify previous relevant research in the area of SA in relation to individuals with CP. The primary aim of this was to identify what previous research existed, and if there were any potential ‘gaps’ in terms of findings, knowledge, or methodological approaches.

The systematic search was conducted using the following databases:

- EBSCO
  - Academic Search Complete
  - British Education Index
  - Child Development & Adolescent Studies
  - Education Abstracts (H.W. Wilson)
  - Education Research Complete
  - Educational Administration Abstracts
  - ERIC
  - PsycARTICLES
  - PsycINFO
- JSTOR
  - Articles from Education & Psychology journals
- PUBMED
- SAGE Journals
- Science Direct
- SCOPUS
- ZETOC

The primary terms used were ‘*cerebral palsy*’ and ‘*self-advocacy*’, within the parameters of ‘peer-reviewed journals’ and ‘dissertation theses’. After the initial search of all the databases listed above, further searches were conducted using additional related terms (see *Table 2.2*) to ensure that the broadest range of articles were captured and important material was not overlooked. Finally, searches using Google and Google Scholar were used to identify research that might not have been located in the listed databases.

Primary search terms	Related terms
‘Cerebral Palsy’	‘CP’; ‘Physical impairment’; ‘Physical disability’; ‘Neuro-developmental disorder’
‘Self-advocacy’	‘Advocacy’; ‘Voice of the child/young person’; ‘Empowerment’; ‘Autonomy’; ‘Agency’; ‘Control’

**Table 2.2: Primary search terms and related terms used during the systematic literature search.**

### **2.3. Results of the literature search**

- EBSCO returned 22 articles from the primary search terms. Seven were duplicates, resulting in 15 articles. An additional 216 articles were returned from the related search terms. This resulted in a total of 231 viable articles.
- JSTOR returned 668 articles from the primary search terms, and an additional 58 articles for the related search terms, resulting in a total of 726 articles.
- PUBMED returned two articles.
- SAGE Journals returned 1, 435 articles in total.
- Science Direct returned 424 articles.
- SCOPUS returned three articles, however, two were dismissed as duplicates of those located in the PUBMED database, resulting in only one article.
- Wiley Online returned 146 articles, with 129 of these being peer-reviewed journals.
- Zetoc returned three articles, all were dismissed as duplicates of the SCOPUS search.

After identifying 2, 890 articles from the search, each was scrutinised individually, and excluded based on the following criteria. Articles were dismissed if they explored neuro-developmental disorders more generally, where CP was discussed in a broader context, and findings were presented alongside other conditions such as autism spectrum disorder (ASD). Articles were also rejected if CP was explored in general terms as a physical impairment, such as when discussed alongside other physical disabilities like spina bifida.

Initially, the researcher had hoped to utilise only UK-based articles, due to the relevance of legislative considerations, as well as the prevailing socio-political discourse. This was not possible due to the lack of relevant research that was obtained from limiting the search in this

way. Also, articles were not excluded based on the period of publication. However, all articles selected were published between 2004 – 2013, and as they were published within the last 13 years it seems reasonable that they encompass recent developments. Finally, the researcher had hoped to select from articles exclusively related to YPCP aged 16 – 25 years, however, this was not viable due to the lack of relevant research for this specific group.

The 19 articles selected were deemed to be most relevant and useful for the purpose of the research and its aims (*see Chapters 1.6 & 1.7*). 18 of the articles were peer-journal reviews, whilst one was a doctoral dissertation.

## **2.4. *Themes derived from previous research***

Literature regarding the concept of SA in relation to YPCP is sparse. Consequently, areas of research that are conceptually similar to SA, such as ‘*participation*’ and ‘*quality of life*’ (QoL), were deemed relevant for further investigation.

After the 19 articles were selected, four themes within the literature were identified by comparing areas of interest such as; the research design, country of origin, and participant recruitment/sampling technique:

- ‘Quantitative research that explores participation in young people with cerebral palsy’. This represents the largest theme, with seven articles included for review (*see Table 2.5.1*).
- ‘Research that focusses on quality of life through the assessment of quantitative data’. Five such articles were included for review (*see Table 2.5.2*).
- ‘Research investigating barriers to/facilitators of participation and adaptations to professional practice’. Three of the articles focus on this theme (*see Table 2.5.3*).
- ‘Research that adopt novel qualitative research methodologies focussed on promoting the voice of individuals with cerebral palsy.’ This theme comprises four articles (*see Table 2.5.4*).

## **2.5. *Detailed critique of research articles via thematic review***

### **2.5.1. *Theme 1 - Quantitative research that explores participation in young people with cerebral palsy***

‘*Participation*’ is an important concept, Article 23 of the United Nations Convention on The Rights of The Child (UNCRC, 1989) states that a mentally, or physically, disabled child should



have the opportunity to participate and access services that promote participation. Furthermore, Articles 23 – 30 of the 2006 UN Convention of The Rights of Persons with Disabilities (UNCRPD, 2006) states that children with disabilities should be able to participate on an equal basis with others in matters related to family life, health maintenance, education, public life, recreational life, and sporting activities.

In the context of the articles critiqued in *Table 2.5.1*, ‘*participation*’ is widely defined as ‘the nature and extent of a person’s involvement in life situations’ (WHO, 2001). This is understood to be both an objective and subjective experience. The WHO (2001) also categorizes participation in terms of; personal maintenance, mobility, information exchange, social relationships, home life, education, work and employment, economic life, as well as community, social and civic life.

Author(s)	Title of article	Date of Publication	Country of Origin
Hammal, Jarvis & Colver	<i>Participation of Children with Cerebral Palsy is Influenced by Where They Live</i>	2004	UK
Imms, Reilly, Carline & Dodd	<i>Diversity of Participation in Children with Cerebral Palsy</i>	2008	Australia
Engel-Yeger, Jarus, Anaby & Law	<i>Differences in Patterns of Participation Between Youths with Cerebral Palsy and Typically Developing Peers</i>	2009	Israel
Fauconnier, Dickinson, Beckung, Marcelli, McManus, Michelsen, Parkes, Parkinson, Thyen, Arnaud & Colver.	<i>Participation in Life Situations of 8 – 12 Year Old Children with Cerebral Palsy: Cross Sectional European Study</i>	2009	Europe (Seven Countries) Denmark, France, Germany, Ireland, Italy, Sweden & UK
Shikako-Thomas, Shevell, Lach, Law, Schmitz, Poulin & Majnemer	<i>Picture me Playing – A Portrait of Participation and Enjoyment of Leisure Activities in Adolescents with Cerebral Palsy</i>	2012	Canada
Longo, Badia & Orgaz	<i>Patterns and Predictors of Participation in Leisure Activities Outside of School in Children and Adolescents with Cerebral Palsy</i>	2013	Spain
Shikako-Thomas, Shevell, Schmitz, Lach, Law, Poulin & Majnemer	<i>Determinants of Participation in Leisure Activities Among Adolescents with Cerebral Palsy</i>	2013	Canada

**Table 2.5.1: Research articles that explore participation in young people with cerebral palsy.**

#### **2.5.1.1. Establishing levels of participation for young people with cerebral palsy**

There are apparent differences in the patterns of participation between CYP with CP and typically developing adolescents (Engel-Yeger, Jarus, Anaby & Law, 2009). Their research in

Israel recruited 22 participants with CP (10 boys and 12 girls) and 30 typically developing peers aged 12 – 16. They measured '*participation*' using the Children's Assessment of Participation and Enjoyment (CAPE). This quantifies objective and subjective elements to comprehensively measure participation in a range of domains, and three scores were generated regarding participation '*diversity*', '*intensity*' and '*enjoyment*'. The results suggest that although the YPCP had a lower diversity and intensity of participation than that of the typically developing YP, they did not indicate less enjoyment participating.

In Australia, Imms, Reilly, Carline and Dodd (2008) investigated the participation of children with CP in activities outside the school context, comparing their participation with a large representative sample of children. Data was acquired through a population-based survey of 114 individuals with CP aged 10 – 12 years, and scores from the CAPE measurement tool were compared with population-based data for 11-year olds. The results indicated that children with CP participated in a wide variety of activities with relatively '*low intensity*' and '*high enjoyment*'. Children with the most severe forms of CP did exhibit the lowest levels of participation diversity and intensity, however, the lack of variation in children with less severe CP suggests that motor ability alone may not be a significant factor until impairment is severe.

The researchers expressed concern that children with CP reported reduced participation, as this could limit the development of skills, and opportunities, for socialisation. The study reports that children with CP may encounter increased barriers to social inclusion as they tended to participate alone, with Imms et al. (2008) finding that children with CP appear to desire to perform these activities with friends. However, physical restrictions may limit their ability to engage in these activities outside of the home-setting, where parental assistance, as well as the necessary physical or socio-environmental adaptations, are easily accessible.

#### ***2.5.1.2. Participation and socio-environmental factors***

Participation of children with CP has been explored in the UK in the context of where they live (Hammal, Jarvis and Colver (2004). This study involved a relatively large sample of children with CP (443 participants) in Northern England. It adopted the social model of disability to determine whether the degree of participation for children with CP is influenced by geographical location. Participation was measured using the Lifestyle Assessment Questionnaire that generates six-domain profiles. These domain scores, and the overall Lifestyle Assessment Score, were the dependent variables. 13 attributes were also recorded for each child, such as the type

of CP or intellectual impairment. The attributes and location formed the independent variables used in the analyses.

The findings indicated that the participation of children with similar types and severity of CP varied according to where they lived. Variations in social exclusion were accounted for entirely by geographical location, and did not appear to be influenced by the type of CP. Hammal et al. (2004) conclude that environmental factors may have an important role in participation, and are as influential as the type of CP, or degree of intellectual impairment. The authors acknowledge that there are potential methodological issues, but this research appears to suggest variations between localities are associated with differences in the participation of children with CP.

Another research project conducted in Europe established that participation varies substantially depending on geographical location (Fauconnier et al. 2009). This research evaluated involvement in life situations (referred to previously in this chapter as '*participation*'). This cross-sectional study of 818 children with CP in nine European regions used the Life-H questionnaire to assess participation. The Life-H questionnaire comprises 62 items that are grouped into 11 domains covering aspects of daily activities and social roles.

Fauconnier et al. (2009) found substantial variation between regions within seven European countries. Participation was highest in Denmark across all domains except '*relationships*'. The authors purport a social model of disability similar to Hammal et al. (2004), suggesting that these differences in participation could relate to a range of socio-environmental factors. They conclude that the variation in participation across regions suggests that some countries may promote participation better than others through policies and regulation at a national level.

#### ***2.5.1.3. Patterns of participation and determining factors for young people with cerebral palsy***

Research by Shikako-Thomas et al. (2012) provides insight into the patterns of participation for YPCP. This cross-sectional study also utilised the CAPE questionnaire with 175 YP. The types of activities that YPCP engaged in most frequently were '*social*' and '*recreational*' activities. Overall, there was less variety in the participation of YPCP and the activities tended to be more passive. YP educated in SEN settings experienced lower diversity and intensity of engagement in domains related to '*leisure*' activities. Furthermore, participation in leisure activities was found to be more restricted for children with the most severe impairments, as previously reported by Imms et al. (2008). Although YPCP appeared to enjoy participating in a variety of activities, participation was limited, particularly in '*self-improvement*' activities. They also found that

there was greater participation in '*informal*' activities. Again, these informal activities tended to be home-based with family. A concerning finding was that participation appears to decrease with advanced age during later adolescence.

Shikako-Thomas et al. (2013) stated that participation is a multi-faceted construct that appears to be associated with a variety of factors. For instance, participation was impacted by the adolescent's functional characteristics and attitudes, as well as contextual factors such as socioeconomic status, family environment, school setting and local service provisions. Like previous studies (Imms et al., 2008 & Shikako-Thomas et al., 2012), there were strong correlations for severity of functional limitations and participation. However, in predictive models the '*environmental factors*' and '*individual characteristics*' were found to be more accurate predictors of participation. For example, communication ability was one of the functional characteristics that had a significant predictive value for participation in self-improvement activities.

Shikako-Thomas et al. (2012) conclude that a systems-based approach towards adolescent development should be adopted that conceptualises multiple-levels of potential interactions, ranging from biological characteristics to policies and services. This mirrors the conclusions of the large-scale study in Europe (Fauconnier et al., 2009). However, Shikako-Thomas (2012) go further by stating that professionals need to actively participate to ensure the promotion of healthy development for adolescents with CP. This research informs professionals and families about the potential intrinsic and extrinsic characteristics that may contribute to greater participation for YPCP. This is useful because individual characteristics such as motivation, as well as the environmental factors and potential barriers encountered, may be modifiable through specific intervention strategies. As Fauconnier et al. (2009) previously highlighted, awareness of these factors may result in strategic planning and changes to policy that promote health and well-being for this at-risk population.

Longo, Badia and Orgaz (2013) conducted a similar study during the same period in Spain. A larger sample of CYP (N = 199) participated in a cross-sectional study utilising the CAPE measurement tool (Spanish translation). The findings support earlier research by Imms et al. (2008), that CYP with CP exhibit lower diversity and intensity in relation to participation, but report high levels of enjoyment in both formal and informal activities. Furthermore, CYP with CP participated more frequently and in a wider range of '*informal*' activities, as opposed to '*formal*' activities, supporting the findings of Shikako-Thomas et al. (2012). Longo et al. (2013)

established that predictors of diversity and intensity of participation are variables predominantly related to the CYP's impairment and environment. This includes individual factors, such as the specific levels of gross motor-function and intellectual ability, as well as the specific socio-environmental factors related to home and educational settings.

#### ***2.5.1.4. Conclusions from Theme 1***

Overall, levels of participation for YPCP appears to be lower than typically developing people. This is concerning, as participation is widely recognised as a key outcome in health for all CYP, in addition to being a protected human right (UNCRC, 1989; UNCRPD 2006). Activities of CYP with CP are mostly performed at home and are usually dependent on adults to provide the necessary support. Differences in participation between YPCP and their typically developing peers may have further implications for skill development, developing friendships, as well as impacting self-confidence and autonomy. This might explain why YPCP seem to experience growing isolation as they mature, which may lead to limited participation in activities and a passive lifestyle.

Although YPCP report lower diversity and intensity towards participation, they do not indicate less enjoyment whilst participating. This suggests that socio-environmental factors can significantly impact the participation of YPCP. This has important implications for intervention programs that focus on intrinsic and environmental factors that promote social inclusion. The literature seems to suggest the need to move beyond diagnosis and to focus on the predictors of participation in activity. Generally, researchers in this area purport a social model of disability suggesting that potential barriers and facilitators need to be explored further to fully understand the issues that could lead to increased participation. By understanding the factors and processes influencing whether and how people with CP engage in activity, it may be possible to encourage their participation by removing barriers to active involvement.

Predictors of participation are also important because they can help to guide effective strategies and policy initiatives to enable children with CP to participate more fully in society. The considerable variation in participation across Europe suggests that some countries may promote participation better than others through policies and regulation at a national level. Policies need to guarantee that environments are accessible to ensure YPCP are able to participate in meaningful activities of their choosing, which is believed to be essential for promoting skill competencies, personal autonomy and a sense of inclusion.

There are several limitations to the methodologies and findings that the authors acknowledge. The first relates to the relatively small sample sizes and the potential impact on the multivariate models, which may lack adequate statistical power to carry out the necessary sub-analyses. Although the use of less rigorous indexes to estimate effect size is justified by the sample sizes, future studies might consider a larger sample size to verify that effect size values are measured accurately. The second issue is the lack of homogeneity within, and between, the groups that resulted in models of poor fit. Matched samples might provide a better understanding of the effects of physical abilities, and gender, on participation. Finally, the literature is arguably constrained by the lack of instruments to measure participation and the relevant characteristics of socio-environmental context. Articles generally relied on the CAPE to provide measurements, however, there are concerns that this may not fully capture the extensive domains that a broad and subjective concept like participation encapsulates.

### **2.5.2. Theme 2 – Research that focusses on the quality of life of children and young people with cerebral palsy**

Article 23 of the UNCRC (1989) states that CYP with disabilities are entitled to a “full and decent life”. It has been proposed that a good QoL is a key outcome for all individual CYP. The WHO (1995) defines QoL as, “an individual’s perception of their position in life in the context of the culture and value systems in which they live in relation to their goals, expectations, standards and concerns”. QoL is considered subjective in nature and accurate measurement relies on self-reports obtained from individuals.

It is important to highlight that although QoL is conceptually different from SA, its inclusion in the literature review is due to the fact that many of the factors that encapsulate SA are also considered to be important factors in assessment tools that provide QoL measures. For instance, several of the research articles related to QoL in *Table 2.5.2* utilise the Quality of Life Instrument for People with Disabilities. It incorporates items that focus on aspects of control and active participation, which are central components of SA (*see chapter 1.2.1*).

<b>Author(s)</b>	<b>Title of article</b>	<b>Date of Publication</b>	<b>Country of Origin</b>
Livingston, Rosenbaum, Russell & Palisano	<i>Quality of Life Among Adolescents with Cerebral Palsy: What Does The Literature Tell Us?</i>	2007	Canada
Rosenbaum, Livingston, Palisano, Galuppi & Russell	<i>Quality of life and Health-Related Quality of Life of Adolescents with Cerebral Palsy</i>	2007	Canada

Dickinson, Parkinson, Ravens-Sieberer, Schirripa, Thyen, Arnaud, Beckung, Fauconnier, McManus, Michelsen, Parkes & Colver	<i>Self-Reported Quality of Life of 8 – 12-Year-Old Children with Cerebral Palsy: A Cross-Sectional European Study</i>	2007	Europe (Seven countries): Denmark, France, Germany, Ireland, Italy, Sweden & UK
Livingston & Rosenbaum	<i>Adolescents with Cerebral Palsy: Stability in Measurement of Quality of Life and Health-Related Quality of Life Over 1 Year</i>	2008	Canada
Arnaud, White-Koning, Michelsen, Parkes, Parkinson, Thyen, Beckung, Dickinson, Fauconnier, Marcelli, McManus & Colver.	<i>Parent-Reported Quality of Life of Children with Cerebral Palsy in Europe</i>	2010	Europe (Seven countries): Denmark, France, Germany, Ireland, Italy, Sweden & UK

**Table 2.5.2: Research articles that explore quality of life in young people with cerebral palsy**

#### **2.5.2.1. Research conducted in Canada exploring quality of life for young people with cerebral palsy**

Rosenbaum, Livingston, Palisano and Russell (2007) state that there are conceptual differences between the constructs of QoL and health-related quality of life (HRQoL) that can be objectively measured. QoL refers to the notion of holistic well-being that considers factors such as social inclusion or access to education. HRQoL focuses on the health-related components judged to be associated with life satisfaction, such as mobility or communication skills.

Rosenbaum et al. (2007) assessed the QoL and HRQoL in YPCP. The study involved 203 YPCP aged 13 – 20 (mean age of 16 years). Two separate measures were used to determine QoL and HRQoL. Perceived well-being (QoL) was assessed with the Quality of Life Instrument for People with Disabilities, which groups nine areas of life into three domains. HRQoL was assessed via the Health Utilities Index – Mark 3, which describes functional health status for eight attributes covering a wide range of abilities or disabilities. The results indicate that the relationship between the constructs of QoL and HRQoL is weak. The implication is that unlike participation, QoL is not correlated to the severity of CP or the associated functional impact.

This cross-sectional study by Rosenbaum et al. was useful in determining that QoL and HRQoL should be treated as separate dimensions, but it was unable to determine if these separate constructs were stable or varied over time. Consequently, two of the researchers incorporated a subsequent phase into the design to form a longitudinal study. After one year Livingston and Rosenbaum (2008) were able to recruit 185 of the YPCP that took part in the initial study. They

found that measures of QoL and HRQoL of YPCP were moderately stable over a 1-year period. Whilst no significant differences were notable from a group effect, when the researchers focussed on individual scores within the study, substantial differences emerged in terms of the magnitude and direction of change. Livingston and Rosenbaum (2008) propose that HRQoL measurements might be more applicable to medical based interventions whereas measures of QoL might provide insight for determining predictors of well-being.

Livingston, Rosenbaum, Russell & Palisano (2007) also reviewed 20 original articles that were grouped by design, comprising eight cross-sectional studies, nine validation studies and three exploratory studies. Several themes emerged from the meta-review of QoL. 'Well-being' was reported as being lower among YPCP when their data was compared with normative representative samples. Whilst the evidence was inconclusive, some articles also concluded that severity of impairment impacted psychosocial outcomes. Physical impairment, however, did not appear to have a significant impact on QoL, regardless of the type of CP. It appears that although YPCP experience different life situations and issues than children and adults, there is limited research on factors associated with well-being for YPCP aged 16 - 25.

#### ***2.5.2.2. Research exploring the quality of life for children with cerebral palsy conducted in Europe***

Substantial research into QoL for children with CP has been conducted in several countries across Europe to form a wider cross-sectional project known as the Study of Participation of Children with Cerebral Palsy Living in Europe (SPARCLE). Dickinson et al. (2007) initially recruited 814 children with CP aged 8 – 12 years from seven European countries. This selective sample comprised the same participants that were utilised by Fauconnier et al. (2009) in *Chapter 2.4.1.3*, who were co-collaborators in the SPARCLE project. Dickinson et al. (2007) adopted the social model of disability as a conceptual framework to examine the relationships between QoL and environmental factors. Children that were capable of self-reporting their own QoL and experiences of pain (N = 500) were assessed using the KIDSCREEN instrument. This psychometric tool uses questions derived from focus-group work with CYP across Europe to assess the QoL and provides data in ten separate domains. In addition, frequency and severity of pain was assessed with two questions from the Child Health Questionnaire.

When scores were compared to a general sample, the QoL for children with CP was similar in all domains. The findings indicated that severity of impairments was not associated with QoL in six of the domains. Overall, impairments explained little of the variation in the QoL with



children with CP. Pain was associated with poorer QoL in all domains, however, it could not account for the variation in QoL. The implication is that QoL is not associated with impairment but may largely be determined by socio-environmental factors. Dickinson et al. (2007) believe that social and educational policies need to reflect this approach to ensure that individuals with CP are able to participate fully in society in accordance with the UNCRC (1989).

Another article from the SPARCLE project examined parental reports of the QoL of their children with CP from the same selective sample (Arnaud et al., 2010). Similar to the findings of Dickinson et al. (2007), the conclusion of the research is that there are other substantial factors that influence how parents of children with CP report QoL, aside from the severity of impairment alone.

### ***2.5.2.3. Conclusions from Theme 2***

There are conceptual differences between the constructs of QoL and HRQoL that can be objectively measured, and the relationship between the two appears to be weak. ‘Well-being’ (QoL) is reported to be lower among YPCP when compared with normative data, and whilst the evidence is inconclusive, severity of impairment may impact psychosocial outcomes. Physical impairment, however, does not appear to have a significant impact on QoL, regardless of the type of CP.

Studies have increasingly adopted the social model of disability as a conceptual framework to examine the relationships between QoL and environmental factors. Overall, impairments appear to explain little of the variation in the QoL with children with CP. Pain is associated with poorer QoL in all domains but it does not account for the variation in QoL. The implication is that for most aspects of life, QoL is not associated with impairment but may largely be determined by socio-environmental factors.

Research relating to QoL has been conducted by small groups of collaborative researchers in Canada & Europe that utilise cross-sectional research designs. Furthermore, these group of researchers tend to base their findings on the same population of YPCP for multiple studies. A shortcoming of this approach is that there is a distinct lack of direct comparisons with control groups, which has implications for the reliability and generalisability of findings. The findings may also be skewed by the fact that CYP with severe CP might not be able to self-report as required when adopting the KIDSCREEN instrument. New measurement tools may therefore be required, or alternative research methods should be adopted. Future research might

investigate which factors can enhance the QoL of people with CP through the adoption of increased qualitative methodologies that focus on the views of the people themselves. Ultimately, this information may contribute to planning appropriate interventions as well as informing effective policies and programs on broader systemic levels. Social and educational policies need to reflect the potential impact of socio-environmental factors to ensure individuals with CP are able to participate fully in society, and in accordance with the UNCRC (1989).

### ***2.5.3. Theme 3 – Research exploring barriers to participation and the need to adapt professional practice to overcome socio-environmental factors***

The previous two themes indicate that there is a need for greater exploration of socio-environmental barriers, as well as the adaptations or changes to professional practice that can reduce their impact (Dickinson et al. 2007; Fauconnier et al. 2009). The research articles listed in *Table 2.5.3* adopt the social model of disability to examine the physical, emotional, social and environmental factors that influence participation for YPCP.

<b>Author(s)</b>	<b>Title of article</b>	<b>Date of Publication</b>	<b>Country of Origin</b>
Mihaylov, Jarvis, Colver & Beresford	<i>Identification and Description of Environmental Factors That Influence Participation of Children with Cerebral Palsy</i>	2004	UK
Lawlor, Mihaylov, Welsh, Jarvis & Colver	<i>A Qualitative Study of the Physical, Social and Attitudinal Environments Influencing the Participation of Children with Cerebral Palsy in Northeast England</i>	2006	UK
Shimmell, Gorter, Jackson, Wright & Galuppi	<i>“It’s the Participation that Motivates Him”. Physical Activity Experiences of Youth with Cerebral Palsy and Their Parents</i>	2012	Canada

***Table 2.5.3: Research articles that explore barriers to participation and the need to adapt professional practice.***

A meta-review exploring the socio-environmental ‘barriers’ and ‘facilitators’ to participation was conducted in the UK by Mihaylov, Jarvis, Colver and Beresford (2004). The authors state that the socio-environmental factors can be described at three principal levels: the individual’s experience of their local environment; an objective assessment of the disability-friendliness or conduciveness of the local environment in relation to promoting participation; and the legislative, attitudinal and regulatory framework for the environment at a national level. A key point that emerged is that there is relatively little research specific to CYP that seeks to identify potential socio-environmental factors, nor is there adequate instrumentation to measure them with accuracy and validity.

Following on from the meta-review, the researchers sought to involve the families of children with CP more closely in terms of the research design to identify key socio-environmental features that are reported to facilitate or restrict participation (Lawlor, Mihaylov, Welsh, Jarvis and Colver, 2006). Conducted in the UK, this small-scale qualitative research design utilised 12 in-depth semi-structured interviews with the parents of children with CP (6 boys; 6 girls). The interview structure was set out in a topic guide and the transcribed data was coded using a generative thematic approach as a framework for analysis. Socio-environmental barriers and facilitators to participation were identified and coded within themes. It emerged during the thematic analysis (TA) that the socio-environmental factors could be grouped into sub-themes that were further divided into barriers to, and facilitators of, participation.

Lawlor et al. (2006) found that the main facilitators of '*mobility*' were equipment and structural adaptations that enabled access in the home setting and the wider community. Specific specialised equipment was reported as being invaluable to facilitating the child's independence for participation in activities. Furthermore, it is reported that this reduced the level of support and supervision that was required from parents. The main barriers were structural aspects, such as steps and a lack of ramps or lifts, evident in both home and community settings.

Children's participation was often reliant on the commitment and support of adults, mainly provided by parents. This sub-theme was described as '*support by and to the family*'. Overall three main facilitators to participation in this theme were identified: physical support for activities of daily living; supervision of leisure activities; and advocacy for parents when seeking equipment and services for their children. The main barriers to participation were financial, as the additional costs of specialised equipment, and the reduction in potential earnings, often restricted a family's ability to support participation.

A final emergent theme was '*attitudes of individuals and institutions*'. Facilitators of participation were physical support, supervision and advocacy by parents, which were deemed to be central factors to the child's participation. Reported barriers to participation were the attitudes of individuals and ingrained approaches of institutions. Whilst some parents focussed on tangible barriers, such as the design of buildings, others highlighted barriers inherent in systems and policies.

Whilst Lawlor et al. (2006) acknowledge methodological limitations, such as the small sample size, the consistency with which themes were reported means that attention should be directed to alleviating potential barriers. They tentatively suggest that due to the variety of impairments observed related to learning, vision and language, findings from this article might be applicable to children with other impairments.

This work has been complemented by research conducted in Canada. Shimmell, Gorter, Jackson, Wright and Galuppi (2012) also utilised qualitative research methods by adopting a phenomenological approach to understand how YPCP experience physical activity within their daily lives. Shimmell et al. (2012) conducted focus-groups and individual interviews using a semi-structured, open-ended question method with 17 CYP with CP (aged 10 – 18 years). The transcripts were coded using content analysis to identify key concepts and recurring themes. This was refined to seven selected codes that formed the four main themes.

Overall, '*environmental*' and '*personal*' factors were mentioned most frequently compared to other potential factors as being both facilitators and barriers to physical activity. Personal factors are the background of an individual's life that are distinct from their health condition and are unique to individual context. Environmental factors were either individual or societal. Individual environmental factors refer to the immediate environment of the individual, such as the home setting. Societal factors on the other hand refer to the formal and informal structures, services and systems that impact the individual.

The availability and use of adaptive equipment, systems that allow for spontaneity and access to facilities or programs, were recurrent sub-themes reported by individuals and their parents. Personal factors like self-perception and psychosocial features, such as being a nervous or confident individual, contributed to individual preferences for different forms of physical activity. Some limitations were also reported relating to impairments in body structure and function. Barriers to physical activity included fatigue and pain, which would sometimes prevent CYP with CP from participating in activities that they enjoyed. Shimmell et al. (2012) conclude that professionals and service providers can offer strategies that promote participation in CYP with CP by making adaptations to positively influence personal and environmental interactions and the inter-related processes between the two.

### ***2.5.3.1. Conclusions from theme 3.***

The adoption of qualitative research designs that focus on in-depth information through semi-structured interviews seems to be beneficial for gaining insight into the barriers or facilitators that individuals with CP experience. In addition to this, TA can be a useful technique for grouping socio-environmental factors into themes, promoting a greater understanding of the underlying phenomenon by identifying environmental, social and personal factors.

Overall, environmental and personal factors were mentioned most frequently compared to other potential factors, as being both facilitators to, and barriers of, participation. Availability and use of adaptive equipment seemed to be an important recurrent sub-theme reported by individuals and their parents. Personal factors may also contribute to individual preferences for participation in different activities. Some limitations were reported that related to impairments in body structure and function. In particular, fatigue and pain are common barriers to participation.

Participation is often reliant on the commitment and support of adults, commonly provided by parents. A main facilitator was advocacy for parents when seeking equipment and services for their children. Specific specialised equipment and adaptations to existing equipment are also reported as invaluable for facilitating participation. Commonly reported barriers to participation were the attitudes of both individuals and institutions. In general families were not aware of disability legislation related to participation and professionals could have an important role in raising awareness. They could also offer strategies that promote participation for YPCP by making socio-environmental adaptations.

Socio-environmental barriers, such as a lack of access to social activities, could potentially result in loss of friendships and social networks. The evaluation for the effectiveness of current interventions should be considered in terms of fostering opportunities for communication, development of friendships, social integration, and personal control. Adopting novel ways to deliver programs might also be considered a central feature to policy development.

Overall, researchers seem to be increasingly focussed on the importance of socio-environmental factors. However, there appears to be relatively little research specific to CYP in this area. Whilst the current research has methodological limitations, the consistency with which themes were reported means that attention should be directed to alleviating potential barriers.

#### **2.5.4. Theme 4 – Research that adopt novel qualitative research methodologies focussed on promoting the voice of individuals with cerebral palsy**

This theme focusses on novel research methodologies that move away from post-positivist approaches and medical-based models. The articles in *Table 2.5.4* focus on the experiences of people with CP, as well as the families and professionals that support them, using qualitative research methods.

<b>Author(s)</b>	<b>Title of article</b>	<b>Date of Publication</b>	<b>Country of origin</b>
Shikako-Thomas, Lach, Majnemer, Nimigon, Cameron & Shevell	<i>Quality of Life from the Perspective of Adolescents with Cerebral Palsy: ‘I Just Think I’m a Normal Kid, I Just Happen to Have a Disability’</i>	2009	Canada
Flad, Berger & Feucht	<i>“Can You Hear Me Now? Augmentative Communication, Methodological Empowerment, and the Life Story of Jon Feucht</i>	2011	United States of America
Munger	<i>Telling a Different Story: Marginality and Empowerment in The Lives of Adults with Cerebral Palsy</i>	2011 (Doctorate thesis)	United States of America
Stasolla, Caffo, Picucci & Bosco	<i>Assistive technology for promoting choice behaviours in three children with Cerebral Palsy and severe communication impairments</i>	2013	Italy

**Table 2.5.4: Research articles that adopt novel qualitative research methodologies focussed on promoting the voice of individuals with cerebral palsy.**

##### **2.5.4.1. Important factors related to quality of life from the perspectives of children and young people with cerebral palsy**

Due to the need to gain the perspectives of children, adolescents, and adults with CP, research has attempted to adopt and implement increasingly novel qualitative research methodologies that capture detailed experiences. A qualitative study conducted by Shikako-Thomas et al. (2009) obtained the perspectives of adolescents with CP focusing on factors that positively or negatively influence their QoL. A purposive sample of 12 adolescents (aged 12 – 16) provided accounts of the ‘*intrinsic*’ and ‘*extrinsic*’ attributes that made a difference in their QoL. In the context of this research intrinsic attributes were broadly defined as child-related factors, whereas extrinsic attributes were socio-environmental factors.

Following a constructivist grounded theory approach to data collection, narratives were coded into categories and themes. A variety of factors such as friends or family, as well as the home and school settings, highlighted the socio-environment influences in the CYP’s perception of QoL. For instance, adolescents articulated that the school environment plays an important role as a place to socialise and make friends. School is also a setting in which individual personality

traits and intrinsic strengths, such as mastery and motivation to engage in activities, are developed. Both '*mainstream*' and '*specialist*' school environments had advantages and disadvantages. Specialist environments were more protective, with CYP facing less challenges and benefitting from more accommodations to meet their needs. However, mainstream environments provided more opportunities for the development of SA and intrinsic strengths. Indeed, one potential area of concern for those in specialist settings is that the CYP with high QoL spoke about situations they found challenging, but had developed a strategy to overcome by advocating for their rights.

Important intrinsic factors included how they were perceived by others, which also impacted their self-image. CYP who expressed comfort with their abilities and the challenges they encountered generally expressed a positive QoL. In general, adolescents demonstrated that when they were aware of their strengths and limitations, they could have a better perspective on their lives and benefit from better experiences.

Several themes also involved a dynamic interplay between intrinsic and extrinsic factors. A vital aspect of this interaction between the external environment and internal reflections was the ability to pursue preferences. Being able to do the activities of their choice, with the people they preferred, was presented by Shikako-Thomas et al. (2009) as crucial for adolescent '*well-being*'. For higher levels of QoL it appears fundamental that YPCP are able to pursue and participate in a broad range of activities of individual interest and engage in activities of their choosing. However, this ability was often hindered by environmental factors including a lack of accessibility or lack of opportunities. Good ratings of QoL were associated with the '*availability of resources*' that promoted '*participation*'.

Shikako-Thomas et al. (2009) conclude that there is a gap between the understanding of the inter-related nature of intrinsic and extrinsic factors, as well as the translation of that knowledge to actual real-world practice. They reflect that the scope of interventions needs to be broadened beyond mobility, self-care and other functional domains in order to promote participation in preferred activities, with the aim of increasing the QoL for a YPCP. This study also suggests that there are many potentially modifiable attributes that could help to promote health and well-being. In particular, professionals should assume a more significant role in advocating for better access to, and involvement in, different activities in a variety of environments.

Munger (2011) recognized the lack of emancipatory disability research in this area with a qualitative, phenomenological exploration into the social and psychosocial experiences of adults with CP. This research sought to explore how stigma impacted the personal identity, as well as the social and psychological well-being, of individuals with CP believed to have significant implications for QoL. 12 individuals with CP aged 26 – 49 completed two individual interviews and participated in a ‘virtual focus group’. The first interview focussed on their social experiences and interactions with others. The second interview focussed more towards personal identity and psychological well-being.

Most participants described instances of being treated differently or of feeling stigmatized. Many felt that they struggled for control, not only over their physical difficulties but to also define and maintain their own identities, in a culture that devalues disability. The findings have significant implications for researchers and professionals who are concerned with the overall well-being of YP and adults with CP. As more individuals with CP are becoming integrated into mainstream society, it is important to consider not only their physical health but also the factors that can elevate participation, improve psychosocial health, promote general well-being, and increase QoL. Munger (2011) concludes that there should be an increased focus to remove social barriers, facilitate interpersonal relationships, and build disability identity within research paradigms.

#### ***2.5.4.2.Promoting the voice of people with CP using assistive technology and qualitative methods***

Rapid advances in technology during the 21<sup>st</sup> Century has resulted in the promotion of communication skills for some individuals with CP. This has enabled increased opportunities to express choices and promote self-determination. For example, a technology-based program (Stasolla, Caffo, Picucci and Bosco, 2013) in Italy, promoted independent choice behaviours for three children with CP using assistive technology. The findings indicated increased levels of engagement and happiness as a result of the intervention. The conclusion is that programs that enable CYP to make choices with adapted technology, such as a specialised mouse that reduces the impact of fine-motor impairments, may be invaluable. Stasolla et al. (2013) believe that the availability of these kind of programs could mark a significant change for these children, shifting them from a position of relative passivity, to a condition of self-determination and personal control. They highlight that ‘*individual differences*’ and ‘*personal factors*’, such as severity of motor impairments or intellectual disability, could impact access to technologies for some



individuals. Therefore, future research needs to investigate new opportunities and solutions of more accessible assistive technology and adaptations that might help increase participation.

Stasolla et al. (2013) speculate that promoting opportunities for self-determination might allow children with CP to improve their social image. There may also be additional implications for participation, engagement and enjoyment if individuals have increased opportunities to make choices independently. Three key suggestions are noted for future research: Technologies need to be developed to make them easier to use within home and educational contexts; adopting a preference check procedure can verify the participant's satisfaction on the usability of technologies; and validating adaptations with parents, caregivers and professionals can help determine the impact of the technologies.

The final article in the literature review adopted a social model of disability to champion methodologies that are undertaken on behalf of, and to empower, research participants (Flad, Berger & Feucht, 2011). In the context of disability studies, particularly in the UK, this approach has been framed as the practice of '*emancipatory research*' (see Chapter 1.5), which aims to give a voice to those marginalised by society. They abandon the post-positivist ideal of adopting a role that is removed from the experience being observed. Rather, this research methodology strives for an empathetic and intersubjective understanding between scholarly researchers and the individuals with whom they collaborate to produce empirical knowledge, embracing the researchers' subjectivity in the research process. The authors argue that this approach makes experiences more accessible to professionals so that they can help to facilitate equal access to opportunities, which Flad et al. (2011) describe as '*methodological empowerment*.'

The research conducted by Flad et al. (2011) was part of an ongoing life history project with an individual with CP named Jon Feucht. This paper reports Jon's thoughts and experiences about augmentative communication but it also explores some of the challenges and opportunities that researchers may potentially encounter when conducting collaborative research alongside participants. The adoption of alternative research methods such as this require unconventional techniques, such as self-reflective practice, to determine how the researchers are situated within the design. The production of new knowledge, firmly rooted in experience and located in sociological context, requires clear goals regarding the process of the research. Furthermore, committing to an epistemological stance of co-producing knowledge between researchers and 'informants' requires an ongoing assessment of the process of research production.

Flad et al. (2011) state that the ability of researchers to recruit and empower agentive actors to transform social structures that constrain the lives of people with disabilities can be further facilitated by advances in augmentative and alternative communication (AAC) devices and innovative technologies. They conclude that by empowering participants to be able to share their experiences, researchers are also able to reveal their own, situated within their individual professional discourse. This is a research journey that they argue leads to methodological empowerment, where the researcher's primary obligation should always be to the people studied.

#### ***2.5.4.3. Conclusions from Theme 4***

Participation is fundamental for healthy development and QoL, yet very little is known about factors that influence outcomes for YPCP, as there is a distinct lack of emancipatory approaches in this area of research. YPCP commonly report instances of being treated differently, or of feeling stigmatized. Many feel that they struggle for control, not only over their physical difficulties, but also to define and maintain their own identities, in a culture that devalues disability.

There appears to be a range of socio-environmental factors that influence YP's perception of QoL. School settings and support services in general appear to be of extreme importance for QoL, as these are places where individuals with CP can experience a series of preferred activities without major external barriers. Furthermore, these environments have an important role for developing social skills and making friends. There also appears to be a dynamic interplay between intrinsic and extrinsic factors. A vital aspect of this interaction between the external environment and internal reflections is the ability to pursue preferences. Being able to do activities of their choice is crucial for YPs 'well-being'. However, this ability is often hindered by environmental factors, including a lack of accessibility or opportunities. There is also a gap between the understanding of the inter-related nature of intrinsic and extrinsic factors, as well as the translation of that knowledge to actual real-world practice. The scope of interventions needs to be broadened in order to promote participation in preferred activities, with the aim of increasing the QoL for YPCP. Generally, good ratings of QoL are associated with the access to resources that promote participation. Therefore, professionals should also assume a greater role in increasing accessibility and promoting opportunities to achieve this.

The research emphasises the importance of appreciating the perspectives of individuals with CP about their QoL. This has significant implications for researchers and professionals who are

concerned with the overall well-being of YPCP. It appears important to consider not only their physical health, but also factors that can elevate participation, improve psychosocial health, promote general well-being, and increase QoL. This should focus on removing social barriers, facilitating interpersonal relationships, and building disability identity within research paradigms.

Rapid advances in technology during the 21<sup>st</sup> Century have resulted in the promotion of communication for some individuals with CP. This has enabled increased opportunities to express choices to achieve self-determination. Furthermore, technology-based programs, and tailored input devices, seem to be beneficial for promoting engagement. Refining these interventions could be beneficial for increasing participation and promoting personal control. Research should, therefore, address and investigate new opportunities and solutions for more accessible assistive technology. This may lead to increased opportunities for participation, engagement, and opportunities to make choices independently. Three key suggestions have been noted for future research: upgrading technologies to make them easier to use within home and educational contexts; adopting a preference check procedure to verify the participant's satisfaction on the usability of those technologies; validating adaptations with parents, caregivers and professionals to determine their opinions of the technologies and their impact. Furthermore, Researchers argue that the increased adoption of a social model of disability promotes the argument that research should be undertaken on behalf of participants, with the goal of empowering those participants.

## **2.6. *Research questions***

Taking the values of the researcher into account, as well as the findings and conclusions of the literature review, led to the development of four primary research questions:

- What are the potential benefits for young people with cerebral palsy being able to access multimedia self-advocacy tools?
- What are the challenges of using multimedia self-advocacy tools with young people with cerebral palsy and what barriers must they overcome to be able to self-advocate effectively?

- What adaptations to professional practice are necessary to facilitate the participation of young people with cerebral palsy so that they can access multimedia self-advocacy tools?
- What are the implications for my own practice, and other Educational Psychologists, who work with and conduct research with individuals presenting similar impairments or needs?

## **2.7. *Summary of chapter***

This chapter has reviewed research in this area using a systematic approach. 19 relevant articles were explored with key findings and observations used to inform the direction and focus of the current piece of research. Four research questions have been outlined. The next chapter provides details of the Methodology (*Chapter 3*).

## **Chapter 3: Methodology**

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### **3.1. *Introduction to chapter***

This chapter briefly revisits the considerations, principles and values that directed the research design. An overview of the research design is provided with in depth discussions of the ontology, epistemology and axiology. Justifications and reasoning for decisions are provided, as well as explanations of how these concepts appear to complement one another in relation to the research. An outline of the procedure and action research cycles is provided. The concept of active participation is revisited as well as how this was assessed during the research process using an adapted ladder of participation framework. Data collection procedures and analysis for the action research cycles are shared. This is followed by details of the thematic analysis (TA) from the semi-structured interviews with the facilitator(s) and the parent(s)/caregiver(s). Rationale for the selection of participants and a complete summary of the recruitment procedure is provided. There is also a brief explanation for the inclusion of a facilitator and their role within the research design. Finally, ethical considerations are explored including; informed consent, the maintenance of confidentiality and anonymity, data protection, as well as the additional safeguarding measures that were implemented for the protection of the YP and the researcher.

### **3.2. *Considerations, values and principles that underpin research design***

In the previous chapter, the literature review highlighted that research in this area almost exclusively adopts traditional research methods, reflecting a medical model of disability. It has tended to be quantitative or employs close-ended questions or hypotheses. There is a distinct lack of qualitative case studies, particularly in the age range and specific topic area(s) that the current research investigates. Furthermore, there is an absence of research that focusses on the topic of SA for YPCP. In addition, there appears to be no prior research that has explored the use of MMSA tools exclusively with YPCP at any developmental stage or age.

Due to the lack of previous research in this area, and the novel research techniques and methods that are adopted, the current research is fundamentally exploratory in design. As mentioned in *chapters 1.4; 1.5 & 1.6*, it was important to adhere to my core values so that the research design emanated from an emancipatory orientation (Kemmis & Wilkinson, 1998), and encapsulated the principles of disability AR (Oliver, 1992).

### **3.3. *Overview of research design***

#### **3.3.1. *Ontology and philosophical stance***

The ontology of research explores how the researcher views knowledge (Creswell, 2003). The researcher holds a set of values that lean towards a social constructionist paradigm and tends to adopt this stance whilst training as an EP. It is important, however, to acknowledge that within the prevailing context this could be considered inappropriate, since medical practitioners still ‘diagnose’ individuals with CP due to certain characteristics or traits they exhibit, regardless of whether an individual (or whole groups within society) refuse to recognise such labels. Research in this area has tended to be framed using quantitative designs, thereby purporting the post-positivist worldview where there is a notion of absolute truth of knowledge that can be captured and measured objectively. Consequently, it was necessary to recognise these factors and position the research from a critical realist perspective.

Critical realism is often viewed as being positioned centrally in a continuum, with positivist stances at one end of the spectrum and social constructionism at the other end. Critical realism can be argued to incorporate elements of both positivist and social constructionist paradigms. For instance, it accommodates reality or truth, similar to a positivist viewpoint. However, it also purports that the context of the situation, as well as the individuals who are involved, will inevitably impact how the reality or truth is viewed and understood.

This research assumes that there is a shared truth, or reality, to several of the concepts explored including SA, responsible and ethical professional practice, and institutionalised power imbalances. Furthermore, it is assumed that the individual differences of the YP in this research, such as their abilities, difficulties or needs and unique personalities, impacted the practice of the researcher, and the subsequent steps taken to empower them.

#### **3.3.2. *Epistemology and theoretical approach***

Methodologies refer to the way in which research is undertaken, and the epistemology of research explores questions including, ‘who can supply the answers to the questions that are being sought?’ (McNiff & Whitehead, 2011). As the researcher adopted a critical realist approach for the ontology, it seemed logical to adopt an epistemological and theoretical approach that complemented this reality. Given the factors discussed in *Chapters 1.4; 1.5; 1.6 & 3.2*, as well as the research aims and questions in *Chapters 1.7 & 2.2*, AR appeared to be an appropriate methodology. Indeed, the methodology of AR was initially developed from the theoretical assumptions of critical-realism (McNiff & Whitehead, 2011). They have also argued

that a critical-realist view highlights the importance of understanding a situation before it can be changed. AR seems to complement this assertion as within AR, the researchers, “*do not look for a fixed outcome that can be applied everywhere*” (McNiff & Whitehead, 2011, p32).

AR does not look to study other people but rather focuses on personal accountability in order to improve practice (McNiff & Whitehead, 2011). As such, the epistemology was guided by the fact that the object of the enquiry was the development of personal practice in an attempt to promote opportunities for YPCP to self-advocate using MMSA tools. Knowledge was gained by working with a sample of YPCP alongside a facilitator who had experience of working with these YP. AR methodology offered the opportunity to work co-operatively with the YP and the facilitator on this research journey. Feedback from the participants, in addition to discussions with the facilitator, were used to evaluate and develop adaptations to practice. This was further facilitated by a ladder of participation (Hart, 1992) to provide a more formalised and structured method of assessment (*see chapter 3.5*).

The production of new knowledge, firmly rooted in experience and located in sociological context, required clear goals shared by all the stakeholders in the research (Flad et al. 2011). AR seeks to promote participant power and encourages a research partnership towards building better ways of working (McNiff & Whitehead, 2011). The research methodology, therefore, strives for an empathetic and intersubjective understanding through a collaborative process to produce empirical knowledge, which embraces, rather than eschews, subjectivity in the research process (Flad et al. 2011). It was not the intention to take up a spectator or observational approach, but undertake enquiries with others to create ‘*living theories*’ of practice (McNiff & Whitehead, 2011). This approach allowed for in-depth case study reports of individual thoughts and experiences. It also facilitated exploration of some of the challenges and opportunities encountered when conducting collaborative research with these individuals.

To maximise the potential for knowledge acquisition, insight from the parent/carer(s) of the YP involved in the research was obtained via interviews. This information was further supplemented with interviews with the facilitator(s). The interviews were analysed using TA and were used to triangulate or augment findings from the AR process.

### **3.3.3. *Axiology and positioning of the researcher***

When conducting research there are variations in the researcher’s position and what he/she bring to the research in terms of his/her own personal knowledge, values and assumptions. This is

known as axiology and is influenced by the philosophical paradigm that the researcher adopts (Matthews, 2003). When undertaking research from a critical realist ontology, as is this case in this instance, it is particularly important to acknowledge inherent assumptions within the research design and McNiff and Whitehead (2011) state that:

- Knowledge creation is an uncertain and subjective enterprise
- Answers to questions should be sought through negotiation with others
- Knowledge is the property of individuals and is thus biased and subjective

Critical realist positions emphasise the importance of an individual's impact on the way reality is viewed, the clarification and expression of the researcher's position is important. The researcher has already expressed his personal views in *chapters 1.5 & 1.6*, highlighting the values and influences that could have led to bias. The researcher adopted the social model of disability to challenge traditional power imbalances, which all too often disempower individuals with disabilities or limit their ability to self-advocate. The values that stem from these issues are professional development, power of the participants, and equal opportunities.

The researcher has past experiences of supporting CYP with a range of physical and intellectual impairments in several contexts. Employment within a SEN school, developed an awareness of barriers that often act to disable individuals, as well as the skills and strategies to overcome these challenges. Volunteering for over a decade with MENCAP, resulted in an ability to form trusting relationships with YP and their families, as well as developing the ability to perceive situations, and individuals, as unique. It highlighted that institutions and systems often disenfranchised, or acted to disempower, YP and their families. Furthermore, institutions and wider society in general, did not always provide the skilled professionals or necessary support systems to meet their needs effectively. This compounded impairments in a manner consistent with the social model of disability (*see Chapter 1.2.3*). Working within EPS(s) as a trainee EP has provided insight for different techniques and approaches that are used to support CYP with a range of physical, psychological and learning difficulties.

This research draws upon all these experiences of working within specialist provisions and combines it with knowledge acquired during study towards a Professional Doctorate in Educational Psychology to support YPCP access to emerging MMSA tools. The research assumes that YPCP face challenges to effectively self-advocate within a broad spectrum of

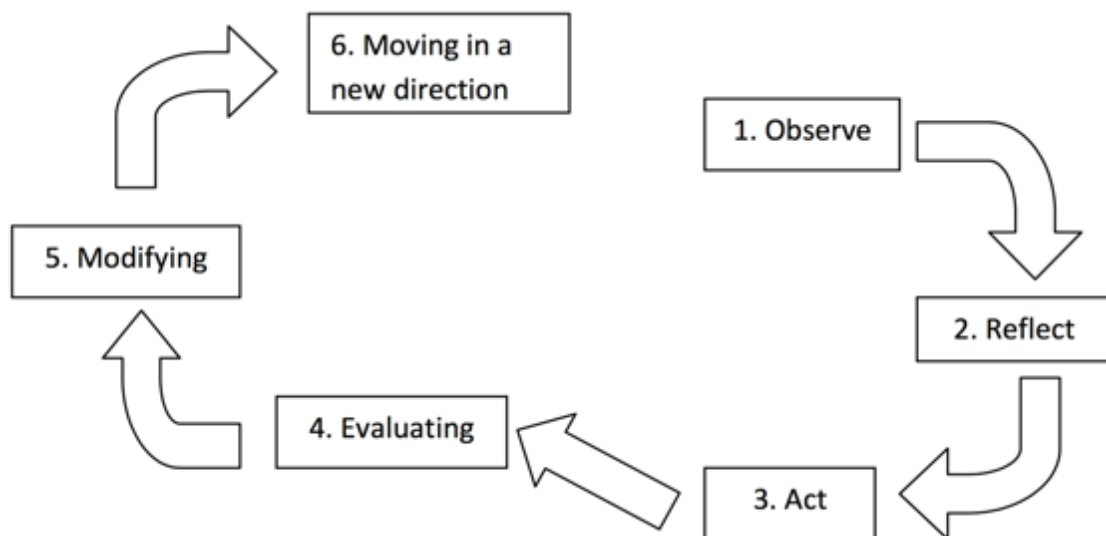


need(s). It also assumes that novel tools, such as wiki-pages, are valid and beneficial for promoting SA in YPCP.

Taking up a critical-realist position created an increased awareness of how the researcher's values and knowledge potentially influenced interactions throughout the research process. The adoption of alternative research methods, therefore, required unconventional techniques, such as self-reflective practice, to determine how the researcher was situated within the design (Flad et. al., 2011). For this reason a research journal (*see Appendix B*) was utilised to inform the detailed reflections provided in *Chapter 4*. The researcher was mindful of his position as an active agent and reflected on how this was acknowledged and managed during the research. How the researcher interacted with the participants, as well as the facilitator, inevitably impacted the focus and outcomes of the research. Committing to an epistemological stance of co-producing knowledge also required continual reflections of how knowledge was generated. Furthermore, the interpretation of any social phenomenon needs to consider personal agency and social structure, as well as the dynamic interplay between the two (Shikako-Thomas et al., 2012). Consequently, reflections tended to focus on revisiting mutual goals for the research and the effective management of power dynamics that manifest in research.

### **3.4. Action research methodology and action research cycles**

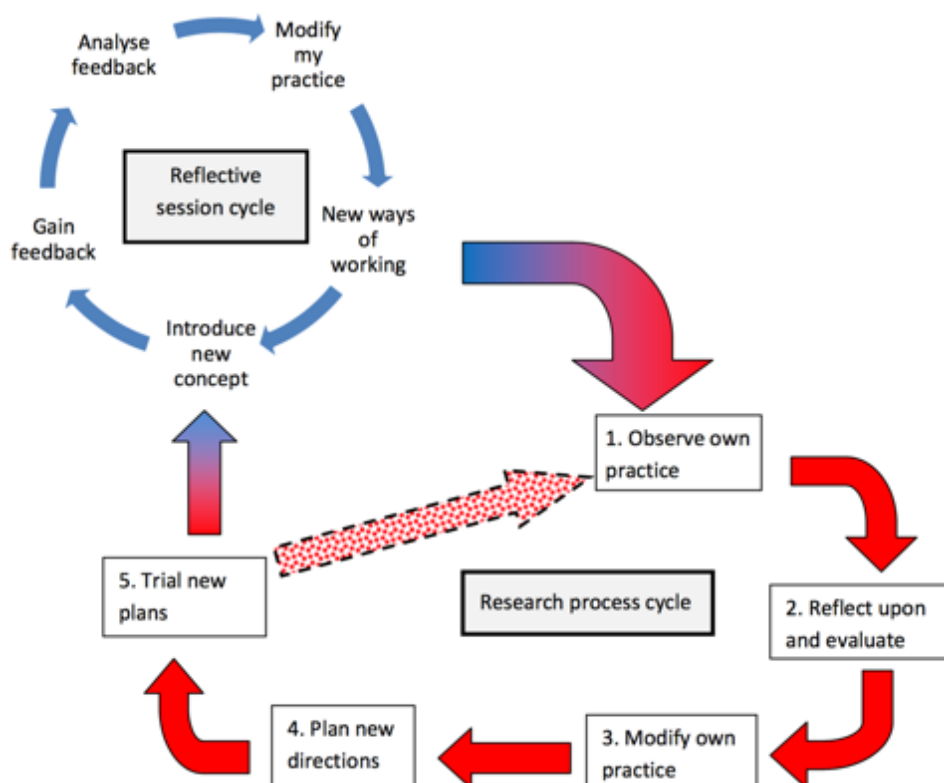
AR typically follows a cyclical process, which is commonly known as the '*Action-Reflection Cycle*' (McNiff & Whitehead, 2011, p.10). This cycle is a continual process, with a set structure of phases that include; observing, reflecting, acting, evaluating, modifying, and moving in new directions. This structured process is represented in *Figure 3.4*.



**Figure 3.4: Action-reflection cycle. Adapted from McNiff & Whitehead (2011).**

On further examination, it was felt that the cyclical model developed by McNiff and Whitehead (2011) was not appropriate to manage the complexity of the research design, as well as the challenges that working with the individuals in the research presented. Adaptations were made to represent the multiple cycles and levels that were required. These changes were inspired by a colleague in the EPS and a former trainee at the University of East London (UEL). Laura Barton (2015) developed an additional layer to the cyclical model design, resulting in two layers (see *Figure 3.4.1*). This dual layer of interacting cyclical models facilitates the progression of knowledge of the practitioner in addition to supporting developments in the research process. Furthermore, the dual-layer model supports the flexible nature of practice-based research, whilst accommodating the research design and the complex needs of the individuals involved in the research.

The initial cycle develops through the research process, similar to that suggested by McNiff & Whitehead (2011). This was repeated six times to coincide with each wiki-page session with the YP. In addition to this model of the research process, there is a reflective model that occurs within each of the individual wiki-page sessions. This captured the complexity and nuances of adaptations during the sessions themselves. The researcher also reflected upon the practice of the facilitator, as well as encouraging them to do the same. This was often a collaborative process to reduce or eliminate potential power imbalances.



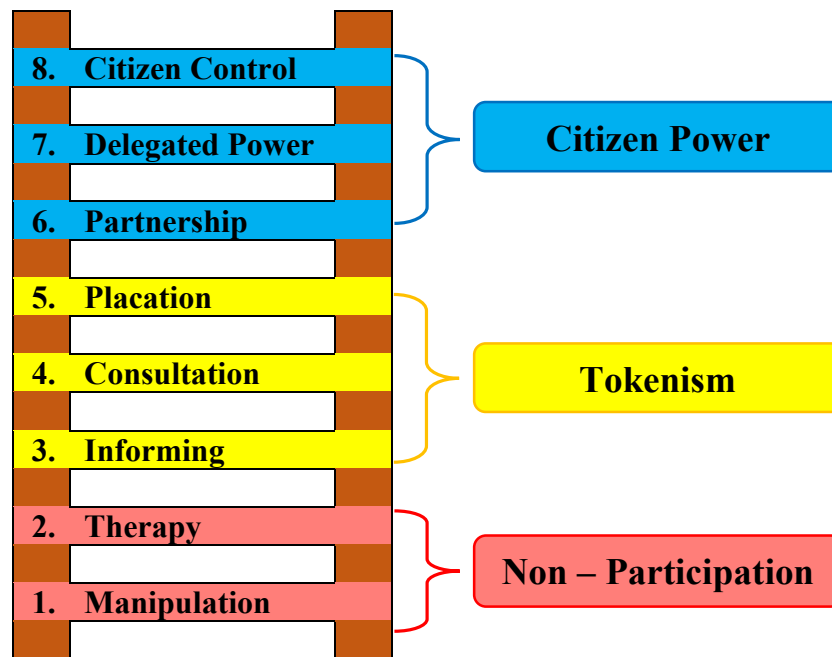
**Figure 3.4.1: Representation of the dual layer cyclical models as adapted from Barton (2015).**

### 3.5. *Adapted ladder of participation*

According to Klein (2003) YP with SEN are a marginalised group and are often excluded from basic decision-making processes (Klein, 2003). Contradictory to legislation and good EP practice (*see chapters 1.3.1 & 1.3.2*), all too often their voices are overwhelmed by the views of their parents, or incorrectly interpreted by the professionals working with them. Jelly, Fuller and Byers (2000) suggest that active participation teaches thinking skills, which in turn can increase learning and raise self-esteem. Increasing learning and self-esteem are benefits which educational professionals should be supporting and attempting to foster in young people, particularly those with SEN who are at increased risk of marginalisation. It was therefore important when designing the methodology that the YP were involved in the decision-making processes, as well as undertaking an active role in the creation of their wiki-pages.

Lewin (1946) believed that AR could raise the self-esteem of minority groups by providing them with equality and independence through cooperation. Following an AR methodology allowed the researcher to work with the YP in a collaborative manner. The researcher did not envisage this being ‘*tokenistic*’. The aim was to assist the YP to develop feelings of control, autonomy, and ownership over their wiki-pages. It was imperative not only to respect the YP who were involved, but also to adhere to the values of active participation that would provide increased opportunities for them to self-advocate during the wiki-page sessions. The use of an AR design encouraged the YP to participate actively, not only in the creation of their wiki-pages, but also in development of strategies, techniques and adaptations that were implemented. The researcher promoted active involvement through a process of feedback, assessing this within a framework known as the ‘*ladder of participation*’ (Hart, 1992).

Arnstein (1969) developed an eight-rung ladder designed to represent the hierarchy of participation (*see Figure 3.5*). The ladder begins with ‘*manipulation*’ and rises through to ‘*citizen control*’. According to Arnstein, the bottom two rungs are actually ‘*non-participation*’. Rungs 3 – 5 are degrees of participation that represent ‘*tokenism*’, whilst rungs 6 – 8 are degrees that represent ‘*citizen power*’.



**Figure 3.5: Ladder of participation. Adapted from Arnstein (1969).**

The model was initially created in clinical therapeutic settings. Whilst the current piece of research is not therapy based, it provides a useful framework. A revised ladder of participation adopted by Hart (1992), however, appeared to be more appropriate as a measurement tool for this research (see Figure 3.5.1). Developed for The United Nations Children's Fund (UNICEF), it emphasises ‘degrees of participation’ and operates according to an eight-rung hierarchy:

**Rung 1 – Manipulation:** Activities or decision-making processes are adult-led, in which youth do as directed without understanding of the purpose of the activities or decisions being made.

**Rung 2 – Decoration:** Activities or decision-making processes are adult-led, in which youth understand the purpose, but have no input as to how they are planned.

**Rung 3 – Tokenism:** Activities or decision-making processes are adult-led in which youth may be consulted with minimal opportunities to feedback.

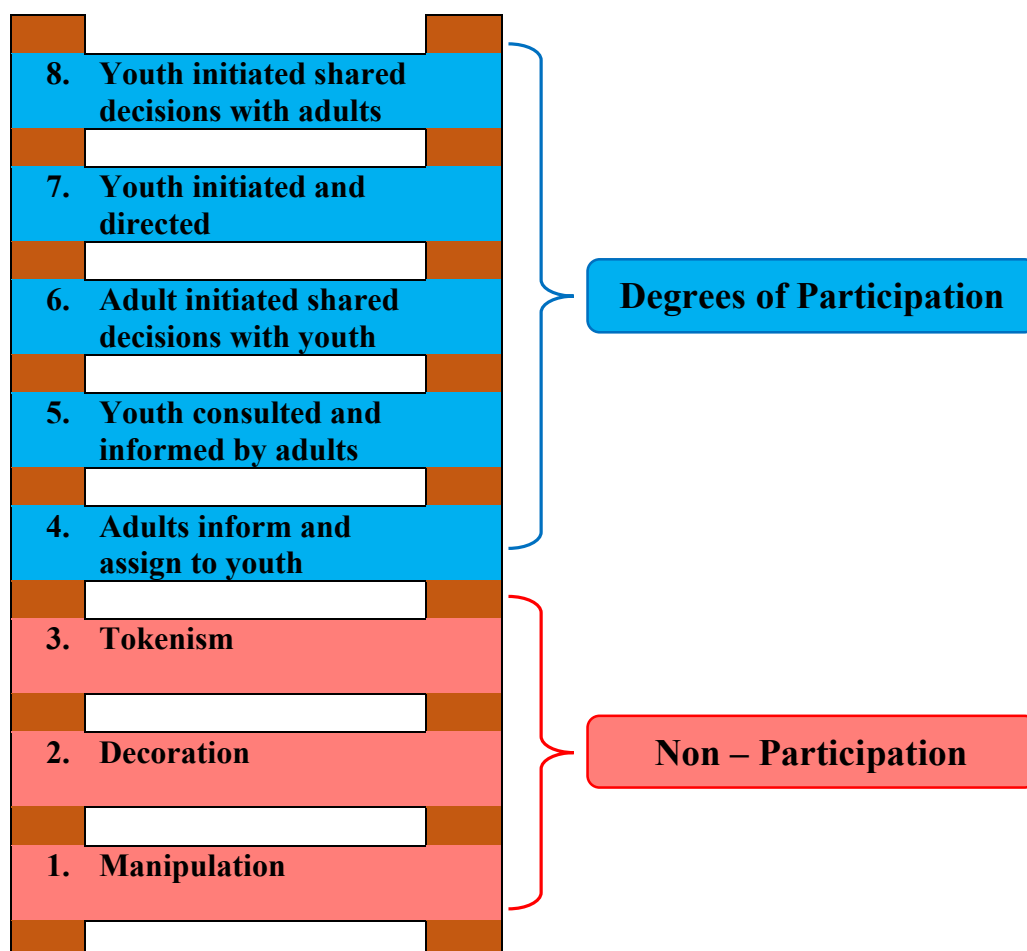
**Rung 4 – Adults assign and inform to youth:** Activities are adult-led, in which youth undertake a role after understanding the purpose and decision-making processes.

**Rung 5 – Youth consulted and informed by adults:** Activities are adult-led, in which youth are consulted and informed about how their input will be used in the outcomes of decisions.

**Rung 6 – Adult initiated shared decisions with youth:** Activities are adult-led, in which decision-making is shared with youth.

**Rung 7 – Youth initiated and directed:** Activities are youth-led with little input from adults.

**Rung 8 – Youth initiated shared decisions with adults:** Activities are youth-led, in which decision-making is shared between youth and adults working as equal partners.



**Figure 3.5.1: Ladder of participation. Adapted from Hart (1992).**

Although initially developed to consider how CYP can participate in community development, environmental care and urban design, it has been used in a range of contexts by professionals seeking to work collaboratively with CYP. As the purpose of the research was to work with the YP in partnership, this model was deemed to be appropriate and was used to assess the YP's active participation in decision-making processes, in addition to their ability to access the wiki-page platform during the sessions.

### **3.6. Data collection and analysis procedures**

#### **3.6.1. Action research**

As previously discussed in *Chapters 1.4; 1.4.1 & 3.3.2*, AR methodology complements this exploratory research. Within AR cycle, data is continually collected and acted upon and hypotheses generated, tested and adapted. The data collection and analysis process are evident throughout the entire research and not viewed as separate events. Feedback from the participants, as well as the facilitator, was analysed and used to adapt practice as it was received. The identification of barriers or challenges and the subsequent solutions developed to overcome them are therefore the basis of the data set. This is in line with Lewin (1946).

The data was collected in a variety of forms. Video footage of the individual sessions with the YP provided a rich and detailed account of what happened, as well as how new ways of working together developed, including adaptations to professional practice. With the purpose of the AR being the development of my own practice, another source of data was from the reflective journal. In this journal, points of interest, developments in practice as well as discoveries were documented. These reflections are evident in each of the three individual case studies when reporting the AR process (see *Chapter 4*).

#### **3.6.2. Semi-structured interviews**

A final source of data was individual interviews. Separate, semi-structured interviews, were conducted with the facilitator(s), the parent(s)/carer(s), and one participant. The interviews were conducted after the conclusion of the AR cycles. They were audio-tape recorded and transcribed as part of the thematic analysis. This data was used to triangulate findings from the AR and evaluate the impact of the research, as well as providing insight for developing professional practice in the future. In addition, the interview process was another opportunity to develop EP techniques, with questions and prompts skilfully employed. Further details of the interview process, TA and findings are outlined in *Chapter 4*.

#### **3.6.3. Thematic analysis**

Generally, TA is the most widely used qualitative approach for analysing interviews. According to Braun and Clarke (2006), TA is a way of identifying, reporting and analysing complex data into themes. Indeed, it has been suggested that TA is useful for exploring complex, multidisciplinary phenomena, and probably the only way to begin thoughtful inquiry. Overall, this research seeks to describe the people in the context of their experience during an event, and TA helps to make that description clearer and potentially more useful to other researchers.

The strategy for developing a codebook and analysing the data from the interviews, primarily adopted an inductive method. Codes were derived from the raw data, which is also known as a data-driven or non-theoretical approach (Braun & Clarke, 2006). This was necessary because there was no previous research in this area, and consequently no theory-driven or prior-research driven codes available applicable to the research design (Boyatzis, 1998). As this is also an exploratory piece of research, which intends to provide insight into several key areas, such as the challenges and potential benefits of using MMSA tools with YPCP, and promoting further knowledge and understanding for potentially similar research projects in the future, there is a deductive element. Due to the aims of the research, as well as the research questions, exploring the potential barriers and challenges of using MMSA tools with YPCP was a central focus. The subsequent adaptations to practice, as well as the potential benefits or applications of MMSA tools, were also of interest.

It was never the intention of the researcher to move into a more interpretative, or latent approach of analysis, but rather to analyse the data at a purely semantic level. This was a primary reason why the researcher did not adopt Interpretative Phenomenological Analysis (IPA). The researcher intended to extract general themes in order to triangulate the findings of the AR, as well as provide insight to other educational practitioners who might be able to generalise these findings to other CYP with similar needs. Whilst, IPA is generally considered to be a methodology rather than a method, TA is generally perceived as a method. This means that there are conceptual differences and other factors that need to be considered when selecting the appropriate analysis technique. This includes the ontological and epistemological underpinnings of the research, as well as the theoretical framework. The researcher chose TA for its flexibility as it can be used across the epistemological and ontological spectrum (Smith, Flowers & Larkin, 2009), whereas IPA requires more specificity (Larkin, Watts & Clifton, 2006). Furthermore, TA can be underpinned by any number of theories, whereas specific theoretical frameworks generally inform IPA research. TA can be also used to address a wide range of research questions, which seemed appropriate for this piece of exploratory research. A final reason that IPA was not adopted is that the individuals recruited did not represent a homogenous sample as their needs were varied and unique. Overall, the researcher felt that TA complemented the research questions by facilitating an investigation of the interview data from two perspectives: first, from a data-driven perspective and a perspective based on coding in an inductive way; second, from the research question perspective to check if the data were

consistent with the research questions and providing sufficient information. Subsequently, six phases of TA advocated by Braun and Clarke (2006) were utilised:

1. Braun and Clarke (2006) refer to the importance of the researcher ‘immersing themselves’ in the data to become thoroughly familiar with the content. The initial phase was to familiarise myself with the interview data collected and the transcription process was an efficient method of achieving this. Braun and Clarke (2006) state that there is no single way of carrying out TA or specific guidelines for transcription. The researcher transcribed verbatim all responses from the audio-recorded interview data. This was purposefully done to maintain the accuracy of the interviewees use of language.
2. According to Braun and Clarke (2006) latent codes identify elements of data of interest to the researcher, and shed light on the research question(s) under investigation. Initial codes were developed after familiarisation with the data set. During this process, the researcher began to code organised data into broad meaningful groups prior to theme generation. Thought was given to the importance of inhibiting, or reducing, the conceptual interference from individual cognitive abilities when formulating concepts Boyatzis (1998). Coding procedures were primarily research question-driven, but also data-driven at the semantic level (Braun & Clarke, 2006). Coding analysis involved using highlighters, coloured pens and ‘post-it’ notes to indicate potential patterns within segments of the data (see *Figures 4.8.3 & 4.8.3.1*).
3. Braun and Clarke (2006) emphasise the need to re-focus the analysis at the broader level of themes, rather than codes. As such, after the initial codes had been generated, the researcher considered how the codes combined to form a general theme. Forming clusters of themes was a useful way to organize the code and organise the array of themes identified (Coffey & Atkinson, 1996). These clusters were also important for the presentation of the findings (Boyatzis, 1998). The themes were organised as independent clusters of themes as well as hierarchical themes where appropriate relationships could be identified (Boyatzis, 1998). Phase 3 culminated in a group of candidate themes and additional sub-themes, and thematic maps were used to provide a visual representation of these (see *Figure 4.8.3.1*).
4. Braun and Clarke (2006) state that, “the need for re-coding from the data set is to be expected as coding is an ongoing organic process” (p. 21). This phase involved two levels of reviewing and refining candidate themes and sub-themes. The first level, consisted of reviewing the coded data extracts. The initial round of coding outlined earlier in phase 2, had intentionally focussed on developing codes, which closely mirrored the raw information in its own



language, form and style to avoid placing personal values on the outcome of the themes. In this stage of re-coding, previous codes were given more detail to provide the researcher with a greater understanding of the themes developed, as well as provide an opportunity to develop further themes that might have initially been overlooked. This is important, as according to Boyatzis (1998), a good thematic code is one that captures the qualitative richness of the phenomenon or something important within the data in relation to the research question(s). In addition, codes were also amended to reflect the ‘language’ that is typically utilised by EPs. Reformulating the codes in this manner provided greater richness, detail and understanding to the data set. This is appropriate for this research as the intentions of inquiry and its communication to others are dependent upon the qualitative ‘depth’ of the thematic information available. The second level, considered the validity of the individual themes in relation to the entire data set. This step ended when the themes generated offered insights, and potential answers to the research questions. This resulted in the production of a candidate thematic map (see *Figure 4.8.3.2*).

5. Defining and naming the themes that were illustrated in the thematic maps was the next step. According to Braun and Clarke (2006) this step should, “identify the essence of what each theme is about and what is interesting about them and why?” (p. 22). Identifying the explicit narrative ensured limited overlap between the themes and sub-themes generated. As emphasised by Braun and Clarke (2006), the themes were made clearly definable and limited to descriptions of no more than two sentences.
6. The final phase involved a summary of the data analysis. The aim of the synopsis was to provide a concise and coherent account of the data. This followed an exclusively qualitative and verbally descriptive method (Boyatzis, 1998).

### **3.7. *Participant details and the context of the educational setting***

#### **3.7.1. *Sampling***

This piece of research was an exploration of the use of wiki-pages with YPCP aged 16 - 25. For this reason, purposive sampling was applied to recruit the appropriate participants. Purposive sampling is based on the knowledge of a population and involves selecting participants on the basis of meeting certain criteria for the purpose of the research (Robson, 2011). The participants that were selected were YP aged 16 – 25 with a diagnosis of CP. The nature of their needs meant that they had all experienced challenges, or barriers, to achieving SA in the past. In addition, all

the YP were located in the same SEN setting in a county in South-East England. There were two female participants aged 18 and 19, and 19-year-old male participant.

### **3.7.2. Recruitment**

1. The researcher approached several educational institutions within a single county of South-East England.
2. Consent and approval was initially given by the educational setting's Head Teacher. This was achieved through a meeting where the details of the purpose of the research, and the nature of the AR design, were discussed. Examples of the proposed information sheet and consent form were also provided (*See Appendices C & D*).
3. Discussions were then held with the safeguarding officer, transition team and proposed facilitator to; identify potential participants, explore ethical considerations, and discuss risk assessment procedures. Due to the diversity of the needs of individuals with CP (as previously outlined in *Chapter 1.2.4*), as well as the intentions of the researcher to develop his practice in meeting the needs of a variety and range of individuals, it was not possible, nor desirable, to obtain a homogenous sample. Instead of recruiting participants based on a specific type of need, the researcher used a broad inclusion criteria that accommodated all YPCP aged 16 – 25. There was no specific search for participants to be situated in either mainstream or SEND settings, however, the three participants involved in the research were situated in the same SEND school.
4. The three participants of the research varied slightly in age, but were all 18 or 19. There were two female participants and one male participant. They exhibited a variety of 'diagnosed' difficulties and needs, which led to a range of cognitive and communication abilities. For this reason, the researcher developed detailed 'pen portraits' to convey to the reader greater context and a rich detailed picture of the individuals' needs and abilities (*See Appendix E*). The needs of the individuals were also explored with the facilitator prior to commencing the research (*See Appendix F*).
5. Separate meetings with the YP and their parent(s)/carer(s) were held to discuss details of the wiki-page platform and data collection procedures. Information sheets and consent forms (*See appendices C & D*) were presented and explained to both the parent(s)/carer(s) and YP

in order to make sure all details of the research were fully understood and communicated prior to informed consent being obtained.

6. Further details of the wiki-pages, and the fact that the YP were free to leave the research at any time, was reiterated at the beginning of every session. This was further facilitated by the use of a wiki-page, which provided details of the research that was accessible at any time (*see Figure 1.2.2*).

### **3.7.3. *Inclusion of a facilitator***

It was agreed in step 3 of the recruitment process that a facilitator would assist the researcher in the educational setting during the wiki-page sessions. The first, and most important purpose, related to safeguarding and child-protection measures (*See Chapter 3.9.2 for further details*). Secondly, the facilitator was someone who was familiar with the young people involved in the research. It was felt she could provide increased insight and understanding due to her extensive knowledge of the participants. Finally, it provided an opportunity for the researcher and facilitator to reflect in a collaborative process when changes, or adaptations, to practice were made. It was the intention to empower the facilitator and provide him/her with knowledge and confidence to ensure that the wiki-pages were maintained and developed after the research process. One of the researcher's aims was to move away from assuming the role of 'expert' and gradually empower the facilitator.

### **3.8. *Reliability and validity***

Golafshani makes a compelling argument that validity and reliability are "rooted in [a] positivist perspective" (2003, p. 597.) and are therefore traditionally used in quantitative research. A vital element of any research design is a consideration of its epistemological and methodological validity and relevance (Mays & Pope, 2005). Indeed, Howitt (2010) purports that in this context validity describes the extent to which something measures what it is designed to measure.

For this research, the data was primarily the ability of the YP to access the wiki-page platform based upon feedback and assessment in relation to the ladder of participation (Hart, 1992). Overall, this was assessed by levels of engagement and active participation in the decision-making processes, and the participants' ability to access their wiki-pages. Much of the analysis of data happened within the individual sessions. This required instant analysis of what the YP were communicating to perform the necessary changes or adaptations to practice. As these adaptations to practice often occurred during the sessions, where supervision was not available,

it was beneficial to discuss these in collaboration with the facilitator. This involved extensive dialogue and checking of strategies/adaptions in a collaborative process to consider their efficacy. The researcher also kept detailed descriptions of each session to ensure transparency when evaluating and modifying stages of the action-reflection cycle (*see Appendix B*). All the sessions were video-recorded, which enabled the researcher to review the sessions at a later date. Any potential misinterpretations were noted and some were revisited with further adaptations to practice in subsequent sessions.

McNiff and Whitehead (2011) state that action researchers need to be open to critique to test the validity of their knowledge claims. As part of the research process supervision was received from peers and a senior EP. To maintain the anonymity of the participants, video recordings could not be reviewed. Instead, extracts were discussed, and the potential range of responses or adaptations to practice, were being considered. In addition, there were several discussions with the facilitator outside of the wiki-page sessions that reflected on previous sessions and the planning of further action for subsequent sessions.

Creswell (2003) refers to reliability measures being less relevant in qualitative research due to the data being bound to that individual social situation. The reflections that were made during the research process, and the intent of interpreting the views and needs of the participants, are appropriate measures of the reliability of this research, and have potential to inform colleagues, who can learn from the creation of this knowledge. Adelman (1993) highlights that AR gives support to the development of powerful resources including; reflective thought, discussion, decision-making, and action. By adhering to these principles, the research produced can be deemed credible and valid. For instance, the research journal kept record of the relevant issues, which could potentially impact the dependability of the research. Confirmability, or ‘check-back’ strategies, were utilised to limit the effects of researcher bias and there was also collaborative work with the facilitator to gain an alternative perspective.

The qualitative criteria for judging trustworthiness also considers credibility, and transferability (Mertens, 2010). Credibility was adhered to by the range of appropriate methods of data collection. This process included an audit-type analysis where peers checked the procedures used, and looked for instances that might first invalidate, but ultimately potentially strengthen the TA. This also helped to create what McNiff and Whitehead (2011) describe as construct-validity, where the researcher utilised multiple methods of confirming that their own constructs were not imposed on the data being collected. Further details of how this was achieved is provided in *Chapter 4*. Due to the aims of the research, and the subsequent research design,

there was no intention of enabling the procedures to be transferable to other contexts. McNiff and Whitehead (2011) state that research led by practice is only true of that particular situation, with those particular participants. It is not an expectation that the findings of the research are generalisable to other situations or groups of people. It is plausible, however, that wiki-pages could be used in other contexts and with individuals with different needs in the future.

Further evidence of validity considers recommendations made by McNiff and Whitehead (2011). Due to the ideological nature of the research, and the underpinning emancipatory values (see *Chapters 1.5 & 1.6*), its validity can be judged according to its capacity to liberate people. Indeed, the use of catalytic validity provides evidence that the participants moved towards new, more productive positions, with increased involvement in the wiki-page creation process. Ironic validity was also used to demonstrate that the qualitative interview process and rigorous TA provided an investigation of the underlying assumptions behind the participants' experiences (McNiff & Whitehead, 2011). Finally, rhizomatic validity was used to highlight the interconnected nature of human enquiry, with an emphasis on the multiple directions of influence that the research process may have had on the young people, their families, the researcher and facilitator, as well as wider systems (McNiff & Whitehead, 2011). Overall, it is fair to state that this qualitative research achieves a high-level of ecological validity, with arguably some cost to reliability associated with traditional post-positivist research paradigms (Kirk & Miller, 1986).

### **3.9. *Ethical considerations***

It was imperative to ensure that the research was conducted in an ethical manner that protected and respected the rights of the participants and their families. When planning, and undertaking, this research both the 'Standards of Conduct, Performance and Ethics (Health and Care Professionals Council, 2008) and the British Psychological Society (BPS) 'Code of Ethics and Conduct' (BPS, 2009) were adhered to.

The main areas of ethical consideration for this research were:

- Informed consent
- Anonymity
- Confidentiality
- Secure data storage

### **3.9.1. *Informed consent***

The participants in this study were defined by the BPS (1993; 2010) as a vulnerable group when considering the issue of informed consent due to the nature of the educational setting and the potential for lack of understanding. As such, it was crucial to obtain freely volunteered informed consent before any of the YP were referred to the research. Information sheets and consent forms that were distributed to schools and colleges, parent(s)/carer(s) and the YP were approved by the UEL Ethics Board (*see Appendix G*).

Initial approaches were to the Head Teacher of the educational setting, and the safeguarding officer, to ask permission to undertake research within the school. Only once consent was gained for the research to be conducted within the educational setting, were potential participants discussed.

Letters were then distributed to parent(s)/carer(s) containing information sheets about the research (*see Appendix C*). These clearly explained the purpose and process of the research, as well as outlining the data collection process, highlighting the use of a video camera. During this time the parent(s)/carer(s) were able to contact the researcher to discuss any queries they had and some of them took this opportunity. In addition, the researcher created a wiki-page that they could access (*see figure 1.2.2*). This was specifically created to help contextualise the nature and purpose of the wiki-pages as well as providing further information about the research and the researcher. Informed consent was gained from parent(s)/carer(s) prior to meeting YP involved in the research (*See Appendix D*).

Once the consent of parent(s)/carer(s) was gained, the researcher needed to ensure that the YP themselves understood what the research was aiming to achieve and what would be expected of them if they participated. Due to their age (adult legal status), as well as the prevailing value of promoting SA, they were provided with an adapted consent form and information sheet so that they could provide their individual informed consent (*see Appendices J & K*). These were signed in the presence of parent(s)/caregiver(s). The information sheet and consent letter were also read to the YP before they took part. Any technical vocabulary was explained and clarification of details were carefully discussed using the specialised information sheet. This sheet had more visual aspects to promote understanding and simple language. They were given substantial time to digest this information, as well as opportunities to ask any questions that they had. It was clearly explained that they were free to leave the study at any time, with the use of role-play to ensure that this important point was fully understood and communicated.

### **3.9.2. Confidentiality and anonymity**

The confidentiality, and anonymity, parameters for the research were made explicit to all involved before informed consent was gained. This included consideration of potential child protection disclosures and situations where confidentiality might have to be breached. It was made clear that the researcher would assume responsibility for taking the necessary steps to protect the YP, if during the research information was disclosed that indicated that the young person was ‘at risk of significant harm’ (BPS, 2010). Procedures for this were discussed with the educational school safeguarding officer, the facilitator and parent(s)/carer(s) prior to the commencement of the research. Pseudonyms were used to ensure anonymity of the participants and these were selected so that they were relevant to the context of the research. An effort was made to ensure that the pseudonyms reflected the cultural background of the participants to limit preconceptions or impressions being drawn by the audience. Anonymity was also maintained by not naming the educational setting. Consideration was also given when describing the context and location of the research.

### **3.9.3. Data protection**

With the use of video data, additional protection measures were required to ensure the research adhered to The Data Protection Act (Great Britain, 1998). The information sheet provides an in-depth account of how data was stored and treated (*see Appendix C*). There were some adaptations that had to be made during the research process. This was due to unforeseen circumstances regarding the safe transference and deletion of multi-media data, such as photographs and videos. Agreements were made with staff on how to do this in an ethical manner, which adhered to school policy. All data was recorded and accounted for after each session in the presence of the safeguarding officer.

### **3.9.4. Safeguarding**

Discussions regarding the location for the research took place prior to commencement, however, environmental and logistical restrictions meant that it was not always possible to prevent the YP and the researcher being isolated and ‘out of view’ of other adults in the school. Due to the participants’ needs, the research often had to be conducted in quiet environments, which by their very nature were often secluded and in areas where other members of staff would not be present. Ensuring the safeguarding of the YP involved, as well as ‘protecting’ the researcher, was one of the primary reasons for having a facilitator present during the wiki-page sessions. This was important as the YP were deemed particularly vulnerable (BPS, 2010), an issue compounded by

the difficulties in communication that several of the participants presented. Although it had additional benefits to the research design, and there were other reasons behind this action, it was the researcher that insisted that a facilitator ought to be present for ethical purposes. The researcher simply did not feel it was appropriate or ethically good practice to be alone with vulnerable adults for such substantial periods of time.

### **3.10. *Summary of chapter***

This chapter has outlined the considerations and values that directed the research design, as well as the principles that underpin it. It provided details of the ontology, epistemology and axiology. It outlined the AR procedure and AR cycles providing insight as to how previous research was adapted and applied to the current research. It explained that the research sought active participation of the YP and how this was assessed using an adapted ladder of participation framework. Data collection procedures and analysis for the action research cycles were outlined. This was followed by details of the TA used to analyse the data from the semi-structured interviews. Rationale was provided for the selection of participants, as well as the methods of the recruitment process, including the sampling methods and a summary of the procedure. Ethical considerations were explored, focussing on informed consent, the maintenance of confidentiality and anonymity, data protection, and additional safeguarding measures. The next chapter outlines findings from the action research cycles and results from the TA.



## **Chapter 4: Findings from action research and results of the thematic analysis.**

### **4.1. Introduction to Chapter**

For the purpose of this chapter the author assumes the role of practice-based researcher. For this reason, a first-person perspective is used, as and when necessary. Details of the preparatory work and data collection process are outlined. It is then demonstrated how the research was conducted, and how outcomes were analysed simultaneously. Each of the three case studies includes reflections from every cycle undertaken, and outlines proposed actions for subsequent cycles. Overviews of the unique AR process that was utilised for each individual case study, and adaptations to professional practice are then provided. Finally, details of the interviews, the steps taken to analyse the data, and general findings from the subsequent TA are provided in a brief synopsis.

### **4.2. Preparation for action research**

As the detailed pen portraits of the participants (*see Appendix E*) indicate, the young people that I worked with have a range of complex needs, some of which potentially impact their ability to develop effective relationships. Furthermore, they were all located in a special educational setting which also has further implications for developing rapport.

To build and develop my relationship with the young people I prepared for the research by visiting the school on several occasions and spending time with each individual student in their class as well as their work experience settings. I felt it was important to interact with them in a setting that they were familiar and comfortable. Furthermore, it provided an opportunity to meet and familiarise myself with other members of their class so that I would cause minimal disruption when working in the educational setting. It also enabled me to meet the class teachers and learning support assistants; gain useful information about the individuals that could benefit my approach to the sessions; provide opportunities to observe the teaching staff working with the individuals to better understand their abilities and communication requirements.

Overall, I spent three days with each individual in a range of settings, both in school and at other work experience placements. In addition to this, I spent several hours with 'Lola' who would act as the 'facilitator', to provide some basic training on the creation and use of wiki-pages, as well as cementing the collaborative aims of the research project.

### **4.3. *Action research cycles***

Barton's (2015) dual layer cyclical models (see *Figure 3.4.1*) supported the emancipatory aims of the research as it promoted the involvement and feedback from the YP throughout the entire research process. Furthermore, it also facilitated brief discussions and 'reflection checks' with the facilitator to evaluate adaptations in 'real-time' during the sessions.

Whilst there may be some overlap regarding adaptations that occurred in the cycles for the individuals, generally the processes involved in the decision-making process that led to those outcomes are very different. Consequently, the AR process is presented as individual case studies, outlining the five cycles for each individual in a sequential manner. Therefore, the five cycles and subsequent adaptations to practice should not be considered uniform across individuals. Finally, adaptations should not be perceived as specific or unique to a particular cycle as adaptations were often revisited in subsequent sessions as part of a fluid process.

### **4.4. *Data collection and reporting the results***

A wealth of data was collected from the individual sessions with each of the three-young people. Two cameras were utilised simultaneously to provide data from front and rear facing perspectives. I met with each young person six times and sessions lasted between 25 minutes and 90 minutes. This resulted in the collection of approximately 15 hours of video footage. During the sessions, a range of alternative communication methods were used by myself, the facilitator and the YP we were working with. These included the use of photographs, symbols, facial expressions, gestures, Makaton signing and eye-gaze technology. To present the results, short extracts from some of the sessions are utilised. Furthermore, anonymous screen shots of the video data provide rich context to provide examples of adapted practice.

### **4.5. *Case study 1: Pauline***

Pauline is a young adult female who is 18 years of age. She has a diagnosis of hypotonic quadriplegic (or tetraplegic) CP that is characterised by decreased muscle tone, resulting in loose, floppy limbs. This is generally considered the most 'debilitating' of CP types as it results in the partial or total loss of use of all four limbs and torso. Pauline has significant difficulties with learning (SLD); she is non-verbal and exhibits significant difficulties with speech, language and communication (SLC); she has considerable gross/fine-motor impairment with limited movement in her right hand only and the ability to shift the orientation of her head. For a more detailed descriptive summary of Pauline's needs and abilities see *Appendix E*.

#### **4.5.1. *Pauline: Cycle 1 – Situational and environmental factors***

Although I had gone to great lengths to identify a facilitator who had extensive knowledge of Pauline and her needs; had trained them in the basic principles of the wiki-page technology; discussed the aims of the project with her; and negotiated a suitable room to conduct the research, this was compromised due to a child protection issue in the school setting. Consequently, the facilitator was unavailable (as designated child protection officer) as was the room of intended use.

I went ahead with the session in another room and with an alternative member of staff to facilitate. The limited time available to prepare the session and lack of rapport between myself and the facilitator was evident during interactions:

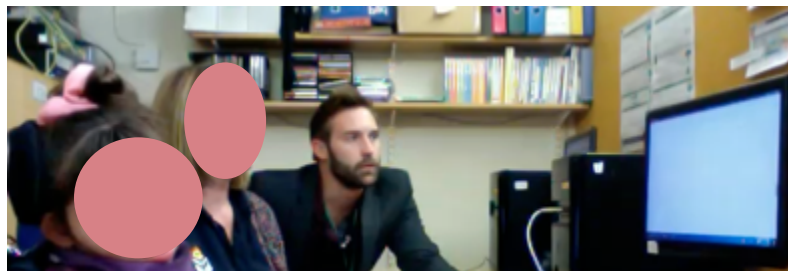
**Facilitator:** “Can you just give me some more information about these pictures?”

**Researcher:** “Erm yeah, so if you go into that folder, they are photos related to school...  
And in this one there are a couple of images of when Pauline turned 18...”

**Facilitator:** [Turning to Pauline] “Oooh, you were quite excited about that weren’t you so...”

**Researcher:** “There are a couple of photographs in each folder that are meant to provide Pauline opportunities to select her favourite.”

This interaction highlights several significant issues. Firstly, the facilitator had very little previous information regarding the aims of the research project or the process involved. Secondly, Pauline was not provided with opportunities to be involved at any point. In fact, the facilitator seemed to make judgements based on her interpretation, appearing to pre-empt Pauline’s choice without involving her. I noted this at the time and attempted to model through language that Pauline should be making the choices to select her favourite multimedia as this was the aim of the session. *Figure 4.5.1.* illustrates how Pauline lost interest and disengaged during this interaction between the researcher and facilitator, instead turning her head to look at the video camera.



**Figure 4.5.1:** *Pauline demonstrating disengagement due to a lack of opportunities for participation.*

Indeed, communication was problematic in general and ascertaining Pauline's choices accurately was difficult with the initial method used to select her favourite photographs. This method relied on browsing through several photographs on the computer from an area of interest, such as 'birthdays' or 'favourite activities'. However, like a slideshow only one photograph could be viewed at any given time. The researcher also did not consider the implications that potential difficulties in working-memory might present, such as holding the previous photographs in mind whilst inspecting others, on her ability to make informed choices as well as the level of effort it required. Pauline lacked agency when browsing through the photographs as it was the facilitator who assumed control of the mouse. The following interaction indicates the level of uncertainty that the facilitator appeared to have regarding Pauline's communication needs, as well as the apparent lack of systematic structure to ascertain Pauline's intended choice:

**Researcher:** "You can browse through the options by pressing on this arrow. [*Researcher demonstrating*], There's that one, that one and one final picture. So maybe we can try that nice and slow."

**Pauline:** [*Inaudible vocalisation, smiling and makes pointing gesture towards the screen, (see Figure 4.5.1.1)*]



Pauline is able to perform limited fine motor skills with her right hand, in this case pointing towards a photograph of herself

**Figure 4.5.1.1:** Pauline pointing/gesturing towards photographic multimedia.

**Facilitator:** "Right, look Pauline [*Whilst gesturing and pointing towards the screen, (see Figure 4.5.1.2)*] It's your 18<sup>th</sup>. Who is with you?"



Facilitator reciprocates pointing communicative gesture

**Figure 4.5.1.2:** Facilitator reciprocating pointing/gesturing towards photographic multimedia to check-back.

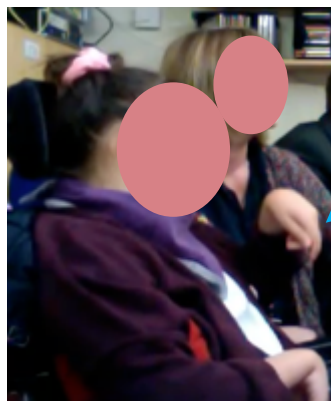
**Pauline:** *[More inaudible vocalisations].*

**Facilitator:** “Justine *[Facilitator assumes control of the mouse]* “That’s you and Justine. *[Clicks onto next photograph]* This is you, Justine... and ... I think that’s Sarah. I think this is at Crafty Drama. Is it?”

**Pauline:** *[Makes “Yes” gesture with right hand, (see Figure 4.5.1.3)].*

**Facilitator:** *[Turns to face Pauline]* “Yes” *[Returns to facing the computer and clicks onto next photograph]* “...So.... Here is another one look. Which one does Pauline like best? *[No response from Pauline]* Which one do you like? That one? Lets do a yes or a no Pauline. *[Pauline begins to motion “Yes” with right hand but is looking away from the computer screen at the table in front of her]* You like that one best? *[Facilitator turns to face Pauline who is still motioning yes and looking at the table]* No? do you want me to show you the others again? *[Facilitator clicks on the initial photograph]* Or that one? That one has got Sarah in it, look. You want that one? *[Pauline makes slow “Yes gesture”]* Or that one? *[Whilst facilitator clicks on next photograph and Pauline is still motioning “Yes”]* Just push down on my hand when you like one. *[facilitator turns to Pauline]* That one?”

**Pauline:** *[Gestures “Yes”].*



Pauline is able to gesture “Yes” with small vertical movements of right hand

**Figure: 4.5.1.3: Pauline gesturing “Yes” with vertical motion of her right hand.**

In addition to the practical difficulties discussed above, I was also aware of the environmental factors that impacted the session. I felt the room was too small to meet Pauline’s physical needs. Furthermore, it was hot and claustrophobic by the end of the session. In addition to this, it was not possible to access specific resources such as the interactive whiteboard.

#### **4.5.1.1. Pauline: Reflections from cycle 1 and proposed action for cycle 2**

When I reflected on some of the interactions during this session it was apparent that Pauline was passive for long periods and a lack of opportunities to participate led to disengagement (see Figure 4.5.1). Pauline did not add any content to her wiki-page during this session but rather

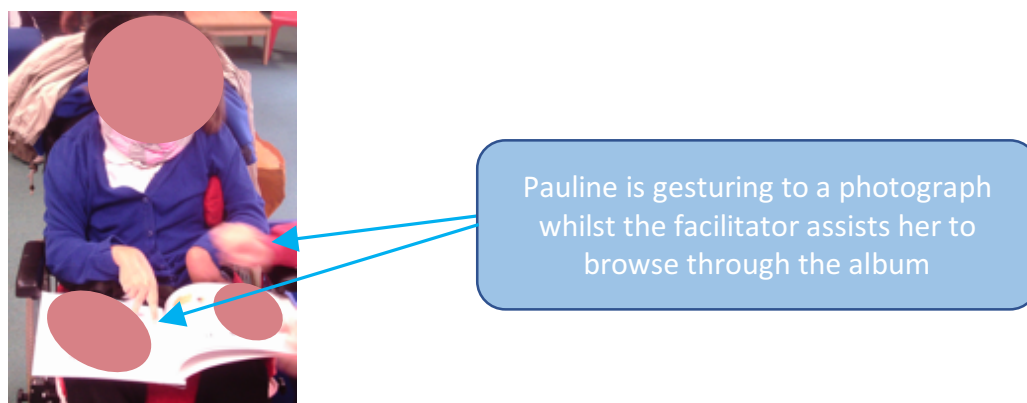
made several choices regarding her favourite multi-media that would be added in the next cycle. However, in this cycle the facilitator assumed control of the computer and Pauline had limited direct input in terms of the ICT processes.

When referenced against Hart's (1992) ladder of participation, it is evident that this represents '*non-participation*' and is an example of '*tokenism*' (rung 3 on the ladder of participation). This initial cycle highlights that it is all too easy to create an imbalance of power, particularly when working with someone who is non-verbal, has difficulties with communication or finds it challenging to express herself.

Consequently, in *Cycle 2* I sought to prioritise a range of strategies that would promote Pauline's ability to communicate so that she could make her choices clearly known. Furthermore, although the school could not foresee the child protection issue and obviously had to act, I reiterated that I would not be able to conduct the research without the presence of the facilitator I had initially recruited or access to the room that had been allocated for the research.

#### **4.5.2. *Pauline: Cycle 2 – Adaptations to practice and strategies to overcome difficulties with communication***

Several communication techniques were adopted to promote Pauline's ability to make choices and communicate more effectively. *Figure 4.5.2* shows Pauline with a photo album that was created by the researcher and facilitator. In this example, the facilitator is assisting Pauline to browse through the photographs by turning the pages. Pauline communicated her preference with vocalisations or gestures with her right hand, as is the case in *Figure 4.5.2*. However, this also created other challenges, such as establishing the correct pace to turn the pages to ensure that Pauline had adequate opportunity to process the images. Furthermore, it did not mitigate any potential difficulties with working-memory in terms of holding previous images in mind as discussed in cycle 1.



**Figure 4.5.2: Pauline with the photo album pointing to a photograph of interest.**



In another method, Pauline was provided with several photographs or symbols to gesture/point to as *Figure 4.5.2.1* indicates. This was beneficial as she could view several items simultaneously. However, due to complete gross-motor impairment in her left hand and the limited function of her right hand it was very challenging for her to make movements in this manner, especially when crossing the midline.



**Figure 4.5.2.1: Pauline selecting from a choice of five photographs.**

The most successful and effective method of communication was when using eye-gaze technology (see *Figure 4.5.2.2*).



**Figure 4.5.2.2: Pauline making choices using the eye gaze technology.**

Although the severity of Pauline's communication needs meant that we were unable to provide open-ended (free) choices, we could provide her with opportunities to make choices at her level of communicative ability. For instance, I collated multimedia for several different topics and saved these into separate folders. These were uploaded to her eye-gaze platform and Pauline could choose which topic she wanted to browse from a choice of three or four folders. A second layer of choice was then available to Pauline enabling her to choose a specific photograph related to that topic to add to her wiki-page. Again, this was typically a choice of three or four photographs (see *Figure 4.5.2.3*).



**Figure 4.5.2.3:** Example of the arrangement for three photographs that Pauline could choose from.

Importantly, multimedia could be viewed simultaneously, reducing any potential impact for difficulties with working-memory. Furthermore, the eye-gaze method of communication seemed to promote more meaningful two-way interactions and increased the ‘checking’ back of choices that ensure accurate interpretation of responses. The following extract highlights how the skills of the facilitator, in addition to the eye-gaze technology, significantly improved interactions from the previous cycle. In addition to this, I was more confident that we were obtaining an accurate representation of what Pauline wanted to include on her wiki-page:

**Facilitator:** “So, do you want to go into your next choices Pauline?” [*Motioning towards the eye-gaze with her finger to direct Pauline’s attention*].

**Pauline:** [*Pauline quickly selects a folder (a camping trip) with eye-gaze*].

**Facilitator:** “Well done that is fantastic. Now you can choose your favourite photograph from these three.” [*Pointing to each photograph as she describes them*] “There is one with you... and... it actually looks like you and ME (A).” [*Laughing together*] “And there is one with you and Justine (B)”. “Do you remember Justine? You are away on a trip there. And there is one of you Pauline (C).”

**Pauline:** [*Pauline appears to select choice B (see Figure 4.5.2.4) as it is repeatedly called out by the eye-gaze*].

**Researcher:** “Is that your favourite?”

**Facilitator:** “Do you like the one with you and Justine cooking [*whilst signing*]?”

**Pauline:** [*Makes “Yes” gesture*].

**Facilitator:** “Yeah?” [*Pauline carries on gesturing “Yes”*]. “Do you want to put you and your friend on?” [*Final gesture for “Yes”*]. “Ok, we have to do some wiki-work now.”





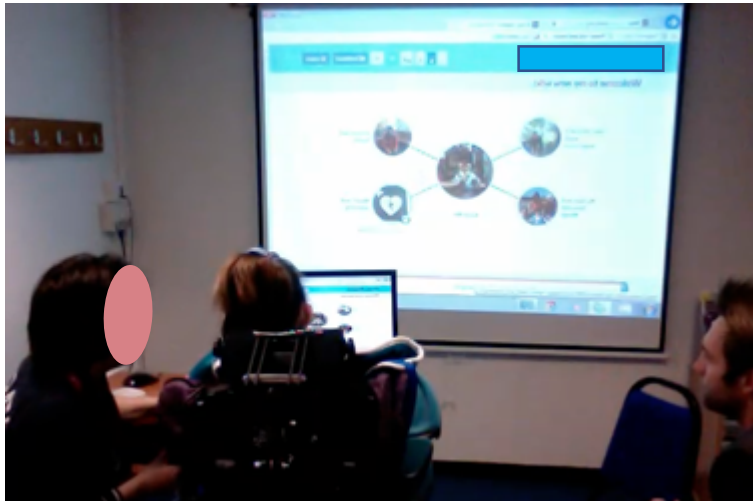
**Figure 4.5.2.4:** *The photograph Pauline (pictured right) selected from the extract above.*

#### **4.5.2.1. Pauline: Reflections from cycle 2 and proposed actions for cycle 3**

It was my impression that Pauline presented as happier and more relaxed than in the previous session. This undoubtedly was influenced by the facilitator who possessed intimate knowledge of Pauline and had a close relationship with her, cultivated over many years. The extract also illustrates how there were instances of humour that stemmed from this trusting relationship. This highlights the importance of developing good relationships and having previous knowledge of an individual to promote participation and engagement.

Overall, Pauline demonstrated competent use of the eye-gaze technology and it seemed to foster increased instances of two-way communication, leading to more meaningful interactions. The skill of the facilitator and the collaborative approach we adopted together also resulted in increased ‘check-backs’ of Pauline’s choices in a more systematic structure to ensure we interpreted her responses accurately.

Pauline was central to the decision-making process and subsequent choices. Consequently, she had now obtained a ‘*degree of participation*’ as purported by Hart (1992). I felt that the descriptive behaviour outlined in this cycle represented ‘*youth consulted and informed by adults*’ (*‘rung 5’*) as activities were adult-led but Pauline was fully consulted and informed about how her choices would be used. She understood that she was choosing photographs to add to her wiki-page and she could see this fluid process in action during the session, which further promoted her understanding (see *Figure 4.5.2.5.*).



**Figure 4.5.2.5: Promoting Pauline's understanding of how her choices related to the wiki-page.**

Although we had made progress in terms of promoting effective communication, a significant barrier to Pauline having more involvement in ICT processes and inputting information onto her wiki-page were factors related to gross and fine-motor impairment. In the next cycle, I aimed to utilise several different adapted ICT technologies that were obtained from the RIX Centre to promote Pauline's participation in these activities.

#### **4.5.3. Pauline: Cycle 3 – Use of adapted ICT equipment to limit the impact of motor-impairment**

Due to her significant impairments related to gross and fine-motor function, Pauline found it particularly challenging to input information onto her wiki-page. In the initial sessions, the researcher primarily inputted information on Pauline's behalf whilst she made key decisions or choices regarding the content uploaded. In this cycle adapted technology was used so that she could participate in the uploading of information to her wiki-page. Initially, we tried using a joystick-style adapted mouse (see *Figure 4.5.3.*).



**Figure 4.5.3: Joystick-style adapted mouse.**

However, due to the lack of strength in Pauline's arms this was not suitable as it required constant pressure in one direction or another to move the cursor. Furthermore, her arm would often 'stiffen' in this position so she was unable to release the joystick at the intended location. Consequently, we tried the rollerball adapted mouse (*see Figure 4.5.3.1.*). This was far more effective than both the traditional mouse and the joystick-style adapted mouse as it only required her to make very small fine-motor movements with her finger, as well as eliminating the need for gross-motor movements with her arms. This was further complemented with the use of a big red switch (to use as a clicking function), which can also be seen in *Figure 4.5.3.1.*



**Figure 4.5.3.1:** *Rollerball adapted mouse and big red switch configuration.*

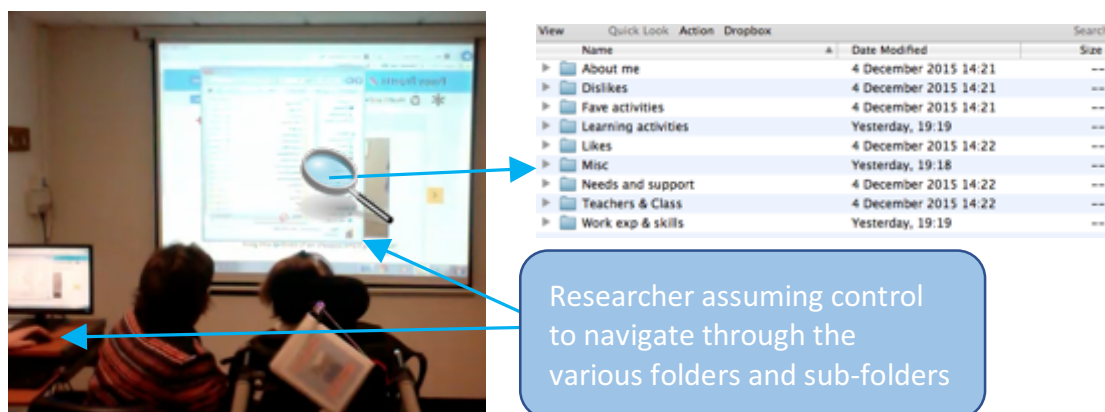
Even with these adaptations the following extract highlights how laborious and time-consuming the process was. It also illustrates the high level of collaboration that was necessary between Pauline, myself and the facilitator.

**Facilitator:** “Should we add some more pictures?”

**Pauline:** [*Gestures “Yes”*].

**Facilitator:** “Yes, ok. Richard is going to help us have a look at what we’ve got.”

**Researcher:** [*Assumes control of the computer to navigate through the vast folders of multimedia (see Figure 4.5.3.2.)*]. “Ok, we’ve got some different pictures to choose from. There are two pictures in this folder so if Pauline wants to change it, she can click.” [*referring to the red switch*].



**Figure 4.5.3.2:** *Researcher assuming control to navigate the complicated folders and sub-folders.*

**Facilitator:** *[Pointing to towards the red button]* “You can red click if you want to look at the other picture. You can choose this picture... *[pointing at the image on the whiteboard (see Figure 4.5.3.3.) ... or the other one.” [whilst signing].*



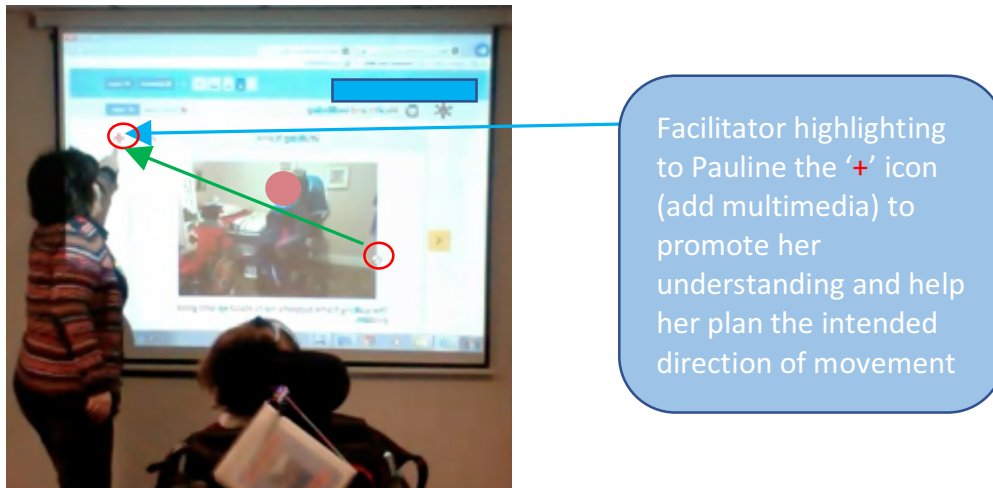
**Figure: 4.5.3.3:** *Facilitator explaining to Pauline that she can choose this picture or use the big red button to look at another.*

**Pauline:** *[Gestures “Yes” without clicking on the big red switch].*

**Facilitator:** “Do you want to red click and see what the other one is?” *[No response from Pauline].* “Do you like this one?” *[Pointing towards the screen. Pauline gestures “Yes”].* “Yes.” *[Reaffirming/checking choice].*

**Researcher:** “Okay dokay *[researcher assumes control of the computer]* so let me take you back to the wiki-page and you can add the photo.” *[clicks on the internet icon and Pauline’s wiki-page appears].*

**Facilitator:** “So to add the photo.... Well done you are looking in the right direction *[pointing towards the target icon].* Can you see the red square?... I mean the red cross.” *[Facilitator stands up to ensure she understands and can identify the target location (see Figure 4.5.3.4)].*



**Figure 4.5.3.4: Facilitator signifying target location to Pauline.**

**Facilitator:** “We are heading up here because we are going to add... We are going to add a photo of you [*facilitator sits back down*]. Let’s have a look [*as she assists Pauline with hand-on-hand support (see Figure 4.5.3.5)]*].



**Figure 4.5.3.5: Pauline using the rollerball adapted mouse with hand-on-hand support from the facilitator.**

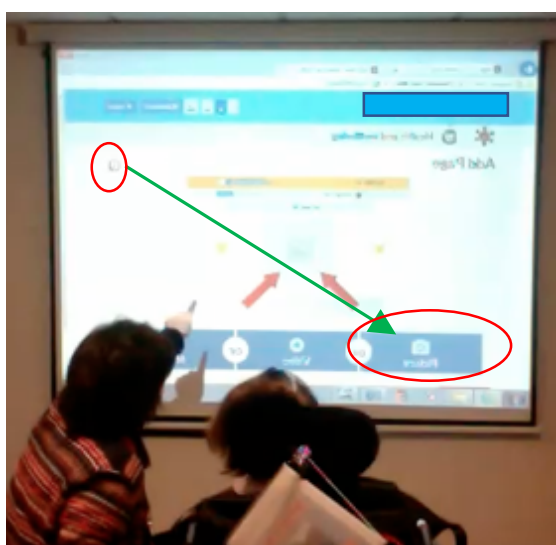
**Facilitator:** “That’s it. We go up, up, up... and across. You are getting it. There we go. And then could you click with the red button please?” [*Pauline clicks the red button but holds it down for a long period of time and everyone laughs together*] “Are you doing those long clicks again?”

**Pauline:** [*Vocalisation with giggle*].

**Facilitator:** “Ready, steady....” [*Pauline releases the red-button and next screen pops up to add different types of multi-media*] “Yay! Well done! Now we just saw a picture of Pauline. So now we need to bring the cursor, which is all the way up there [*gesturing to the location*] all the way down [*drawing a line with her finger towards the target icon to add a picture/photograph (see Figure 4.5.3.6)*] to the one that says picture with the camera on. We can do that can’t we? Ready Pan? [*Facilitator takes Pauline’s hand to support hand-on-hand*]



Now we're looking at the screen, see where the cursor is [*pointing towards it*]  
We'll bring it down."



Facilitator traces a line with her finger from the cursor's current location to intended target, which in this instance is the camera icon (add photo-multimedia) that says picture.

**Figure 4.5.3.6:** Facilitator explaining where the 'add picture' function is through verbal instruction in addition to visual prompt.

**Pauline:** [Makes vocalisation].

**Facilitator:** "That's it, bring that down. Its coming. Well done, and across... Ooh you're almost there. Up a bit. And if you could red click please [*gesturing towards the big red switch*] because you have reached your destination."

**Pauline:** [Clicks red button]

**Facilitator:** Well done!

**Researcher:** [*Assumes control of the computer to once again navigate the numerous folders in order to locate the appropriate file/photograph (see Figure 4.5.3.2).*]  
[*Pauline makes several vocalisations and begins to laugh loudly with the facilitator.*] "We need the equipment folder [*which contains the image of Pauline using her walking frame that she chose*]. [*Researcher selects the appropriate image which then appears on the screen (see Figure 4.5.3.7).*]  
"Was this the one you wanted Pan?"



**Figure 4.5.3.7:** Check-back measures to ensure that this is the photograph Pauline wanted to upload.

**Pauline:** [Pauline makes “Yes” gesture].

**Facilitator:** “Yes – you are sure?” [Pauline gestures “yes” again].

**Researcher:** “Soooo, you can give it a name. [Whilst clicking on the add title feature of the wiki-page]. What should we call it?”

**Facilitator:** “How does, ‘This is me in my walking frame’ sound?”

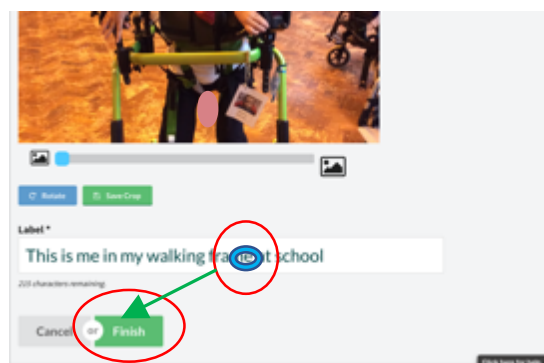
**Pauline:** [Pauline clicks the red button several times].

**Facilitator:** [Laughs gently] “Are you clicking for yes?” [Pauline and facilitator both laugh together as the facilitator types out ‘This is me in my walking frame’ (see Figure 4.5.3.8.)].



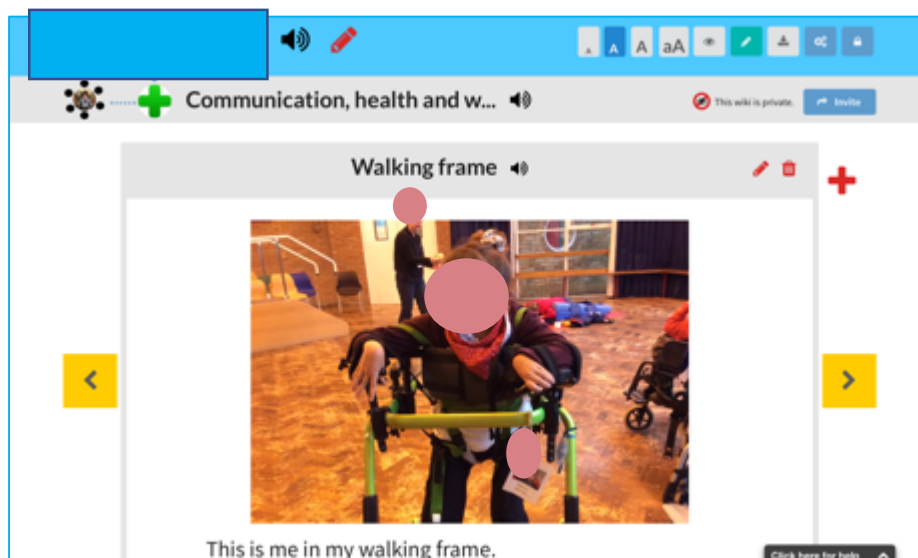
**Figure 4.5.3.8:** Researcher adding title labels and text to Pauline's wiki-page.

**Facilitator:** “So Pan, to say we’ve finished and we are happy with this picture [with signing gestures] we are going to bring the cursor down [as she provides hand-on-hand support to Pauline]. Look, there it is. You’re nearly there already. Up a bit. To the green square that says ‘finish’” (see Figure 4.5.3.9).



**Figure 4.5.3.9:** Moving the cursor to the ‘finish’ icon to complete uploading the photograph and text.

**Facilitator:** “We are there so if you would like to press red click please.” [Pauline clicks the red button and the completed photograph with label comes up on her wiki-page] (see Figure 4.5.3.10).



**Figure 4.5.3.10:** Example of the photograph Pauline added to her wiki-page with support from adults.

**Researcher:** “There we go. Wow, who chose and added that wonderful picture?”

[Pauline makes loud laughing sound and gestures with her hand].

**Facilitator:** Well done!

#### **4.5.3.1. Pauline: Reflections from cycle 3 and proposed actions for cycle 4**

The increased participation that Pauline achieved in creating her wiki-page due to adapted ICT equipment appeared to result in more on-task behaviour and increased engagement. Whilst she still required a high level of support in the form of verbal prompts, visual guidance and hand-on-hand support, Pauline was clearly more involved in the wiki-page process because of these adaptations to practice. Furthermore, this appeared to have additional benefits such as increased instances of laughter and enjoyment between all collaborators.

Whilst it was a time-consuming process that presented some additional challenges, Pauline arguably achieved a higher level of participation. I felt that her ability to take an active role in the inputting/uploading of multimedia, in addition to her ability to make choices regarding content, resulted in a more equal power dynamic. Consequently, I assessed that this cycle represented activities that were *‘adult initiated with decision-making being shared with youth’* (*‘rung six’* on Hart’s ladder of participation, 1992). This is because activities were still initiated and led by the facilitator and me. However, Pauline was an equal collaborator in the process and any choices she made were adhered to. The extract included in this cycle also indicates that there was a vast amount of check-backs used for this approach, increasing the potential for accurate interpretation by adults, as well as increasing the general quality of meaningful interactions.



In the next cycle, I wanted to empower Pauline by trying to ascertain if she had preferences regarding the technology utilised in addition to any further adaptations that could be made to improve the situation further. It was important that Pauline should be involved in decision-making processes and proposed adaptations were not solely based on my own personal assumptions or interpretation. In addition to this, I hoped that we might be able to attempt novel activities to develop her skills further.

#### **4.5.4. Pauline: Cycle 4 – Providing increased opportunities to direct adaptations to practice**

This cycle focussed on making adaptations based on Pauline’s preferences. This was achieved by making a conscious effort to be ‘more attuned’ to Pauline’s behavioural cues and taking adequate time to reflect on her reactions to situations. We attempted to inhibit our own personal assumptions regarding her preferences but rather, reacted to her responses when adaptations were made. At times this involved challenging Pauline to determine her potential abilities or limitations. The following extract highlights this point regarding the positioning of the adaptive equipment:

**Facilitator:** “So Miss Pauline R, we are going to put our hand up onto the mouse... Are we ready to do that?” [*Facilitator takes Pauline’s hand to provide a prompt and support her use of the rollerball mouse*] “And we are going to move the cursor. Can you see it on the screen? Hurray, you’re there!!!” [*Pauline smiles*] “And could you do a big click with the other hand Pauline?” [*The big red button has been positioned towards the left of her midline*]. “Can this hand move forward? [*Gesturing to Pauline’s left hand*]. Or do you want to use this hand to click? [*gesturing to the dominant right hand*]. Or can you reach over?” (see Figure 4.5.4.)



**Figure 4.5.4: Facilitator determining Pauline’s fine and gross-motor function**

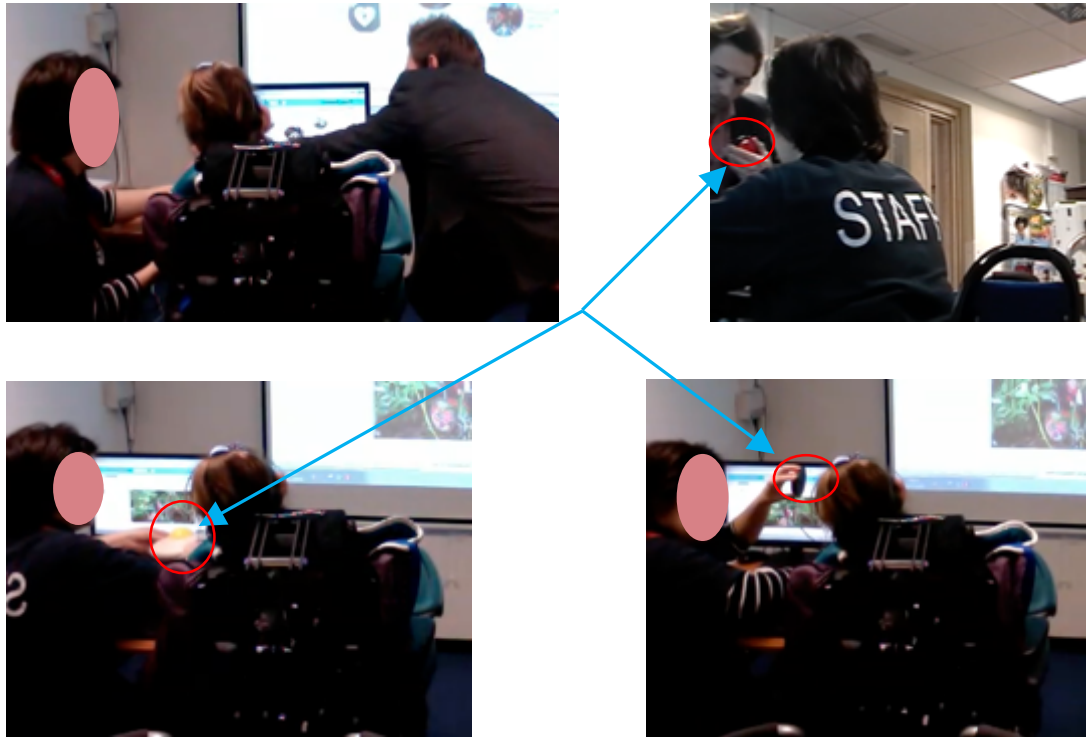
**Pauline:** [*Pauline attempts to reach over and cross the mid-line with her right hand.*]

**Researcher:** [*Realising that this is beyond her capability, he repositions the big red button.*]

**Facilitator:** *[Acknowledges the suggestion by ensuring that the rollerball adapted mouse and the big red switch to the right side of her mid-line (see Figure 4.5.4.1)].*

**Facilitator:** “You’ll need this.” *[Firstly, positioning the roller-ball mouse at a distance that is comfortable for Pauline to reach].* “And the all-important red clicker” *[Holding it up it for Pauline to see before positioning it to the right of her mid-line].* “Oh that’s easier isn’t it Pauline? Is it best we have it here?”

**Pauline:** *[Pauline clicks the red button, to some extent confirming.]*



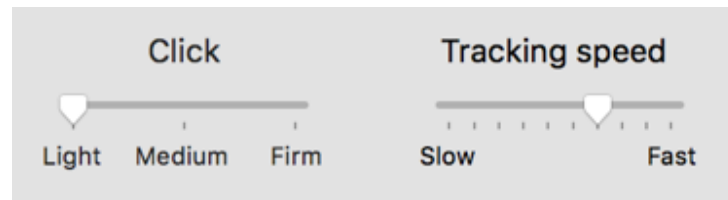
**Figure 4.5.4.1:** *Facilitator and researcher adjusting the positioning of the rollerball adapted mouse and the big red switch.*

The facilitator and I still discussed potential changes and adaptations in a collaborative manner to reach joint-agreements. For instance, during the interaction outlined above, I also considered if the rollerball adapted mouse could be improved for ease of use by altering the sensitivity settings. I consulted the facilitator but we came to the agreement that it was not necessary:

**Researcher:** *[Referring to the rollerball mouse sensitivity]* “Is it too fast or too slow? I can change it.” *(see Figure 4.5.4.2.)*

**Facilitator:** “Its ok I think actually.”

**Researcher:** “Yes, I think you are right. Anymore and it will probably be too sensitive to control.”



**Figure 4.5.4.2.** *Altering the sensitivity settings for the rollerball adapted mouse and big red switch.*

I had already previously altered the tracking sensitivity to a faster setting so small movements that Pauline made with her index finger moved the cursor considerably. Furthermore, I ensured the big red switch was on the lightest pressure setting so that she did not have to apply a lot of pressure to select items.

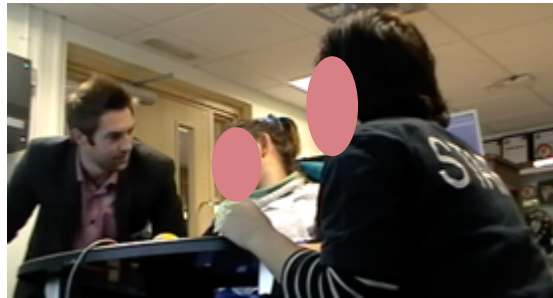
In this cycle, we also tried to consider Pauline’s perspective and made adaptations to practice based upon her recommendations. This was achieved by being vigilant and developing an increased understanding of her subtle communication nuances. The following extract provides an example of how adaptation occurred spontaneously based upon the feedback that the researcher obtained from Pauline’s non-verbal communication. In the previous sessions, we had worked from the large interactive whiteboard as we had assumed that it would be beneficial for several reasons, such as maintaining Pauline’s attention. However, the following interaction indicates that the researcher was in tune with Pauline’s behavioural cues and reacted accordingly to modify practice:

**Facilitator:** “So now we have to do some wiki-work.” [*The small desktop screen is to the left of Pauline in front of the facilitator and the large interactive whiteboard is in front of her. However, Pauline’s head is clearly tilted to the left looking at the desk top screen (see Figure 4.5.4.3.)*]



**Figure 4.5.4.3:** *Pauline communicating a preference for the desktop screen through body posture and behavioural cues.*

**Researcher:** [*Approaches and gestures towards the desktop*] “Do you like this screen?”  
[see Figure 4.5.4.4].



**Figure 4.5.4.4: Gaining Pauline’s perspective on her preference of ICT equipment**

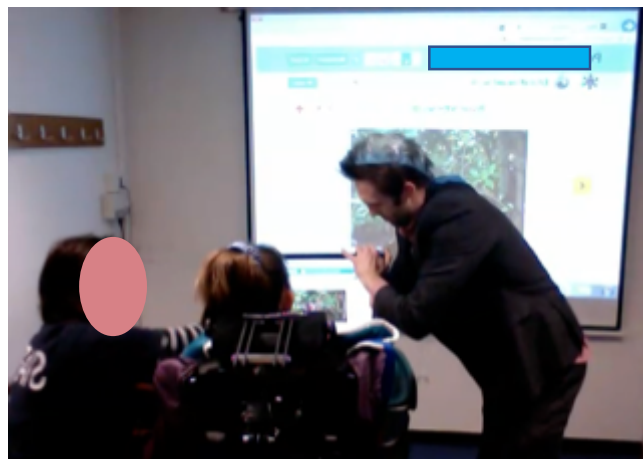
**Pauline:** [Pauline smiles].

**Facilitator:** [*Motions towards the desk top screen.*] “Should we move this over?” [*We reposition the desktop screen in front of the large interactive whiteboard*].

**Pauline:** [*Excited vocalisation*].

**Researcher:** “I agree Pauline, that is a good choice.”

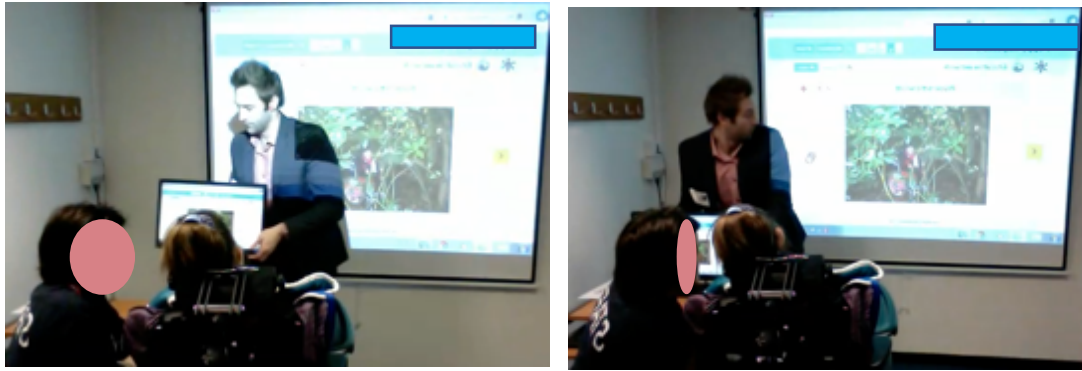
Figure 4.5.4.5. clearly indicates that her posture has changed dramatically and she is now sat facing forwards, looking directly at the desk top screen.



**Figure 4.5.4.5: Repositioning the desktop screen due to Pauline’s behavioural cues that indicate preference.**

Later in the session it appeared that Pauline was not focussed on the desktop screen but towards the interactive white screen behind it and I suggested moving it so she could see the big screen better. Pauline’s behavioural responses seemed to confirm her earlier desire to use the desktop screen:

**Researcher:** “Are you looking at the big screen?” [*Researcher begins to move the desktop away (See figure 4.5.4.6)*]



**Figure 4.5.4.6:** *Pauline's gaze and head position following the desktop screen as the researcher moves it away.*

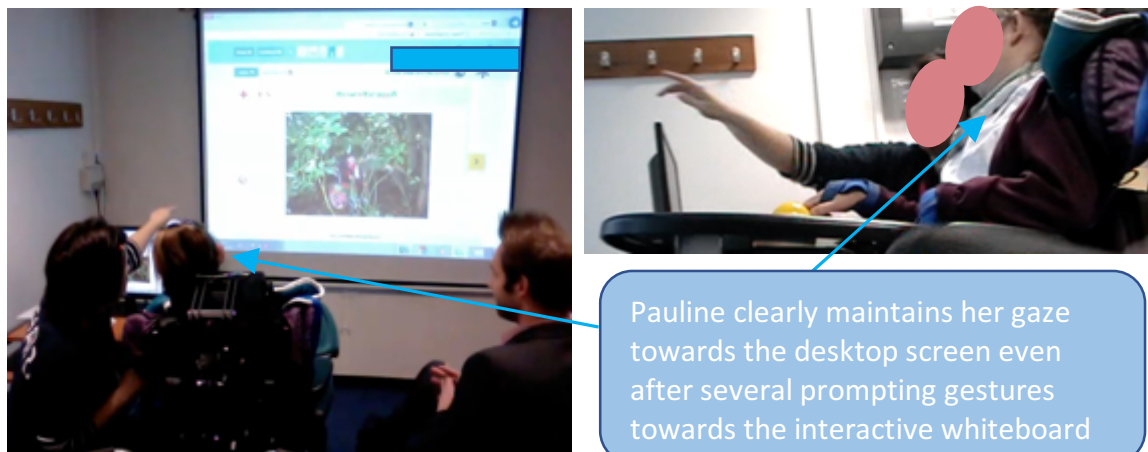
**Facilitator:** “Big screen? Is that easier?”

**Pauline:** *[Pauline's eyes and head follow the direction of the desktop (see Figure 4.5.4.6.).]*

**Researcher:** “Should we look at the big screen *[gesturing with a pointed finger]*.”

**Facilitator:** “That's better isn't it? See where the cursor is at the side *[Also pointing towards the interactive whiteboard]*.”

**Pauline:** *[Turns her head again deliberately in the direction of the desktop] [See Figure 4.5.4.7.]*



**Figure 4.5.4.7:** *Pauline maintaining head position and gaze towards desktop denoting preference of ICT equipment.*

**Researcher:** *[Researcher and facilitator pause for a couple of seconds].* “Ohhh, Ok.”

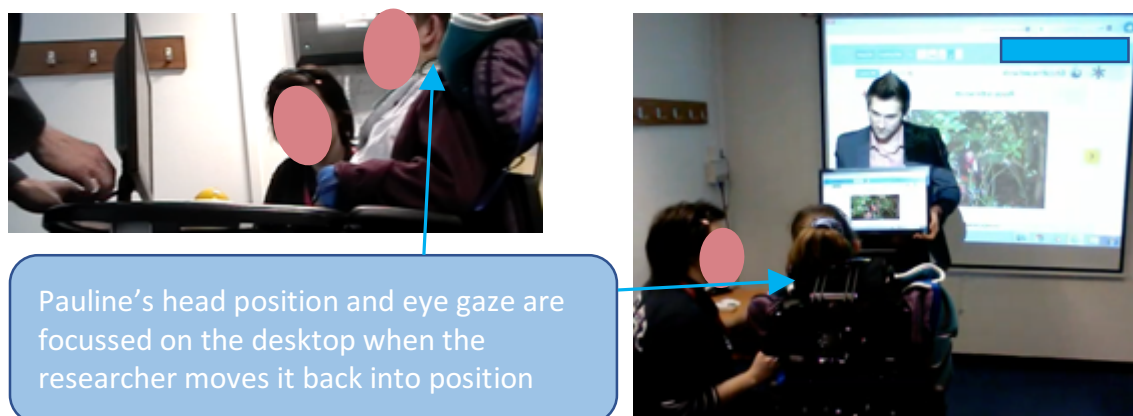
**Facilitator:** *[Motioning with her finger towards the desktop]* “Are you choosing the small one?”

**Pauline:** *[Laughs with excitement].*

**Facilitator:** “Are you? Ok.”

**Researcher:** *[Repositions the desktop in front of Pauline (see Figure 4.5.4.8.)]* “Do you want this one? Yeah? There you go, you can have both the big screen and the little screen.” *[Everyone laughs].*





**Figure 4.5.4.8: Repositioning the desktop screen according to Pauline's preference after check-back questioning.**

Importantly, the researcher and facilitator reacted to Pauline's needs, in terms of her emotional well-being, external to the research aims. During this session, Pauline was struggling with her breathing due to having a cold. The facilitator and myself both agreed that we should cease work on the wiki-page due to health considerations. We consulted Pauline and her behavioural response indicated that she was keen to stop.

#### **4.5.4.1. Pauline: Reflections of cycle 4 and proposed action for cycle 5**

This cycle highlights that the views of Pauline were considered to a much greater extent than in previous sessions. It shows that Pauline was involved in the process of adapting practice, as well as guiding it. This was only possible through an increased awareness and understanding of Pauline's non-verbal communication nuances, such as her posture and head-positioning.

My assessment is that this shift in approach culminated in reaching the '*highest degree of participation*' according to Hart's (1992) model. Extracts from cycle 4 highlight that adaptations were often '*youth initiated with shared decisions with adults*' ('*rung 8*' on the ladder of participation). At other times activities perhaps represented '*rung 6*' as noted in previous cycles, where they were '*adult initiated with decision-making being shared with youth*'.

This cycle also seems to encapsulate emancipatory disability research according as the participant's needs and well-being were prioritised over the aims of the researcher, regardless of the potentially detrimental impact to research outcomes. This shows that potential power imbalances were acknowledged and acted upon by the researcher to ensure equal partnership with all the collaborators in the research.

In the final cycle, I wanted to synthesize the learning from the previous cycles to enable Pauline to have active participation in all aspects of her wiki-page – beginning with making a choice and culminating with her adding that content – in a continuous, fluid process.

#### **4.5.5. *Pauline: Cycle 5 – Combining previous adaptations to form a continuous and fluid process***

This cycle illustrates the level of collaboration that was required from myself, the ‘facilitator’ and Pauline. The researcher and facilitator worked together as a team to manage logistical aspects to ensure that Pauline had access to the specialist equipment to enable her to be actively involved in all aspects of the creation of her wiki-page. The extracts illustrate the level of effort and precision that was required to ensure that the eye-gaze, mouse, switches and screens were all positioned appropriately for Pauline to access. Furthermore, each of these adaptations was deemed necessary and failure to implement one or the other would have resulted in a collapse in the process. The following extract highlights that this was a time-consuming and at times exhausting process but was also immensely rewarding:

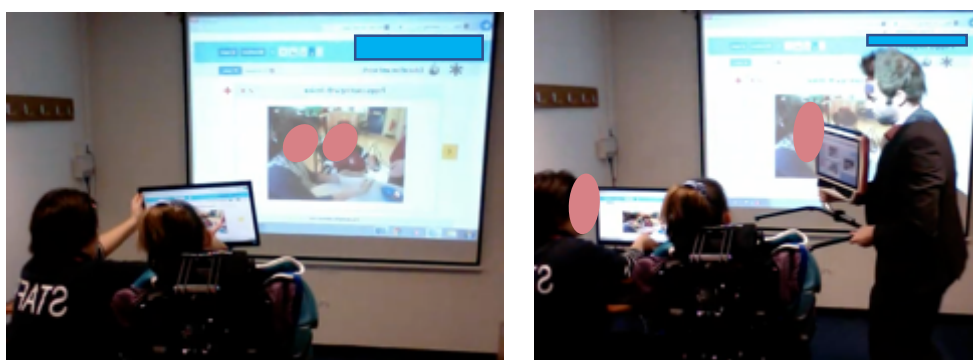
*[Pauline starts the process with the desktop screen in front of her (see figure 4.5.5)].*



**Figure 4.5.5: Pauline has the desktop in front of her to view her wiki-page.**

**Facilitator:** “Should we do another one?” *[Pauline gestures “Yes”]*. “Ok.”

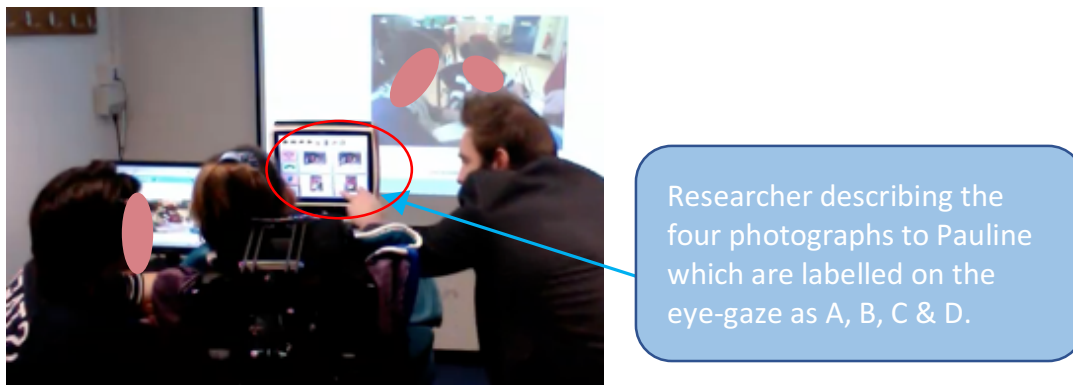
**Researcher:** “Great. Right, so we need to get the eye-gaze to choose.” *[Facilitator moves the desktop, the rollerball mouse and the big red switch, whilst the researcher positions the eye-gaze in front of Pauline (see Figure 4.5.5.1.)]*



**Figure 4.5.5.1: Manoeuvring the desktop and eye-gaze to enable Pauline to make a choice.**

**Facilitator:** “Let’s pop those over there and you can have those back in a moment. This time Pauline we are going to choose a different photo. So, go into your next choices Pauline” [*Pauline selects a folder via eye-gaze*]. “Well done, that is fantastic. So now you can choose your favourite photo from these four.”

**Researcher:** [*Gesturing to all four photographs on the eye-gaze*] “Which one is your favourite? Picture A, B, C & D.” (see *Figure 4.5.5.2*).



**Figure 4.5.5.2:** Ensuring that Pauline understands the purpose of her choice and the options available.

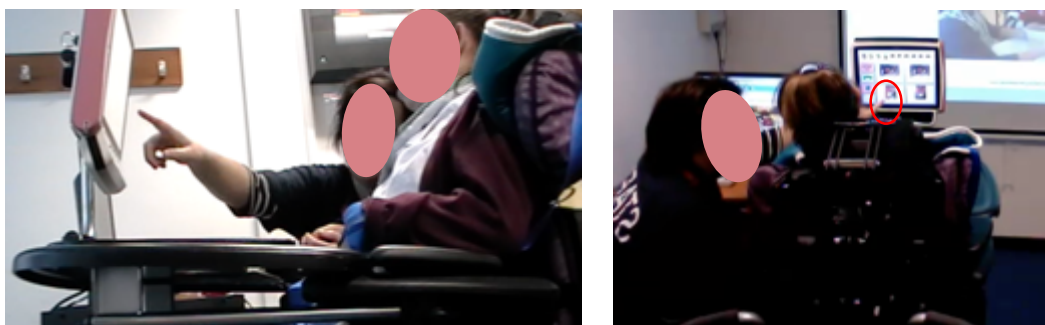
**Facilitator:** “I think I know which one you are going to choose but I am not going to say anything.”

**Pauline:** [*The eye-gaze sounds out several times Picture B, indicating that Pauline is looking toward the second photograph.*]

**Facilitator:** “Is it this one Pan?” [*pointing towards Picture B (see Figure 4.5.5.3).*]

**Pauline:** [*Pauline gestures “Yes”*]. [*The facilitator once again does another check by pointing to each picture individually providing a description*].

**Facilitator:** “Is it Picture B” [*with pointing gesture*].



**Figure 4.5.5.3:** Confirming Pauline’s choice with the eye-gaze using check measures.

**Pauline:** [*Makes vocalisation and once again the eye-gaze indicates Picture B several times*].

**Facilitator:** “Yes..?” [*with thumbs up gesture*]. “Pauline B [*gesturing to photo*]. “Yes?”

**Pauline:** [*Makes loud vocalisation and gestures “Yes” with her hand*].



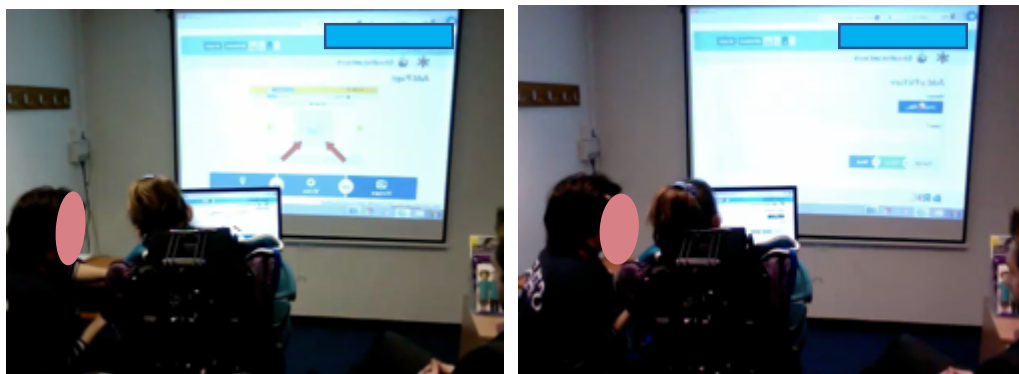
**Facilitator:** “Good talking.”

**Researcher:** “Great choice, nice one. It is a lovely photo.” [*Stands up to move the eye-gaze and replaces the desktop screen (see Figure 4.5.5.4)*].



**Figure 4.5.5.4:** *Swapping the eye-gaze and the desktop screen to enable Pauline to add multimedia to her wiki-page.*

**Facilitator:** “I am going to bring this over so it is in the right place for you to do a nice big red click. [*Referring to the big red switch*]. “Are you going to be able to do that for me?” [*Pauline makes vocalisation and clicks the red switch*] “Well done, we just told it to upload a picture. Now we need to choose a picture don’t we? So we need to go up... up... up” [*providing hand-on-hand support*] “And then click” [*Pauline clicks red switch (see Figure 4.5.5.5)*].

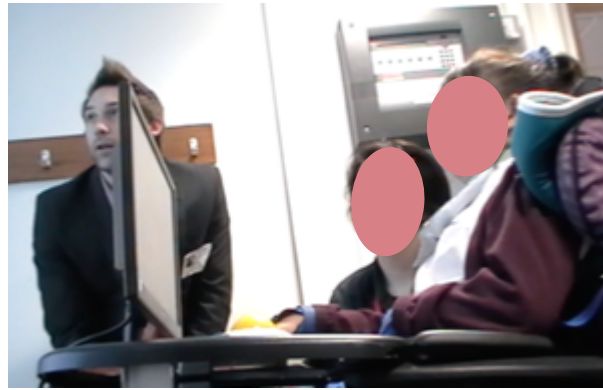
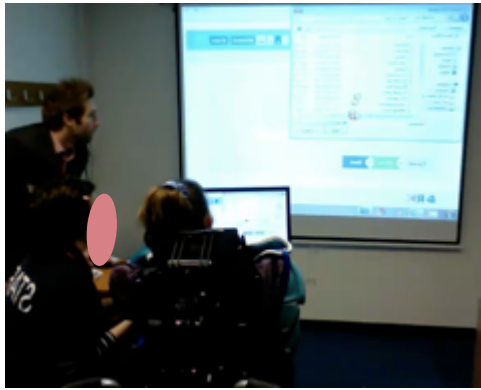


**Figure 4.5.5.5:** *Facilitator supporting Pauline to navigate the ‘add’ photograph menus.*

[*The folder/subfolder menu pops up (see Figure. 4.5.5.6.) The researcher gets up and assumes control of another mouse to navigate the folders and find the photograph Pauline chose on her eye-gaze*].

**Facilitator:** “Richard’s gonna help us find it.”

**Researcher:** “Was it this one with a big smile on your face? If it is can you give me a big click Pauline.”

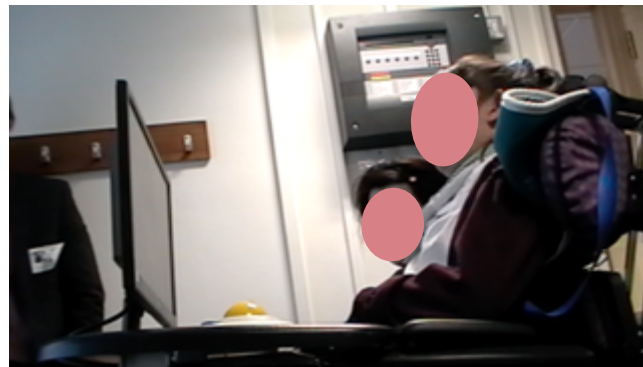


**Figure 4.5.5.6: Researcher locating the photograph Pauline chose on her eye-gaze.**

**Pauline:** *[Pauline clicks the red button and the photograph appears on the wiki-page].*

**Researcher:** “Who is that?”

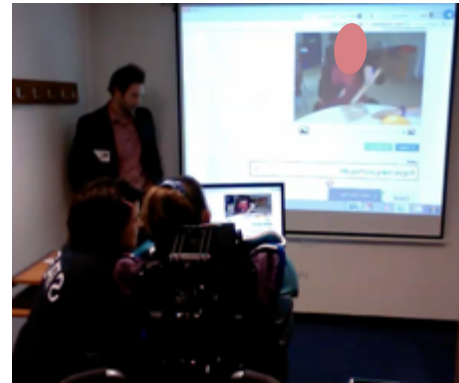
**Facilitator:** “Oh wow, I love your hair that day, it is in a bun.” *[Pauline makes vocalisation].* “Are you happy with that one?” *[Pauline gestures “Yes”].* “Yes? Ok so, ‘This is Pauline using a rolling pin.’ *[Pauline gestures “Yes” and makes loud vocalisation].* “Good girl”. *[Facilitator types out a label/title for the picture (see Figure 4.5.5.7.)]* “Is that spelt right?”



**Figure 4.5.5.7: Facilitator typing out a label/title for Pauline’s photograph.**

**Researcher:** “Hmm, not quite” *[Both facilitator and researcher laugh].*

**Facilitator:** “Ah there we are. Now if you are happy... And I think I have spelt it right... We are going to go down here together.” *[Pointing gesture with finger].* We are going to go to the ‘*finish*’ icon, which is here down at the bottom of the page. *[Whilst providing hand-on-hand support to use rollerball mouse]* “Across... Across, Across... And we made it. And if you could red click for me.” *[Pauline presses red switch]* (see Figure 4.5.5.8.).



**Figure 4.5.5.8:** *Pauline completing the process of adding a photograph with hand-on-hand support.*

**Researcher:** “Great clicking skills Pauline.”

[Completed Wiki-page loads up (see Figure 4.5.5.9.)]

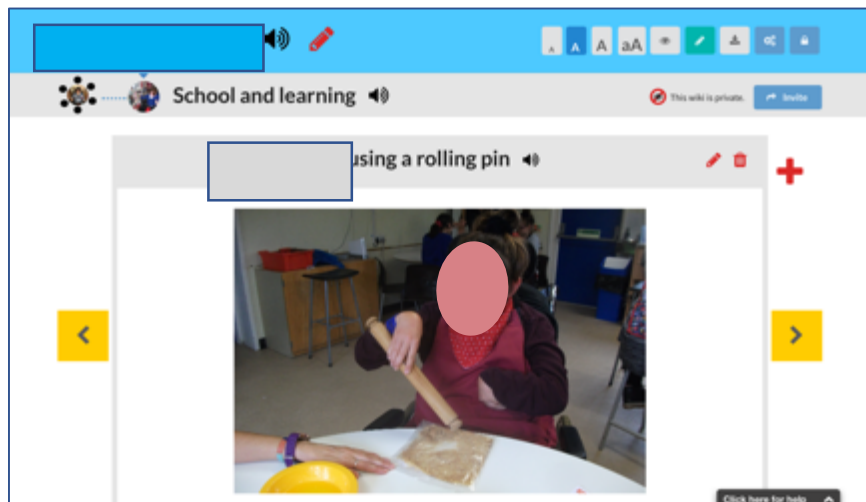
**Facilitator:** “Wow, you’ve just done that, after looking through some photos, doing some good choosing on the eye-gaze and you were amazing with the computer to put it on your wiki-page. When you go home you can show Devon what you’ve been putting on here can’t you?”

**Researcher:** Do you want to try one more Pauline?

**Facilitator:** “Do you feel like you are able to choose one more?”

**Pauline:** [Pauline shakes her head]

**Researcher:** “No?! Have you finished? [Pauline gestures “Yes”]. Would you just like to look through your wiki-page? [Pauline gestures “Yes”].



**Figure 4.5.5.9:** *Example of completed photograph that Pauline selected and uploaded onto her wiki-page.*

#### 4.5.6. *Pauline: Summary of Pauline’s action research journey*

This case study primarily focussed on adaptations that could be implemented to overcome significant impairments with communication and VI. The initial cycle shows that without any adaptations to practice in order to promote her communication, Pauline experienced ‘*non-participation*’, referred to Hart (1992) as ‘*tokenism*’ (‘*rung 3*’).

However, implementing strategies and utilising specialist equipment that promoted Pauline's ability to communicate dramatically improved her '*degree of participation*'. This was increased further with the consideration of supporting her gross and fine-motor skills and adaptations to reduce the impact of these impairments. The facilitator played a central role in providing insight to ensure the adaptations were effective as well as assistance to manoeuvre equipment.

The most significant moment in the research process occurred when the views of Pauline were considered and acted upon to a much greater extent. Pauline became actively involved in the process and took a leading role over the decisions that related to adapting practice. This was only possible through an increased awareness and understanding of Pauline's non-verbal communication nuances, such as her posture and head-positioning by both the facilitator and me.

The result was that Pauline could fully access the wiki-page with the support of the skilled adults but furthermore, was empowered as an equal collaborator in the research design itself. My assessment is that this shift culminated in Pauline reaching the '*highest degree of participation*' ('*rung 8*') according to Hart's (1992) model, where adaptations were often '*youth initiated with shared decisions with adults*'.

#### **4.6. Case study 2: Charlotte**

Charlotte is a 19-year-old female. She has a diagnosis of ataxic hemiplegic CP characterised by damage to motor-control centres that causes an interruption of muscle control in the arms and legs, resulting in a lack of balance and coordination. This is particularly evident for the left side of her body but she also has difficulties in coordinating movements in general. Charlotte presents significant difficulties with learning (SLD) and at times can present challenging behaviour, which reportedly relate to an inability to regulate her emotions effectively and factors related to a diagnosis of autism spectrum disorder (ASD). She also has significant visual impairment (VI) and difficulties with aspects of expressive/receptive language. For a rich and detailed descriptive summary of Charlotte's needs and abilities see *Appendix E*.

##### **4.6.1. Charlotte: Cycle 1 - Strategies to support difficulties associated with visual impairment**

It was immediately apparent that Charlotte faces substantial challenges in activities that require visual abilities or associated skills:

[Percy from *Thomas the Tank Engine* is on the interactive whiteboard].

**Charlotte:** “I can’t see Percy...”

**Facilitator:** “You can’t see Percy? Percy is the small green one isn’t he?”

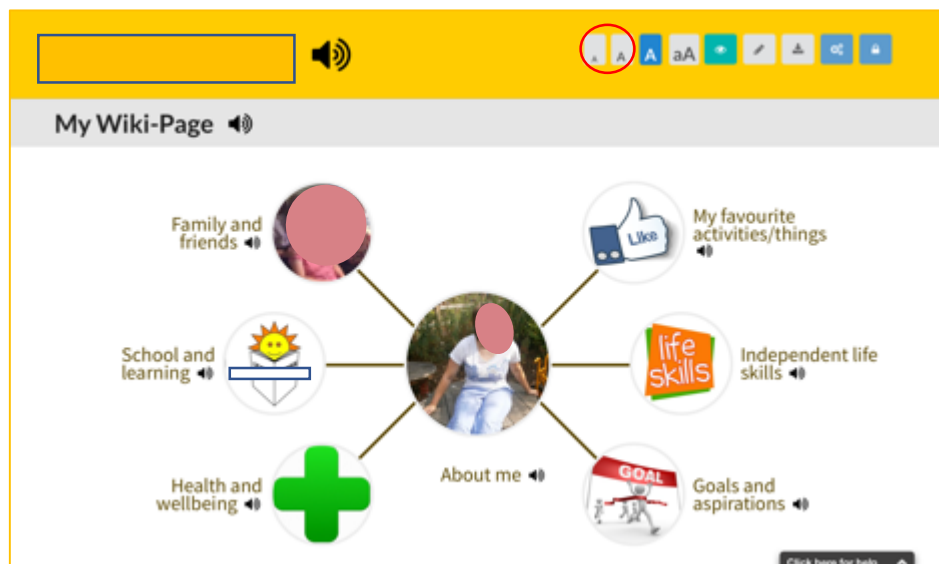
**Charlotte:** [*Pointing in direction of interactive whiteboard*] “Is that Percy, I want him on my wiki-page. I’ll go and have a look.”

**Facilitator:** “You’re going to have a closer look are you?”

**Charlotte:** “Help me please Lola.”

**Facilitator:** “Ok, Let’s have a look together.”

Due to the severity of Charlotte’s visual impairment (VI) the initial cycle focussed on overcoming this potential barrier to participation. A variety of strategies were implemented by the researcher, most of which related to adapting the ICT platforms themselves. Firstly, I used a function on the wiki-page itself that enlarges the size of stimulus (*see Figure 4.6.1.*)



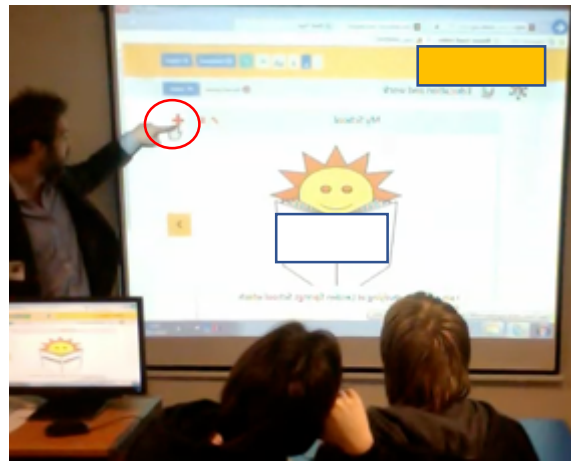
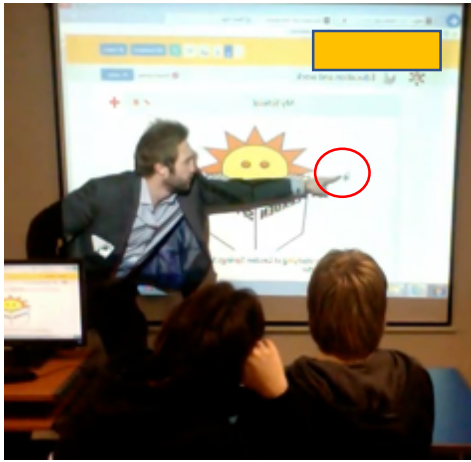
**Figure 4.6.1:** Using a function on the wiki-page platform to enlarge stimuli.

Following on from this, we tested several practical strategies to try and make the cursor more visible to Charlotte. The researcher began by pointing his finger towards the cursor to signify its corresponding location and acted as a guide by replicating the movements she made with the mouse. *Figure 4.6.1.1.* shows that Charlotte could follow the direction of my finger, as her head-positioning indicates, but she found accuracy difficult to achieve due to a combination of her VI and fine-motor impairment. The level of verbal instruction required highlights this challenge:

**Facilitator:** “See where Richard is now? I need you to concentrate.”

**Researcher:** “We need to get from here [*pointing to cursor*] ... to here.”



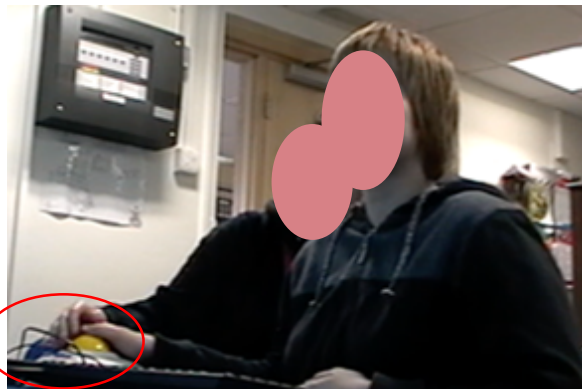


**Figure 4.6.1.1: Using physical indication to replicate the movement of the cursor.**

**Facilitator:** “Can you see where Richard’s finger is pointing? We’ll move it with the rollerball.”

**Charlotte:** “Yeah.” [*Charlotte moves the cursor in the opposite direction*].

**Researcher:** “Good, now can you spin it the other way? That’s it.” [*Facilitator assists by providing hand-on-hand support (see figure 4.6.1.2.)*].



**Figure 4.6.1.2: Facilitator providing hand-on-hand assistance to support fine-motor difficulties and VI.**

**Researcher:** “Well done, keep going... keep going.”

**Facilitator:** “That’s it well done.”

**Researcher:** “Up a bit.”

**Facilitator:** “Go up”

**Researcher:** “And across towards me a little bit... nearly there.”

**Facilitator:** “I am helping a little.”

**Researcher:** “And down.”

**Facilitator:** “And now...”

**Researcher:** “Just up a little bit.”

**Facilitator:** “Stop!”

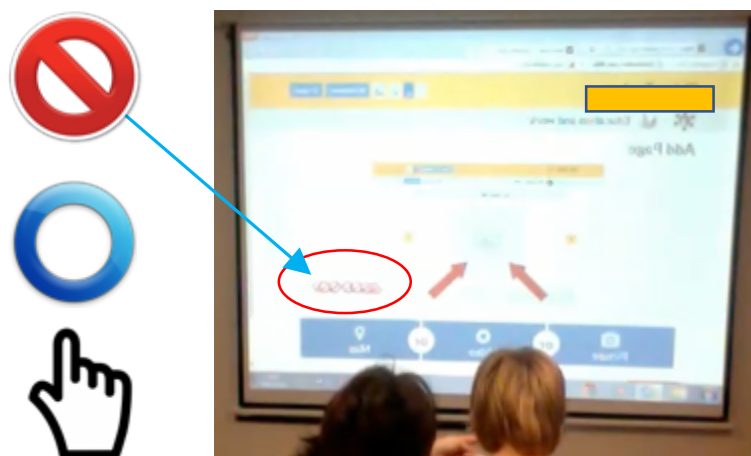
**Researcher:** “That’s perfect.”

With hand-on-hand support from the facilitator and extensive verbal instructions, Charlotte could navigate and input information onto her wiki-page using this technique. However, this strategy was impractical and further modifications were undertaken to make the cursor more visible to Charlotte by changing the system settings on the PC itself. Initially, I enlarged the cursor to the maximum sized-setting and added a cursor trail (*see figure 4.6.1.3*) in the hope that this additional movement would be visible to Charlotte.



**Figure 4.6.1.3: Adding a cursor trail to try to promote identification through movement.**

In addition to this, I altered the icon that represented the location of the cursor to incorporate bright and contrasting colours. Initially, a red ‘no entry’ sign was used for general navigation. When the cursor passed over a ‘clickable’ item the cursor changed to a blue spinning circle, signifying to Charlotte that it was time to ‘click’. This blue circle was later changed to a large, white pointing finger as this seemed to contrast more with the bright colours of the wiki-page (*see Figure 4.6.1.4*).



**Figure 4.6.1.4: The bright contrasting symbols used for the cursor settings and an example of the ‘no entry’ symbol with cursor trail.**

Finally, we experimented with different sized screens using the desktop set-up as well as the interactive whiteboard (*see Figure 4.6.1.5.*) but in general Charlotte’s difficulties associated with her VI meant that she could not identify the cursor on the screen.



*Figure 4.6.1.5: Experimenting with desktop and interactive whiteboard set-ups.*

Subsequently, I thought that audio sources of information might be a more inclusive modality to promote Charlotte's engagement. As a result, we asked Charlotte about her favourite music and noted this down for consideration in the next cycle:

**Facilitator:** "Do you still watch Thomas at home?"

**Charlotte:** "I don't watch it."

**Facilitator:** "No – sorry, I mean listen to it."

**Charlotte:** "I listen to it."

**Facilitator:** "I remember now you don't watch TV do you?"

**Charlotte:** "No I don't like watching it."

**Facilitator:** "You don't like watching TV."

**Charlotte:** "I like listening to music."

**Facilitator:** "That's correct, yeah."

**Charlotte:** "I have my own CDs."

**Facilitator:** "Do you?"

**Researcher:** "What music do you like?"

**Charlotte:** "I like ABBA songs."

**Researcher:** "Did you know Charlotte, that on your wiki-page you can have sounds?"

**Charlotte:** "How do I do that?"

**Researcher:** "So what we could do if you wanted is add some sound. Should we add some of ABBA?"

**Charlotte:** "Yes, I want it."

**Researcher:** "Should I bring in about three different ABBA songs next week and you can choose from them?"

**Charlotte:** "I want to choose."

**Facilitator:** "Yeah."

**Researcher:** "Ok, deal. I'll bring some to choose from next week."



#### 4.6.1.1. *Charlotte: Reflections from cycle 1 and proposed actions for cycle 2*

Overall, Charlotte understood the aims of the wiki-page project but she lacked confidence in her abilities, which impacted participation:

**Charlotte:** “But I don’t know how to use it.”

**Facilitator:** “We are going to teach you, don’t you worry.

**Researcher:** “Exactly.”

**Charlotte:** “I can’t do it.”

**Researcher:** “I believe in you. I am sure you can if you try.”

**Charlotte:** “And I don’t know how to use it.”

**Researcher:** “Well how about at the end of this session we can have a little play together.

And maybe next week you can have more control. And by the end of our work together it will all be you. Does that sound like a good idea?”

**Charlotte:** “Yes but I don’t want Clyde or Wallace to play with it. Only me play with it.”

**Researcher:** “It is your wiki-page.”

**Facilitator:** “That’s right, it’s your wiki-page.”

I hypothesised that VI was a significant factor for the apparent lack of self-confidence. Charlotte was unable to consistently locate the cursor and was reliant on verbal prompts, regardless of the adaptations made to the physical properties of the cursor; changes made to the system settings of the computer; or the type of screen utilised to view the content in terms of desktop or interactive whiteboard.

Due to Charlotte’s passion for music, I concluded that it would be beneficial to focus on providing increased opportunities to access auditory stimulus in the next cycle. Subsequently, I located a Dictaphone in preparation for the next session. Furthermore, having obtained information regarding her music preferences I located, downloaded and organised some audio-files to use in the session.


At this stage in the AR process, Charlotte was informed of the adaptations being made but had very little input in determining them. Furthermore, the lack of direct access to her wiki-page, as well as the lack of impact that adaptations had on her experience, led me to determine that this represented ‘*non-participation*’ (Hart, 1992). The outcomes of this cycle are encapsulated in ‘*rung 2*’ of the ladder of participation known as ‘*decoration*’. This is when activities are ‘*adult-led and the young person understands the purpose but has no input in relation to planning*’.

#### 4.6.2. Charlotte: Cycle 2 – Increased use of audio multimedia to overcome visual impairment

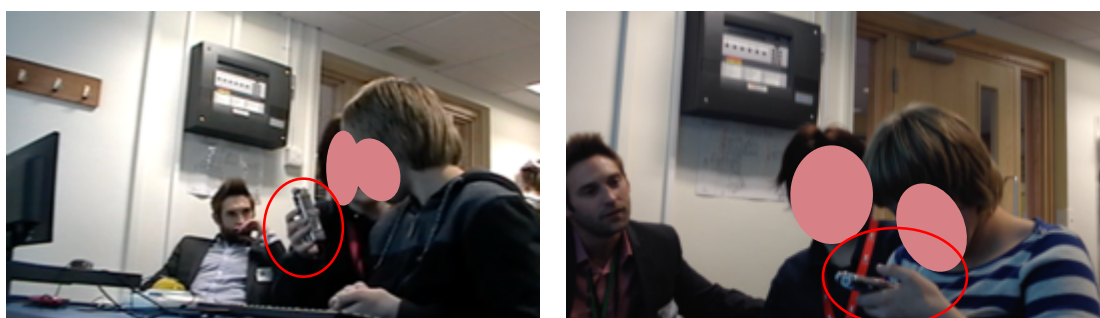
The use of audio multi-media was a viable option as the wiki-page platform incorporates a specific function for this purpose (see Figure 4.6.2.).



**Figure 4.6.2: Ability to add and play audio multi-media on the wiki-page.**

The first strategy we adopted was using the Dictaphone to label multimedia. We supported Charlotte to make choices regarding the content of recordings and provided her with a choice of who created the recording. She initially lacked the confidence to use this tool due to difficulties with her expressive language skills but with encouragement and positive reinforcement she developed the self-confidence to record her own voice. These were added to the wiki-page and could be played by pressing the icons as illustrated  in (see Figure 4.6.2.).

The opportunity to access this device also seemed to develop skills and promote her knowledge in technology. Initially the facilitator or I were responsible for pressing the ‘record’ and ‘stop’ buttons, as well as holding the Dictaphone, whilst Charlotte created audio files. However, with practise, repetition and over-learning opportunities Charlotte could do this independently with the support of verbal prompts (see Figure 4.6.2.1).



**Figure 4.6.2.1: Charlotte creating voice recordings with the support of adults as well as independently with minimal verbal prompts.**

In addition to this strategy we focussed on adding audio multimedia that Charlotte was passionate about. This involved substantial preparatory work to ensure they were compatible

with the MMSA platform. Charlotte particularly enjoyed this activity and it seemed to provide increased motivation and engagement (see Figure 4.6.2.2.).

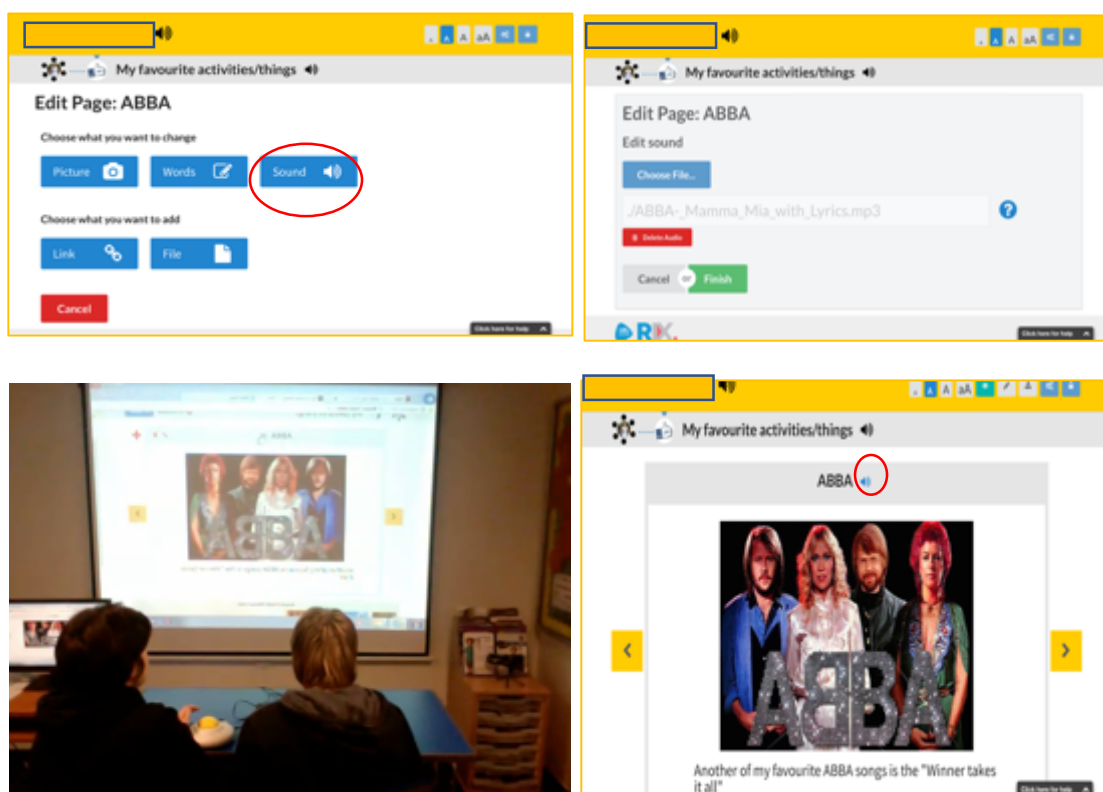


Figure 4.6.2.2: Focussing on creating audio multimedia that captures Charlotte's favourite activities.

#### 4.6.2.1.Charlotte: Reflections from cycle 2 and proposed actions for cycle 3

Charlotte responded well to the use of audio multi-media as this significantly reduced the impact of her VI. Furthermore, she assumed an active role in activities, such as recording her voice and making choices on her preference of audio multimedia. There was a marked increase in the level of independence that she could achieve and this provided her with more opportunities to take a leading role in the direction of activities. The combination of these factors appeared beneficial for promoting her self-confidence.

This cycle highlights that activities were generally ‘*adult-led and she had an active role in the decision-making process*’ representing ‘*rung 6*’ on the ladder of participation (Hart, 1992). However, at times she also assumed a leading role in directing certain activities in collaboration with adults and acquired the necessary skills to perform these activities with a degree of independence. This arguably represents the highest level of participation (‘*rung 8*’) where activities are ‘*youth initiated with shared decisions with adults.*’

It became increasingly apparent that Charlotte is a particularly self-directed individual, which may relate to her diagnosis of ASD and a lack of flexibility in thinking skills. In addition to this,

Charlotte presented a lack of inhibitory responses or behaviours. This was initially identified as a barrier to maintaining her attention during the sessions as she could become ‘fixated’ on certain topics of interest. She often made requests related to her family, which was challenging since all the multimedia I had access to was in the school context and the remit of the research was school based:

**Charlotte:** “Mum and Dad. I want them on and I want to choose which one of them. I want to choose my family as well. I want to choose the pictures.”

**Researcher:** “Ok, who do you want pictures of? Because we will ask your Mum to send some in before our next session. Do you want pictures of Mum and Dad?”

**Charlotte:** “Mum and Dad.”

**Researcher:** “So we will have to ask your Mum if she can send some photos in so we can add them to your wiki-page.”

**Charlotte:** “I want to do it.”

**Researcher:** “We can do it but we need to have photographs first.”

**Charlotte:** “I want to show these to Dad. Can I put my dad on my wiki-page? I want him to do the wiki-page.”

**Facilitator:** “You can show them to Dad”

**Charlotte:** “I want to show them how to use this. I want to show this to Mummy and Daddy.”

**Researcher:** “How about when they next come into school. I could give them a tour of it?”

**Charlotte:** “In school.”

**Researcher:** “Ok, I’ll talk to your Mum, I will give her a call after we finish.”

In addition to her family she often referred to her class and using an iPad:

**Charlotte:** “I want to show Diamond. I want to show it to Diamond class, my wiki-page on the iPad.”

**Facilitator:** “Definitely Diamond.”

**Charlotte:** “Can I show Diamond when it is finished? Diamond, with iPad.”

**Facilitator:** “You can show them when it is finished and sometimes in between as well.”

**Charlotte:** “I want to show it to Diamond. I want to show them when I go back to Diamond.”

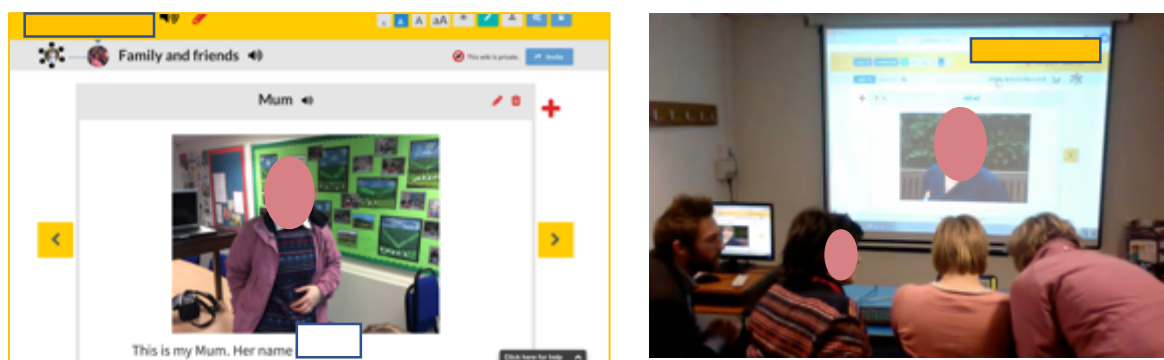
**Facilitator:** “You certainly can, I think Jasmine would like to see it.”

**Researcher:** “They will all be impressed.”

At times the facilitator and I both had to ensure we had the personal resources to manage our emotional responses as these interactions could be quite intense and required patience. We supported each other so that we effectively managed her needs whilst keeping her ‘on-task’. However, I also reflected that these were valid and important issues for Charlotte. Consequently, in the next cycle I intended to embrace Charlotte’s individual characteristics and attempt to appease some of these unmet needs.

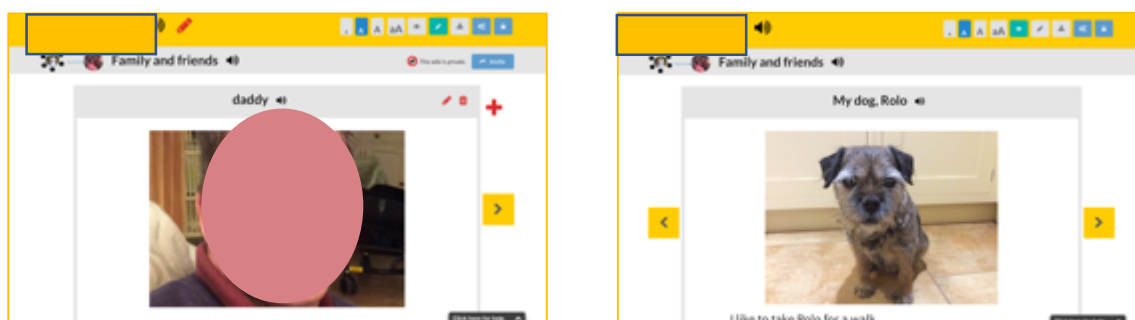
#### 4.6.3. *Charlotte: Cycle 3 – Adaptations to practice and directed by Charlotte*

This cycle focussed on providing Charlotte with increased agency in relation to the evolution of the research design itself. During this cycle, I contacted the parents of Charlotte and invited her mother to join us for the next wiki-page session (*see Figure 4.6.3*).



**Figure 4.6.3: Charlotte’s mother attending a wiki-page session for training.**

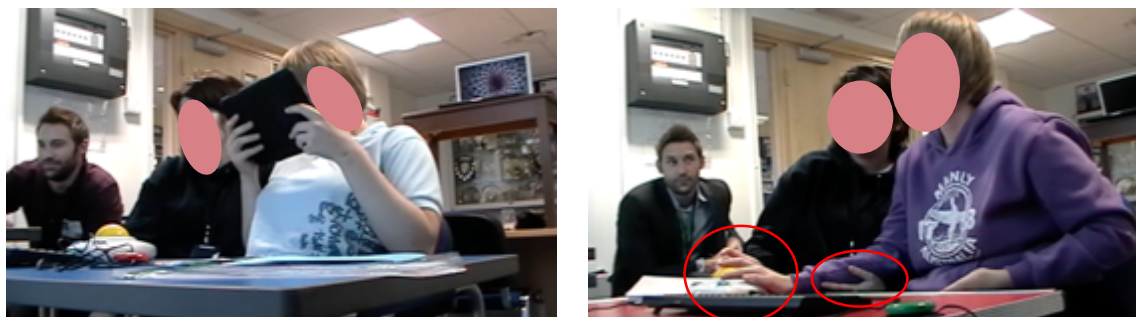
This provided an opportunity for further training so that Charlotte would have support to access the wiki-page at home, further expanding the potential to add content that was not available in the school setting (*see Figure 4.6.3.1*). Whilst this might seem like a simple endeavour, it required significant amounts of time to communicate, organise and make formal arrangements between several stakeholders including the parent(s), school, facilitator, Charlotte and myself.



**Figure 4.6.3.1: Examples of multimedia uploaded in the home context due to increased collaboration.**

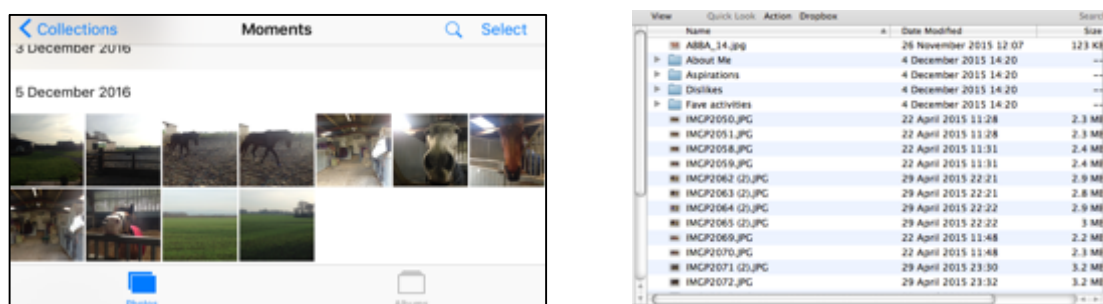
In addition to this, I arranged to loan an iPad from the transition team in the school. To my surprise the iPad appeared to remedy some of the difficulties that Charlotte had experienced in

earlier sessions. It removed some of the barriers associated with her fine-motor impairment that had previously impacted her ability to control equipment such as the mouse. This seemed to be due to the touch screen function, which requires less fine-motor coordination skills in comparison to the rollerball adapted mouse (*see Figure 4.6.3.2*).



**Figure 4.6.3.2.** Charlotte experienced increased independence when using the iPad in comparison to traditional PC systems.

The iPad platform also differs from the PC in terms of the functions that are necessary to add multi-media. It utilises a gallery mode to select the desired photograph whereas the PC requires the navigation of complex folders and sub-folders. It is therefore a more simplistic process for Charlotte to select the appropriate file (*see Figure 4.6.3.3*).



**Figure 4.6.3.3:** Comparison between the iPad and PC-based file selection processes.

This resulted in less intervention from the researcher as Charlotte could use her finger to select a photograph with direct correspondence, again mitigating any issues related to fine-motor impairment or difficulties with coordination. Finally, it also seemed to promote the confidence in her abilities and fostered a sense of ownership over her wiki-page:

**Charlotte:** “I want them on my wiki-page.”

**Facilitator:** “That is a lovely idea, they are your friends.”

**Charlotte:** “I want grown-ups on as well. I want David on. I want to show them how to use it. David does not know how to use it.”

**Facilitator:** “Would you like to choose your favourite photo of them to put on your wiki-page?”



**Charlotte:** “Which one?”

**Facilitator:** “It is up to you.”

**Charlotte:** “It’s my wiki-page, not yours.”

**Facilitator:** “No, it’s not mine.”

**Charlotte:** “It’s all mine.”

**Facilitator:** “It doesn’t say Lola’s wiki-page... It says Charlotte.”

**Charlotte:** “It not for you.”

**Facilitator:** “It’s not, so I can’t choose.”

**Charlotte:** “It is my wiki-page up there.

**Facilitator:** “It is all for you. It is for Charlotte.”

**Researcher:** “I am really happy that you like doing it so much because who’s wiki-page is it?”

**Charlotte:** “Mine! Can I do my wiki-page again? I just have to do it. I’m getting good aren’t I?”

#### **4.6.3.1. Charlotte: Reflections from cycle 3 and proposed actions for cycle 4**

The adaptations in this cycle were initiated by the researcher in response to the requests made by Charlotte. In my mind this clearly encapsulates the highest level of participation according to Hart (1992) when activities are ‘*youth-led with adult support*’ (*‘rung 8’*). It highlights that researchers who engage in emancipatory AR should be open to participant-led action. In this instance, it was extremely beneficial for meeting Charlotte’s needs. This shouldn’t be surprising when one considers that she ‘knows’ better than anyone else, what she wants.

This particular cycle highlighted several ‘*blind spots*’ in my previous thinking. I had assumed that a large interactive whiteboard would be more accessible for someone with VI. However, the iPad clearly supported Charlotte’s needs more effectively than the alternative methods previously adopted. My hypotheses were that this might indicate that the nature of Charlotte’s VI impact her visual field. The large interactive whiteboard requires a wide field of vision, whereas an iPad contains information in a small, compact area. Furthermore, interactive whiteboards are generally very bright and the glare they produce might make it hard for someone with VI to identify small items such as a cursor (*see Figure 4.6.3.4*).



**Figure 4.6.3.4:** Interactive whiteboards produce glare and require a wide field of vision.

This might also explain why Charlotte's visual skills seemed to improve when she made choices using enlarged photographs on paper (see Figure 4.6.3.5):

**Facilitator:** "What we've done is we've printed of some of your really good work and some of your awards that you have got in the past. Yeah?"

**Charlotte:** [*Nods*] "Yeah."

**Facilitator:** "Because I wanted to show Richard some of the good work you do."

**Charlotte:** [*Begins laying the photographs out on the table in front of her*] "Diamond class."

**Facilitator:** "Diamond..."

**Charlotte:** "I know which ones of me are."

**Facilitator:** "Have a little look. Who is that young lady?"

**Charlotte:** [*Smiles*] "Me doing a...err."

**Facilitator:** "And what are you doing there?" [*pointing gesture*]. "Can you see it ok if you hold it there?"

**Charlotte:** "What is that? Err... When I was doing my polar bear."

**Facilitator:** "Yes that's right that is a picture of a polar bear... when you were out at the art cafe."

**Charlotte:** [*Turns to the researcher and offers the photograph (see Figure 4.6.3.5.)*] "My polar bear."

**Researcher:** "Oh wow! That is excellent. Would you like a photograph of that on your wiki-page?"

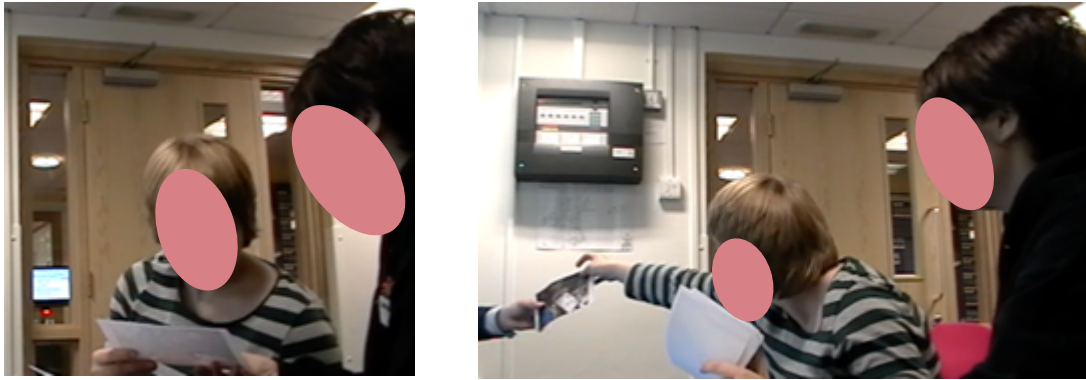
**Charlotte:** "Yes I would" [*Nodding head enthusiastically*].

**Facilitator:** "So these are a good size for you to see aren't they Charlotte? This big."

**Charlotte:** "Yes." [*Nodding*].

**Facilitator:** "You can see this size nicely."





**Figure: 4.6.3.5: Charlotte could identify and discuss enlarged photographs on paper.**

Overall, this cycle was useful for altering my perception towards Charlotte's needs. Furthermore, it seemed to require far less intervention to keep her 'on-task'. Perhaps this was because we were meeting her needs more effectively by approaching the activity from her perspective instead of following our agenda. Regardless, in my view it represented a genuine redistribution or re-balancing of power.

Charlotte had clearly gained self-confidence from the previous two cycles and was acquiring new skills. In the next cycle, I wanted to introduce other novel activities in the hope of further promoting self-confidence in her abilities. This would focus on her ability to express herself to other people that did not include the facilitator, parents or myself.

#### **4.6.4. *Charlotte: Cycle 4 – Strategies to promote Charlotte's self-confidence in skills and abilities***

In this cycle, we encouraged Charlotte to attempt new activities such as practising typing skills. Although her VI meant that she found it challenging to identify some letters, she began to develop skills with repetition and would press larger, familiar keys such as 'enter' and 'spacebar' independently. Overall, she indicated a desire to participate and a perseverance to stay 'on-task': (see Figure 4.6.4.):

*[Researcher is typing]*

**Charlotte:** "Richard is doing it."

**Researcher:** "Do you want to type?"

**Facilitator:** "Do you want to do it?"

**Charlotte:** "I'll do it."

**Researcher:** "Ok, that is great, How old are you Charlotte?"

**Charlotte:** "19."

**Researcher:** [*Providing prompts to type*]. “I’ll help you out - I.. space... can you remember the space?... great... and then ‘a’... down a bit...”

**Facilitator:** “Well done.””

**Charlotte:** “I have to do it.”

**Researcher:** “You are doing great... m,... m. Down a bit. Down one more. Down one more. There. And then space. You are good at the ‘space’ aren’t you? Then we need a 1, which is the top one here. That’s it. And did you say 19?”

**Charlotte:** “19.”

**Researcher:** “So what about a 9? We’ve got a 2, 3, 4, 5, 6, 7, 8, and...” [*counting up the numbers on the keyboard with finger*].

**Charlotte:** “9!”

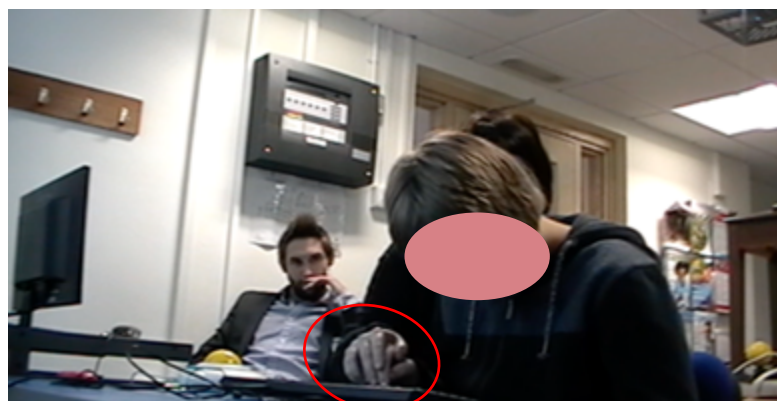
**Researcher:** “And then enter, which is this big one. Great job!”

**Facilitator:** “You’re doing really well. I am very proud of you.”

**Researcher:** “Yeah I am impressed and you are showing really good effort.”

**Charlotte:** “I want to do it.”

**Facilitator:** “You are. Fantastic!”



**Figure 4.6.4:** *Charlotte typing with hand-on-hand support from the facilitator.*

In the second part of the session, we also invited one of her favourite teachers who she has a good relationship with. We provided Charlotte with her favourite mode of accessing the wiki-page (iPad) and encouraged her to share her favourite aspects of it with us all (*see Figure 4.6.4.1.*). She could navigate and browse through her wiki-page with a level of independence and showed considerably more confidence than in the initial sessions.



**Figure 4.6.4.1: Charlotte presenting her wiki-page to adults via the iPad.**

#### **4.6.4.1. Charlotte: Reflections from cycle 4 and proposed actions for cycle 5**

This cycle illustrates the potential applications of the wiki-page as an effective advocacy-tool as it seemed to promote Charlotte's ability to express herself to others. This might be due to the visual support and points of reference provided by the photographs and audio multimedia. It also supports assertions made in previous cycles that Charlotte could access her wiki-page better on the iPad as opposed to other traditional methods.

In the final cycle, I wanted to demonstrate the significance of Charlotte's transformation during this project. I also hoped to further promote the emancipatory nature of the research by providing Charlotte with an opportunity to achieve yet another level of SA. This would be accomplished with a combination of strategies developed from the learning of previous cycles. The nature of the task would therefore focus on the values and principles that underpin my AR methodology, as well as incorporate specific adaptations that had manifested from the research project. The intended result was that Charlotte would engage in an activity that would promote opportunities for choice and SA at a conceptual level as well as practical one.

#### **4.6.5. Charlotte: Cycle 5 – Providing opportunities to capture and create multimedia in 'real-world' situations.**

For the final cycle, I intended to harness the flexibility of the AR methodology, which is not constrained to conducting research in a specific setting or context. I empowered Charlotte by giving her the iPad and instead of remaining in the meeting room typically utilised for our sessions, provided her with the opportunity to navigate the school setting and capture her own multimedia. This was significant as the multimedia previously added was generally pre-determined, originating from the school database. My rationale was that this represented genuine 'autonomy' in relation to SA as the content uploaded would not be restricted or limited by prescribed options.

Charlotte made independent choices regarding the multimedia she desired. She then captured it with the assistance of verbal prompts and support to orientate the direction of the camera:

**Charlotte:** “Am I allowed to take office?”

**Facilitator:** “You want one of the office?”

**Charlotte:** “Outside the office.”

**Facilitator:** “Ah, ok in front of school? Yeah, of course.”

**Charlotte:** “Yeah school office.” [*Charlotte takes photograph of school entrance with iPad (see Figure 4.6.5.)*].

**Facilitator:** “Well done. Now do you want one of you standing outside your class?”

**Charlotte:** “Yes I do.”

**Facilitator:** “Go on then – Take your walker with you so you are safe.”

**Researcher:** “Over this way. Come and stand here with me Charlotte and then I’ll move out of your way ok.” [*Facilitator captures photograph of Charlotte outside of her classroom (See Figure 4.6.5.)*]

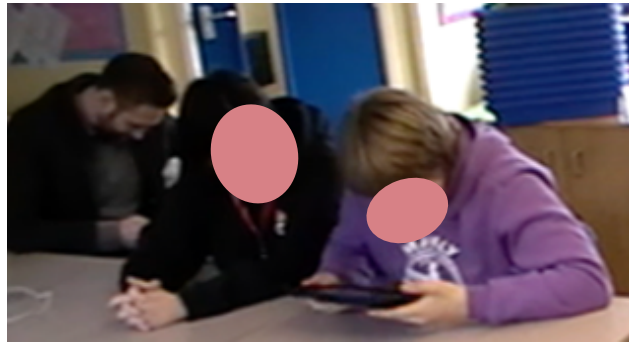
**Charlotte:** Now can we take pictures of playground.

**Researcher:** “Of course, let’s head over there.



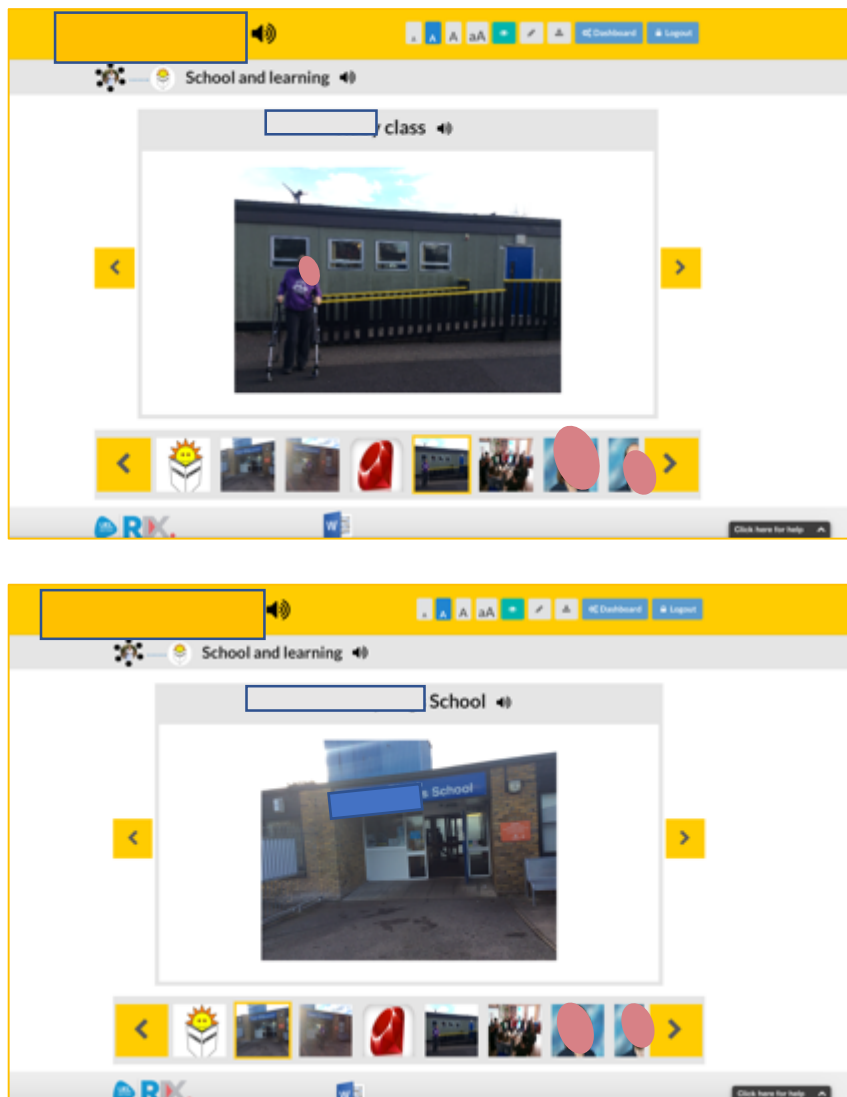
**Figure 4.6.5:** *Charlotte creating multimedia of her choice in the school environment.*

When we returned to the classroom and she uploaded this content to her wiki-page with minimal verbal prompts. Furthermore, she completed the process by creating text and audio labels with the voice recording feature (*see Figure 4.6.5.1*).



**Figure 4.6.5.1. Uploading and labelling multimedia to her wiki-page that Charlotte had created using the iPad.**

Figure 4.6.5.2 represents examples of the multimedia Charlotte captured as it appeared on her wiki-page when the process was completed.



**Figure 4.6.5.2: Examples of multimedia Charlotte captured and uploaded as it appears on her wiki-page.**

#### **4.6.6. Charlotte: Summary of the action research journey**

Charlotte's journey represents a significant shift from a passive role of '*non-participation*' to the highest '*degree of participation*', as prescribed by Hart (1992). Difficulties related to VI and fine-motor difficulties, as well as a lack of understanding of the research process, meant that

Charlotte's involvement in the initial session was perceived as '*decoration*' ('*rung 2*'). However, with several cycles of adaptations to the technology adopted, as well as a shift in the researcher's perception of her involvement in the research design, Charlotte could direct activities that were '*youth-led with adult support*' ('*rung 8*').

This transformation occurred due to the researcher 'listening' to and 'acting' on the needs expressed by the individual, which at first were perceived as subtle off-task behaviours. Collaboration with the facilitator, as well as the involvement of parents, was a central factor in achieving positive outcomes. These partnerships were important in mediating additional barriers associated with individual characteristics, such as assisting Charlotte to regulate negative emotional states and challenging behaviour.

Recognising Charlotte's individual needs was crucial in shifting the focus with regards to the type of multimedia utilised. The use of audio multimedia seemed to be the catalyst for Charlotte's increased willingness to engage and ability to stay on-task. I suggest that this is because it is a domain of communication that is easily accessible for her, which in turn increased active involvement and participation. This appeared to have additional benefits such as promoting her self-confidence as well as her sense of ownership over the wiki-page.

Cycles 5 & 6 highlight the potential applications of the wiki-page platform as an effective SA tool. It enabled Charlotte to express herself to others and provided her with opportunities to make unrestricted choices in matters that were important and significant to her. Overall, this project seems to have provided Charlotte with a platform to express her abilities, whilst also providing opportunities to develop and obtain mastery in novel skills and devices related to ICT.

#### **4.7. Case study 3: Connor**

Connor is a male who is 19 years old. He has a diagnosis of spastic hemiplegic CP, which limits some aspects of movement and coordination of his leg, arm and hand on the left hemisphere of his body. This condition is often characterised by tense muscles and spasms in the affected regions. In addition to this, Connor has also been diagnosed with a diagnosis of autism spectrum disorder (ASD) and exhibits moderate learning difficulties (MLD). Furthermore, he has relative strengths in expressive and receptive language skills. For a rich and detailed descriptive summary of Connor's needs and abilities see *Appendix E*.



For several reasons, it was felt that Connor did not require a facilitator to be present during the wiki-page sessions. Firstly, he did not present with significant communication difficulties or challenging behaviour. Consequently, a facilitator was not deemed necessary to assist in mediating interactions or to provide support in the management of specialist equipment. Furthermore, we had developed a good rapport in the preparatory phase of the research and he generally responds well to male role-models. An agreement was reached that he would work 1:1 with the researcher. Various members of staff would make regular checks to provide safeguarding measures for both the facilitator and Connor. However, they did not take up an active role in the research project itself, nor the AR cycles.

#### **4.7.1. Connor: Cycle 1 – Training to promote understanding of the wiki-page technology**

Prior to working with Connor, I established that he already possessed a range of skills, previous experience and knowledge related to ICT. This was immediately apparent at the beginning our first session:

*[Connor is seated with the laptop in front of him and the researcher enters the room.]*

**Researcher:** “Alright Connor – Do you want to go on the internet for me?”

**Connor:** “I’m already on there.”

**Researcher:** “You are already on there?! Nice one dude.”

This initial interaction provides an indication of the rapport that I had worked hard to establish with Connor in the preparatory stage of the research (*see Chapter 4.3*). The relationship that we had developed resulted in sessions that were very relaxed and informal (*see Figure 4.7.1*). I felt that these types of interactions assisted in preventing potential power imbalances from developing and promoted the aim of maintaining an equal partnership:

**Researcher:** “I think it’s nearly time for a cup of tea pal. What do you think?”

**Connor:** “Most definitively mate. Are you making?”

**Researcher:** “Two sugars is it today?”

**Connor:** “Nice one.”



**Figure 4.7.1: Cultivating a relaxed environment with equal power dynamics.**

Whilst Connor had knowledge of the internet and previous experience using social media platforms, the wiki-page was a novel concept that required some coaching to access. For instance, assistance was needed to locate the web-page and I used this opportunity to assess his receptive language, working-memory and literacy skills. I purposefully did this so that I gained a better understanding of his needs and could provide the appropriate level of support in future sessions:

**Connor:** “Wiki... R. I.” [*Talking out loud*].

**Researcher:** “So put in RIX WIKI... That is R.I.X” [*Calling out letter names*].

**Connor:** [*Connor begins typing incorrectly*]. “I”.

**Researcher:** “Try to remember the R... So if you can go back one.” [*Gesturing with finger*].”

**Connor:** “Yep.”

**Researcher:** [*Using letter sounds and at a slower pace*] “R...I...X

**Connor:** “R..I..” [*Pause*]

**Researcher:** “X for X-Ray... and space... wiki.”

**Connor:** “... wiki”

**Researcher:** “W... I...”

**Connor:** [*Interrupts as predictive text has recognised website*]. “It’s there!.. W.. I...Key..  
“

**Researcher:** Great job!”

**Connor:** “Does that end in an I?”

**Researcher:** “Yup.”

**Connor:** “So it is there – Hurray!”

**Researcher:** “Nice one.. rixwiki.org.. That’s perfect.”

I intended to give Connor autonomy over his wiki-page to use as he saw fit so I left a blank template for him to design. I also reaffirmed my role in the process:

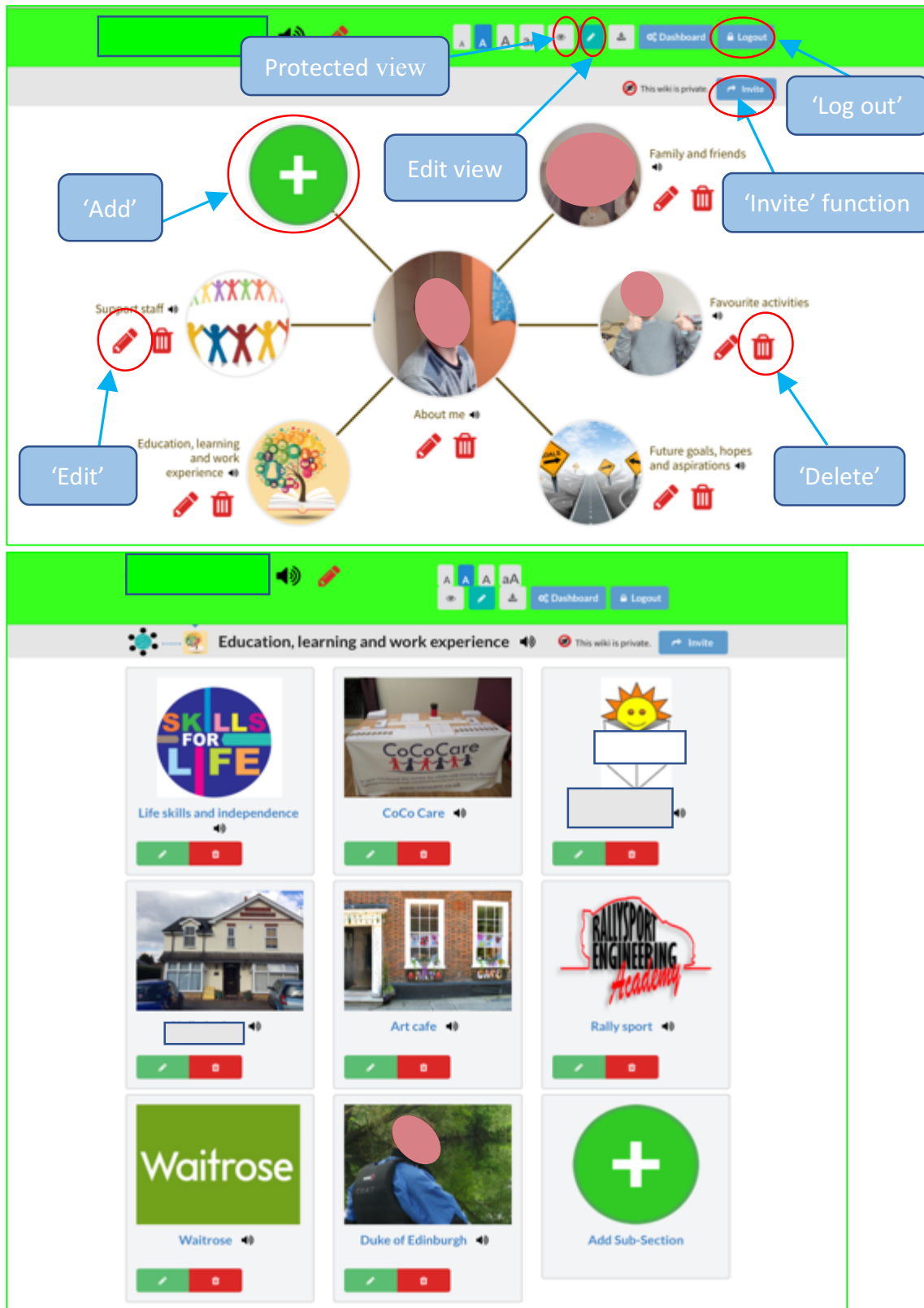
**Researcher:** “Do you see how it is blank?... That is because it is your fresh canvas. I don’t want to put anything on for you so I haven’t done a template [*checking understanding of meaning*] because this is your wiki-page.”

**Connor:** “Yeah.”

**Researcher:** “I am just here to help you out when you need me.”

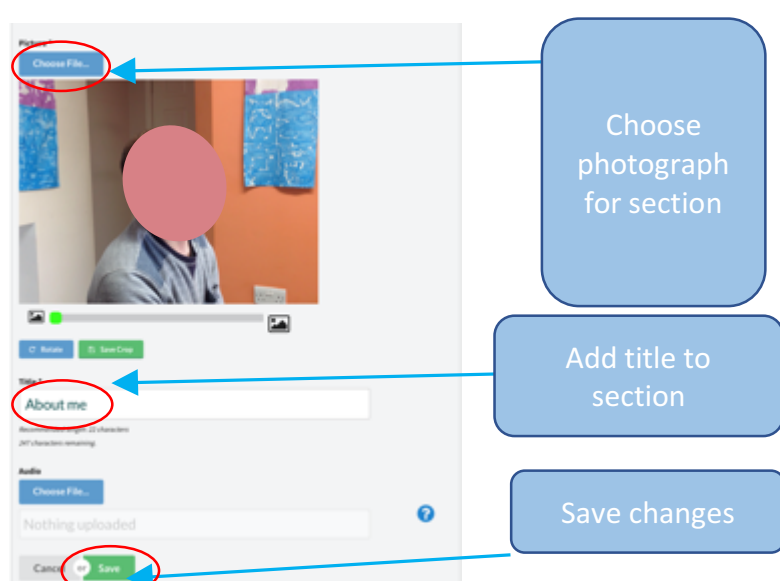


This cycle focussed on coaching Connor to use the variety of functions within the wiki-page platform, generally relying on verbal instruction and pointing gestures. Connor was unique in this research project as I negotiated with the RIX centre to supply him with a multi-layered wiki-page. This means that in addition to the seven main sections there is also the possibility to add an infinite number of sub-folders to each section (*see Figure 4.7.1.1*)

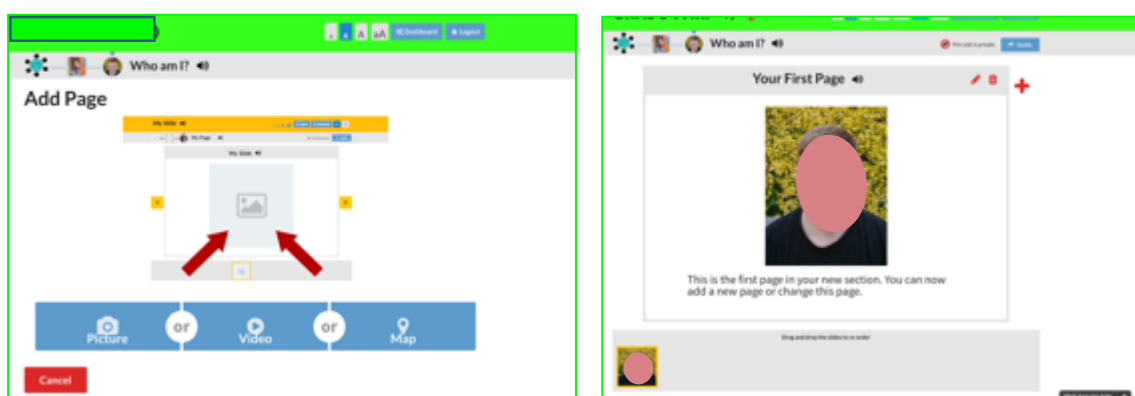


**Figure 4.7.1.1: Connor's multi-layered wiki-page with the seven main sections and various sub-folders.**

I initially explained how the ‘protected view’ and ‘edit view’ functions operated so that he could browse or make changes to his wiki-page. Connor could add, edit and delete content for the main sections and sub-folders with relative ease. Furthermore, he could title or label his sections with minimal verbal prompts, generally only requiring assistance with his spelling. He quickly mastered the skills necessary to create sections and sub-sections so I also showed him how to add multimedia to individual pages within the different areas, which follows a similar process (see Figures 4.7.1.2 & 4.7.1.3). Although I explained the ‘invite’ function we did not use it during the coaching period. At the end of the session he ‘saved’ his work and ‘logged out’.



**Figure 4.7.1.2: Example of Connor creating a main section in his wiki-page.**



**Figure 4.7.1.3: Example of Connor creating his initial page in a sub-section of his wiki-page.**

#### **4.7.1.1.Connor: Reflections to cycle 1 and proposed actions for cycle 2**

Connor clearly demonstrated a good knowledge of ICT in general, as well as a sound understanding of the internet and wiki-page platform. This was due to past experiences using social media, which had been reported to me by others as ‘problematic’. This related to comments or content which some felt were inappropriate. Regardless, Connor quickly developed the necessary skills to create a template for his wiki-page platform and add multi-

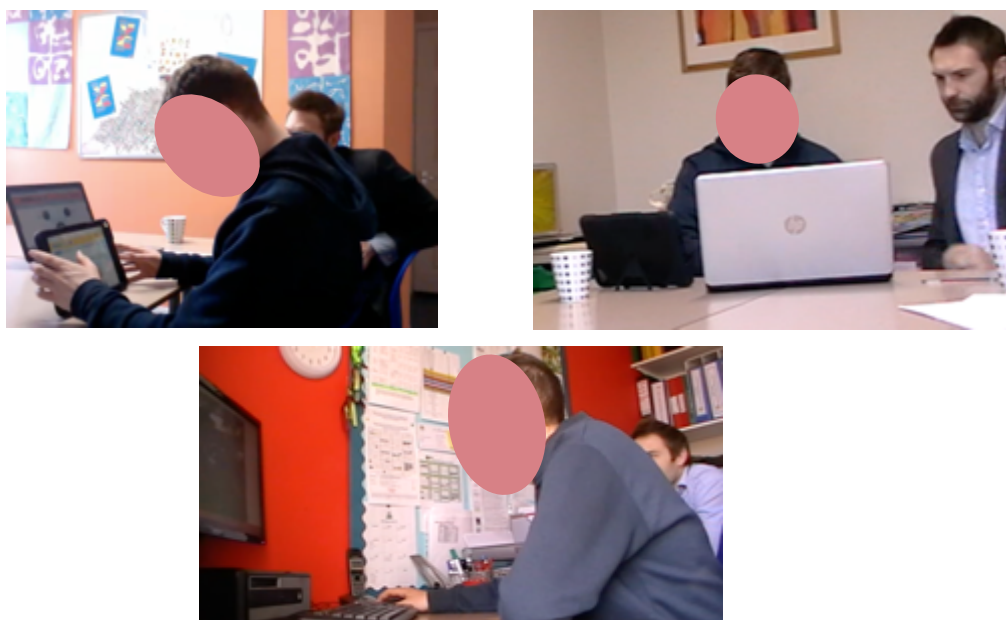
media, such as photographs and videos. Consequently, he was already achieving a high ‘*degree of participation*’ according to Hart (1992).

I reflected on the rapport that we had developed and the style of our interactions. I questioned whether this had been influenced by any of my previous experiences and whether such an informal approach was warranted. I concluded that developing good rapport is a central skill in the role of an EP. Furthermore, working alongside an individual with competent expressive and receptive language skills was a liberating experience that enabled me to utilise my persona. In my opinion, these humorous interactions manifested organically and their authenticity fostered a trusting partnership.

Overall, this seems to represent ‘*rung 6*’ on the ladder of participation (Hart, 1992). In this cycle, activities were ‘*adult-led with shared decisions with youth*’. In the next cycle, I aimed to provide Connor with an opportunity to experiment with a variety of methods to determine his preference for accessing his wiki-page.

#### **4.7.2. Connor: Cycle 2 – Experimenting with different modalities for accessing the wiki-page**

During this cycle, we experimented with several modalities of accessing Connor’s wiki-page. This included the laptop computer, PC desktop computer and iPad (see Figure 4.7.2.). Furthermore, it was not uncommon for him to access several modalities simultaneously.



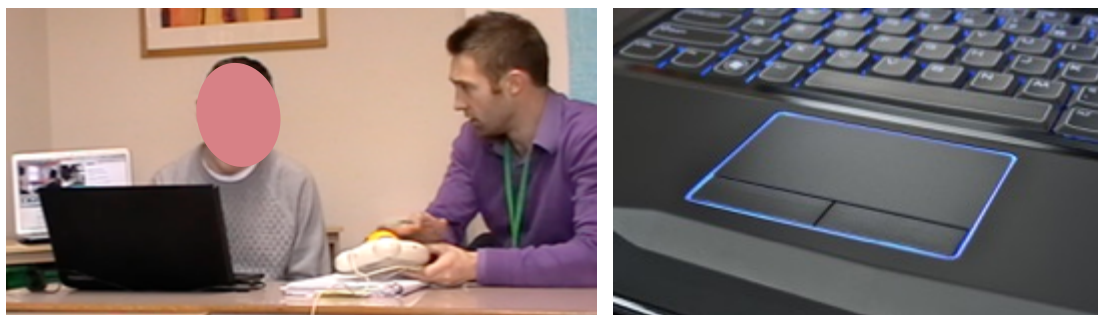
**Figure 4.7.2: Connor experimenting with different mediums to access his wiki-page.**

Connor had used the laptop in the initial session so he was familiar and proficient with it. I checked with him to confirm that he was happy using the laptop touchpad and asked if he wanted to use alternative mouse options, which he declined (*see Figure 4.7.2.1.*):

**Researcher:** “Now - First of all, are you ok using the touchpad or do you want to try a different mouse?”

**Connor:** “I prefer using this one.”

**Researcher:** “Great choice.”



**Figure 4.7.2.1:** *Providing Connor with a choice of a variety of alternative or adaptive technology.*

The PC desktop computer platform is based on the same software as the laptop, so once again he could work with a high level of independence with this modality due to its familiarity. However, with the iPad he initially required more verbal prompts before gaining fluency of skills as the following extract highlights. This coaching requirement was due to slight variations in the process of uploading photographs for this modality:

**Researcher:** “How do we edit? Can you remember?”

**Connor:** “Yup... add” [*presses ‘+’ symbol*].

**Researcher:** Yeah, sure. And what are we going to add? Video or photo?”

**Connor:** “Let’s try video.”

**Researcher:** “Ok, which one?”

**Connor:** “That one we recorded this morning.”

**Researcher:** “Ok so we want to upload our own clip, so we press that button. Now we choose the file.”

**Connor:** “Ok....”

**Researcher:** “And because we recorded it where is it going to be?”

**Connor:** “In photo library.”

**Researcher:** “Exactly, and then we go into...”

**Connor:** “Videos. This one?”

**Researcher:** “Perfect.”

**Connor:** “Let’s put this one on there.”

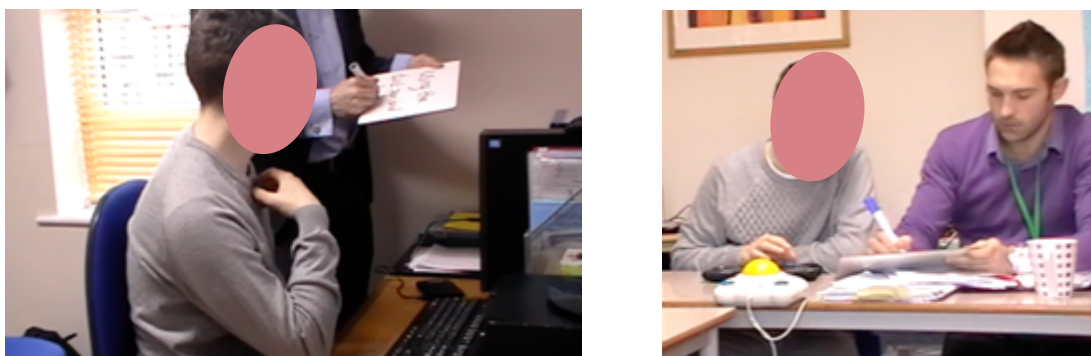
**Researcher:** “Nice, and this is... what were you doing?”

**Connor:** “Cooking marshmallows.”

**Researcher:** “Do you want to add words to this video or add another one?”

**Connor:** “Add words to this one.”

*[Researcher assists with difficult spellings by writing on a miniature whiteboard whilst Connor types independently (see Figure 4.6.2.2.)]*



**Figure 4.7.2.2: Researcher assisting Connor with his spelling whilst he is typing independently.**

However, with repetition and overlearning opportunities he quickly reached fluency of skills with the iPad, using it as his preferred modality for accessing his wiki-page:

**Researcher:** “Do you want the stand back up or do you prefer it led down?” *[Referring to the iPad]*

**Connor:** “It’s fine.”

**Researcher:** “Is it easier like that?”

**Connor:** “Yeah actually it is easier like that.”

**Researcher:** “Cool, you’ve also got the laptop if you want to use that ok?”

**Connor:** “No its alright, I prefer to use this.”

Connor also recognised that he could potentially access the wiki-page from his iPhone, which uses a similar platform to the iPad. However, this was not possible during school hours due to the school policy regarding mobile phones that restricted his access. However, it was positive to see Connor taking increased ownership of his wiki-page during this cycle:

**Connor:** “I’ve actually got photos on my phone that I could add onto this of me on holiday. There are also photos of me, Michael and Sarah but again I’ll have to do that at home because we can’t have phones in school.”

**Researcher:** “That is a shame.”

**Connor:** “If I had it with me then I could get on my wiki-page at any time. I’m actually gonna start using this from home.”

**Researcher:** “Well maybe with Michael and Sarah you can add stuff to family and friends, yeah?”

**Connor:** “Yeah I should have been doing some bits with it actually but I haven’t been on it.”

**Researcher:** “If you can - fantastic, but even if you can’t, we’ll keep working together in school.”

Connor still required support with aspects of literacy (*see 4.6.2.2*) but in general I only intervened when necessary. However, I always tried to provide him with positive reinforcement in all the sessions and it is my view that this helped to foster his self-confidence in his ability, as well as positive emotional states:

**Researcher:** “You are doing fantastic, I am really impressed that you can do this on your own Connor - on all these different devices.”

**Connor:** “Yes I am good with computers and tech.”

**Researcher:** “And you seem to be concentrating and trying hard. I can see you are learning loads.”

**Connor:** “Yeah, I am learning with it.”

**Researcher:** “You are. You don’t take long to learn Connor, you’ve picked this up really quick.”

**Connor:** “Yeah I do and it is helping me as well. We’ve done loads today.”

**Researcher:** “Yeah, and how does that make you feel?”

**Connor:** “Happy to be fair.”

**Researcher:** “Do you like it when there is more on your wiki-page?”

**Connor:** “Ooh yeah, oh yes.”

**Researcher:** “Do you think that you are getting more confident with it?”

**Connor:** “Yes definitively.”

**Researcher:** “I am not giving you as much help am I?”

**Connor:** “No, I’m getting more confident - I can do it on my own now.”

**Researcher:** “Good stuff, you’re a superstar.”

#### ***4.7.2.1.Connor: Reflections from cycle 2 and proposed actions for cycle 3***

Although AR primarily focuses on the practice of the researcher, I did not feel compelled to ‘act’ during the sessions just to be ‘perceived’ as improving my practice. I reflected that sometimes inaction can be a very powerful method for empowering someone else and is a skill in itself. EPs often inhibit their own biased or disempowering responses and it is a central skill

we develop in the doctorate training programme. Furthermore, the overarching concept that I am investigating is SA and providing opportunities for individuals to express themselves is the primary objective. Constantly trying to shift the focus back towards myself instead of the individual at times risks creating a dichotomy to this aim.

Connor's base-line abilities related to ICT highlight that the focus of this case-study might be potentially very different than the two previous case studies (Pauline and Charlotte). This is because individual factors such as difficulties with communication, VI and gross/fine-motor skills were not significant barriers to participation that had to be overcome. Therefore, I anticipated that the subsequent cycles would gravitate towards conceptual and ethical discourses that encapsulate the concept of SA itself. I concluded that promoting SA for Connor did not involve removing physical barriers to participation through adaptation or specialised equipment. Rather, increased opportunities to SA might manifest from exploring the systemic and institutionalised barriers that may act to potentially restrict participation or his ability to self-advocate.

However, although it was evident that Connor demonstrated competent skills associated with using the wiki-page, he also presented difficulties in the retention of information between sessions, such as remembering his password or the website address. Furthermore, it seemed to have a negative impact on his emotional state:

**Connor:** "So now finally I can actually get onto it now. Because I was putting K initially and I was actually getting quite angry, because I couldn't get on it, without the..."

**Researcher:** "Yeah but you're in – you've nailed it now."

**Connor:** "I kept forgetting it's got an x in it."

**Researcher:** "Remember, I told you to try and not get frustrated, this should be fun."

**Connor:** "Yes I know."

**Researcher:** "Yeah..?"

**Connor:** "Yeah, I know sometimes it is hard. But I'm ok with it so it is fine."

**Researcher:** "Good stuff."

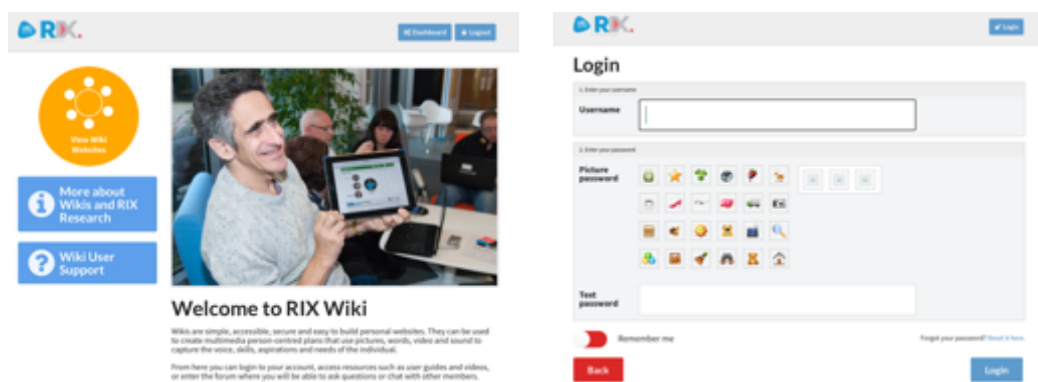
**Connor:** "I just need to remember it has got the x in it."

I felt that these difficulties were a potential barrier for him achieving full autonomy and control over his wiki-page so I prioritised it for the next cycle. In preparation, I asked him to provide a memorable username and password of his choosing.



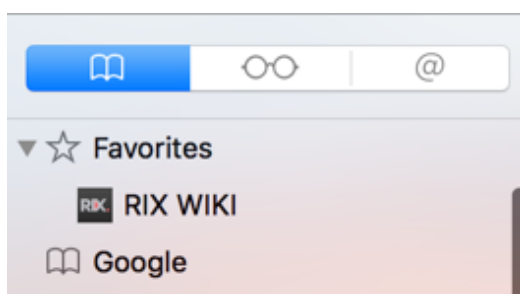
#### 4.7.3. Connor: Cycle 3 – Empowering Connor to have autonomy, control and ownership over his wiki-page

During this cycle, I contacted Gosia Kwiatowska at the RIX Centre to amend Connor's log-in details (username and password) for his wiki-page. This was necessary as it could only be done through access to the central server. During the next session, Connor and I spent significant time practising locating the website and completing the log-in process together (*see Figure 4.7.3*).



**Figure 4.7.3: Familiarising Connor with the log-in process through repetition and over-learning techniques.**

I also created a short-cut using a 'favourite' bookmark tab (*see Figure 4.7.3.1*) so that a single click on the relevant icon redirected him to the log-in screen in *Figure 4.7.3*.



**Figure 4.7.3.1: Creating a shortcut bookmark to the RIX WIKI log-in page.**

I offered to create a picture password but Connor was determined to use his personal log-in details. I supported his attempts with prompts at his level of ability, whilst also incorporating overlearning and elaborative learning techniques:

**Connor:** “And login.”

**Researcher:** “Yeah go for it, you can have a go at your log-in right?”

**Connor:** “Username.. Is that Connor right?”

**Researcher:** “Yes and...? Do you remember your FULL username?... It is your full name. Capital C and capital A by the way.” [*Connor begins typing his username*]

**Connor:** “That’s Connor yeah...” [*typing Connor*]



**Researcher:** “Sorry, I meant capital A for Aske. My fault [*With pointing gesture to promote understanding*]. I thought you wanted Connor Aske?”

**Connor:** “Oh yeah, it is Connor Aske. Sorry.”

**Researcher:** “It is fine, take your time. So, a little a for Connor... and then a big A on Aske. So, it is your full name.”

**Connor:** [*Connor begins typing but forgets to use the spacebar*].

**Researcher:** [*providing prompt*] “Don’t forget the space between. You are a star, well done.”

**Connor:** “Right I’ve put my username in. And then password, which is capital C..a..e..s..a..r..1..9..9..6.. and then login.”

**Researcher:** “Let’s see if it works. [*Wiki-page opens up*] “Woah there we are!

I was aware that generally, Connor’s frustrations occurred outside of the school setting when he was attempting to access his wiki-page at home and I was not available to support him. I therefore suggested that it might be a good idea to note the relevant details down in a safe place (*See Figure 4.7.3.2.*). Whilst he was keen to do this for the website address, I was aware that he was reluctant to do so for his log-in details, particularly his password:

**Researcher:** “How about we note it down somewhere safe for next week, just in case?”

**Connor:** “Yeah alright.”

**Researcher:** “Do you need your log-in details?”

**Connor:** “No I know all that – I just need the website.”

**Researcher:** “Oh – right – so... [www.rixwiki.org](http://www.rixwiki.org) [*sounding it out whilst writing on a miniature whiteboard for Connor to copy*]

**Connor:** “Oh! I got it wrong.”

**Researcher:** “I should have reminded you of the X – that is my fault!”

**Connor:** “Right I’ve got that in there so it is done.”

**Researcher:** “Should I write down your username and password too?”

**Connor:** “I don’t need that because I know what it is.”

**Researcher:** “You sure do buddy but just in case you forget it Connor. Do you want it in case you forget?”

**Connor:** “Yeah go on - write it down for me just in case.” [*Connor passes the notepad to the researcher*] “Put it at the back. Because it is a private thing... I put my things at the back.”

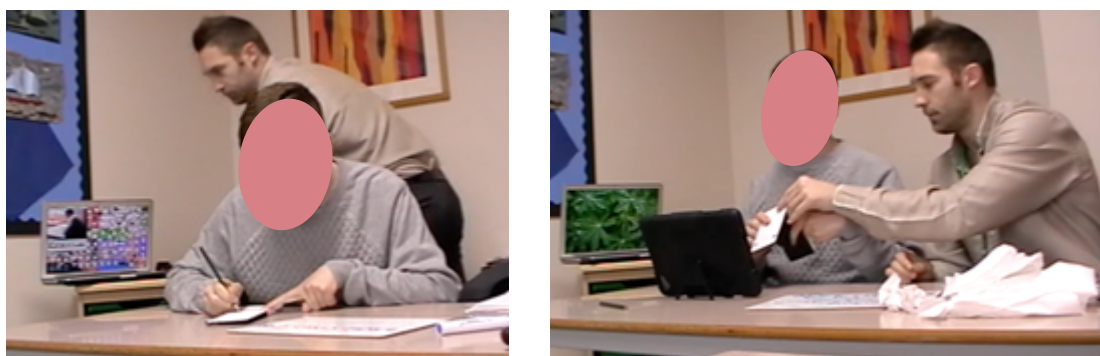
**Researcher:** “This is your personal pad isn’t it? [*Gesturing towards the notepad*] So it will be safe in here right?” (*see Figure 4.7.3.2.*).

**Connor:** “Yeah it is safe, it goes in my bag so no one will see.”

**Researcher:** “I know you will remember it anyway. I’ve underlined the C and A because they are capitals.

**Connor:** “Don’t put the password in there whatever you do just in case they – in case someone does get hold of it... because I know my password anyway.”

**Researcher:** “You’re the boss [*Gestures a mock salute to diffuse the tension and we both laugh*].



**Figure 4.7.3.2:** Connor and the researcher writing log-in details in his private notepad.

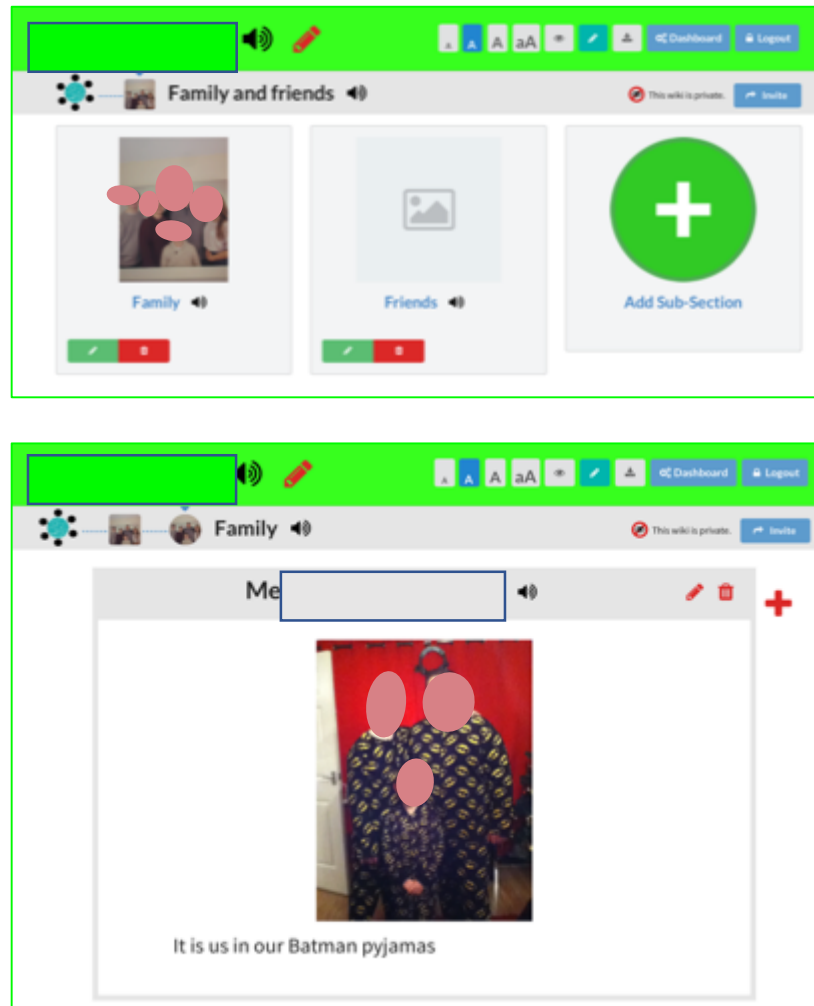
#### **4.7.3.1. Connor: Reflections from cycle 3 and proposed actions for cycle 4**

This cycle illustrates that Connor had now established full autonomy and control over his wiki-page. He was not only able to use the functions of the wiki-page to create content that he chose but could access it independently whenever he wished. I became a passive observer, simply providing support with literacy skills and helping to problem-solve when technical difficulties arose in terms of flaws within the wiki-page platform itself.

This cycle appears to represent ‘*rung 7*’ in relation to Hart’s (1992) ladder of participation. This means that decisions made and activities undertaken were ‘*youth initiated and directed*’. Whilst Connor had now established a high-level of SA within the protective context of our wiki-page sessions I was aware that this was not always the case in my absence. I hoped to identify some of the socio-environmental and institutional factors that acted as barriers for him in achieving SA.

#### **4.7.4. Connor: Cycle 4 – Challenging institutional, situational and socio-environmental barriers**

It was apparent that although Connor discussed his carer(s) frequently, his wiki-page did not seem to reflect the importance of the role they have in his life. For instance, *Figure 4.7.4.* represents the total contribution from the home setting.



**Figure 4.7.4: Lack of family involvement represented by a lack multi-media uploaded related to this area.**

I consulted with Connor to determine if he would like more involvement from his carer(s) or the inclusion of more multimedia from the home setting. He told me that he would like more photos of him at home and gave me permission to contact his carer(s). I made several attempts by telephone and email but this was ultimately unsuccessful.

Whilst I attached no judgement to their lack of involvement, it was apparent that this approach was markedly different from Pauline's and Charlotte's parent(s)/carer(s) who had embraced the wiki-page project, uploading significant amounts of content in a range of settings. Furthermore, it impacted Connor's opportunities to self-advocate about his home setting and could therefore be described as a socio-environmental barrier towards achieving SA.

*Figure 4.7.4.* also highlights the lack of information related to 'friendships'. Indeed, no multimedia was added relating to this area, although this was not Connor's choice. Connor is popular and has many friends in his school setting. Furthermore, he was keen to add them to his

wiki-page. Unfortunately, the policy of the school and concerns voiced by other parents prevented him from doing so.

I engaged in several discussions with the safeguarding officer and advocated on behalf of Connor. I was frustrated that Connor was unable to self-advocate about areas of his life that he had told me were most important to him. Ultimately, I was unable to find a solution that enabled Connor to gain increased agency in this respect. Just as Connor was powerless, so it seemed was I and we both found ourselves disempowered by institutional barriers.

I took this opportunity to discuss moral and ethical considerations with Connor and we made an agreement regarding appropriate content for its purpose. Several members of staff did make enquiries about his log-in details but the previous cycle highlighted Connor's clear desire for maintaining privacy. Furthermore, he had demonstrated that he trusted me implicitly by granting me access to his private notebook. Consequently, my position was that I would not provide access to members of staff in the school without his prior agreement. I posited to the Head Teacher that there were no reasonable grounds for them to access the wiki-page if that was his wish. I directed the school to the agreements and consent forms that were signed prior to the research commencing that highlighted the confidential nature of my work with Connor. In my opinion, the wiki-page was a significant constituent of that agreement and to provide access to Connor's wiki-page without his consent would violate my ethical duty as a researcher. I explained the potential implications for my professional practice as well as how it violated my personal values that the research was based upon. Indeed, the irony of this situation was not lost on me, given the focus of the research.

Overall, this cycle highlights the potential institutional, socio-environmental and individual situational factors that can act as significant barriers to participation and achieving SA. However, unlike individual barriers such as impairment, it appears that these barriers can often be much more challenging to overcome.

#### ***4.7.4.1.Connor: Reflections from cycle 4 and proposed actions from cycle 5***

The lack of multimedia in the family selection potentially reflects the lack of support he received in relation to his wiki-page in the home context. My assumption is that his carer(s) did not engage due to difficult situations that they reported to me related to previous experiences of Connor's use of social media. Whilst I had explained the subtle differences in the aims and intended use of MMSA tools, their anxieties and reservations were evident in our initial meeting.

Another area where I had to be mindful was of my remit as a professional practitioner, in addition to my position as an AR researcher. Whilst individuals who adopt AR as a methodology seek to improve or change practice and emancipatory research often challenges systems that disenfranchise participants, I was aware from my training as an EP that systems should be navigated with diligence and consideration. As a guest in the school, I had the potential to influence that system but I was not part of that system. The school had a specific policy regarding online sharing of information. I have worked in special educational settings in the past and am aware that these safeguarding measures are for the protection of certain individuals who are particularly vulnerable. I therefore understood the school's position on the issue, even if I did not agree with it.

Connor and I had both been completely disempowered by external forces over which we had little control. It highlighted the significance of institutional barriers and the social model of disability. These events provided me with a snapshot into Connor's daily reality and my empathy was palpable. After all, Connor is an adult and my work with him had led to me to believe that he had the mental capacity to make decisions in all aspects of his life. However, attending a SEN school appears to unjustly restrict his human rights. One should question whether he does enjoy the same rights, freedoms and opportunities as other 19-year-old adults in mainstream educational settings.

When I considered the outcomes of this cycle it clearly encapsulates '*manipulation*', the lowest rung according to Hart's (1992) ladder of participation. This is because both Connor and I were placed in a position of '*non-participation*' where outcomes were dictated to us and we had little or no control over them. Feeling somewhat despondent but desperate to empower Connor in my final cycle, I considered the best strategies to demonstrate to Connor how he might be able to advocate for his rights in the future.

#### **4.7.5. Connor: Cycle 5 – Promoting independence and self-determination**

In the final cycle, I modelled to Connor how it was possible to express his views, wishes and abilities via his wiki-page. I reassured Connor that this was a private conversation that would stay between the two of us and reiterated that his well-being was my priority. I also made it clear that if he did not wish to talk about something, he could change the subject or do something else completely. In general, I felt that he could articulate and express his views competently. We spent significant time discussing a variety of different topics that were important to him in terms

of planning for the future. Independent living was an area that we explored in depth. Indeed, the following extract highlights that he has reasonable, realistic and achievable aspirations, comparable to any typical young adult:

**Researcher:** “Do you remember when I first came round to your house and I talked with you, Michael and Sarah?”

**Connor:** “Yeah.”

**Researcher:** “Well we talked about – erm, perhaps there are times when you feel that people don’t listen to you... like when you are in meetings about your future, correct?”

**Connor:** “Yeah, I guess so.”

**Researcher:** “Well I am interested. I am interested in where you would like to be in the future.”

**Connor:** “To be honest in my own flat... But I don’t know if that is going to be an option yet.”

**Researcher:** “Ok, so that might be a goal in the future.”

**Connor:** “Yes, that would be a goal.”

**Researcher:** “In you own flat?... Because when I met you before at your house, you said that you might want to still live with Michael and Sarah?”

**Connor:** “Yeah I know but its err.”

**Researcher:** “Its ok Connor, you can make choices too.”

**Connor:** “Yeah, I know and it is something to think about because I don’t think Michael and Sarah would want me living there forever more.”

**Researcher:** “Hmmm... but... what would you like?”

**Connor:** “To be quite truthful, I would like to stay with them because I love them and that but I also might want my own flat one day... And I might want a cat when I move out because I can’t have one at home. I’d call it tabby.”

**Researcher:** “So which would come first the cat or the flat?”

**Connor:** “The flat.” [*We both laugh*].

**Researcher:** “Ok, any idea what it will look like.” [*Gesturing to the laptop on the table*].

**Connor:** [*Connor opens google images and searches for flats*]. “I would like my own flat when I am older. I hope it looks something like this.”

Following on from this discussion Connor created several sections, sub-sections and pages that illustrated these desires. These areas include abstract concepts that young people with ASD can sometimes find challenging to comprehend, such as planning for the future (*see Figure 4.7.5*).



**Figure 4.7.5: Expressing his desires for the future goals, hopes and aspirations.**

Finally, I sought to end the project from a positive perspective. Connor and I discussed his strengths, abilities and independence skills. I felt that this would highlight to other people Connor's abilities and individual strengths. The intention was that this would challenge preconceptions or assumptions of what he is capable of. I spent an additional day outside of the classroom setting with Connor whilst he demonstrated these abilities to me. I recorded these activities with both photographic and video multimedia. Connor created a sub-section entitled 'life skills and independence'. He selected his favourite photographs/videos from the activities that he wanted to include on his wiki-page (see Figure 4.7.5.1):

**Researcher:** "Do you know what independence is?"

**Connor:** "It is when you do your own kinda thing."

**Researcher:** "Mm hmm, and what independence skills do you think you have?"

**Connor:** "Well I do my own washing now. I wash my clothes. I can cook too.. err.. and I do cycle to school every day."

The content that we added to the wiki-page during this cycle enables Connor to express his ideas, wishes, beliefs, hopes, goals or aspirations. It also promotes his strengths and abilities. I feel that it was a particularly useful exercise in modelling to Connor strategies to promote his SA. Furthermore, presenting his ideas and expressing his views in this manner should be useful during transition into adult life. The wiki-page has the potential to act as a mediating tool during emotive situations. He will be able to use this as a tool during meetings or situations that in the past have disempowered Connor and it reduces the likelihood that his views will be dismissed

or marginalized. Furthermore, Connor can invite professionals like myself, or support workers and mentors, who can view these pages if he chooses to invite them (see Figure 4.7.1.1) so that they can act as advocates on his behalf. This cycle provided Connor with the opportunity to reach the highest level of participation according to Hart (1992). In my view this encapsulates ‘*rung 8*’ where decisions and activities are ‘*youth initiated and shared with adults*’ working as equal partners.

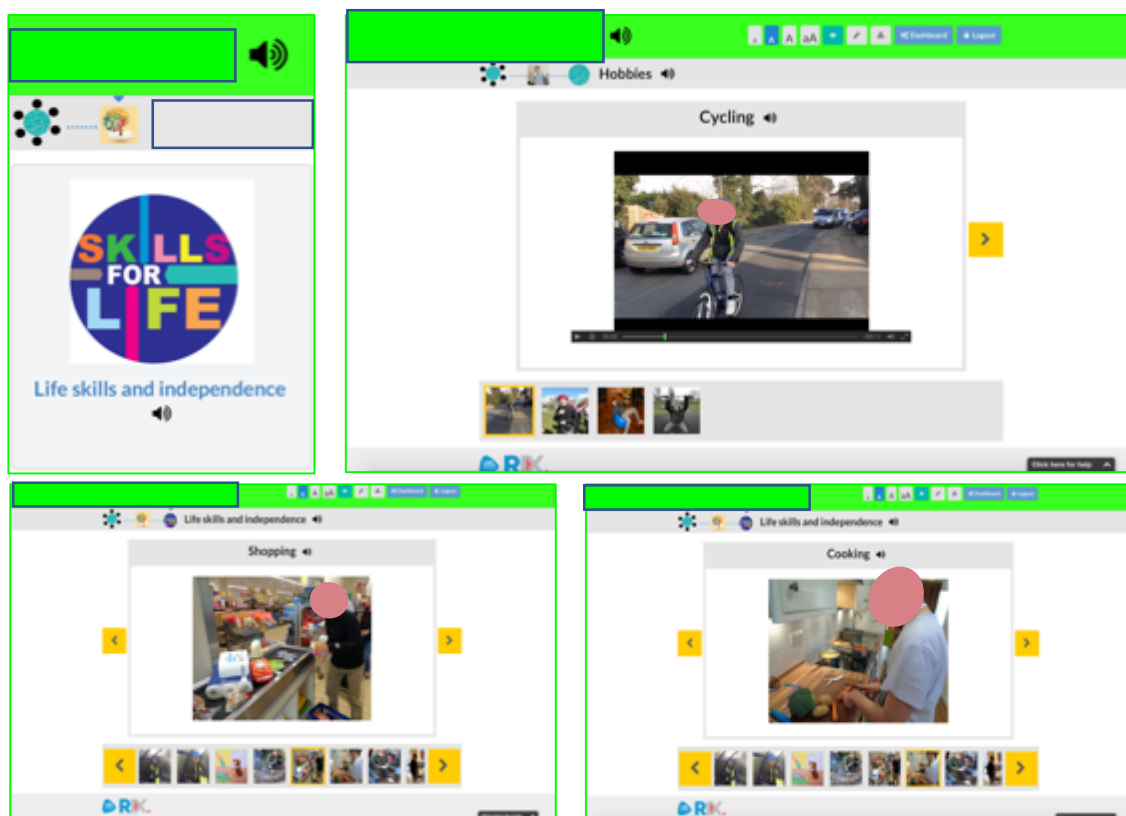


Figure 4.7.5.1: Expressing his abilities, independence and life skills.

#### 4.7.6. Summary of Connor’s action research journey

Connor’s journey offers a very different perspective when considering the concept of SA. The initial cycles highlight that Connor could effectively participate and access his wiki-page with minimal support from myself. His previous knowledge and skills related to ICT meant that he achieved a high ‘*degree of participation*’ during the first two cycles with very little input or adaptations to practice. Whilst collaborative decision-making and collaboration (‘*rung 8*’) might be deemed the ‘gold standard’ of participation, I actively promoted the adoption of ‘*youth-led activities with little input from adults*’ (‘*rung 7*’) to promote independence. This was achieved to some extent by the ‘inaction’ of the researcher that enabled Connor to develop his own skills and create the wiki-page in the manner he desired. During these first two cycles, Connor gained familiarity with the functions of the wiki-page platform and could experiment with several modalities to access it. He had gained mastery of the skills required and was now proficient at



using his wiki-page independently. Through this process we had developed a good rapport and a trusting relationship.

Cycle 3 represented a significant shift in the action research process. This cycle was the catalyst for considering participation and SA as complex, multi-faceted conceptual constructs. Dominant narratives in the sessions focussed on the autonomy and control of Connor's wiki-page. Strategies were implemented by the researcher to ensure that Connor assumed and maintained 'ownership' of his wiki-page. However, in cycle 4 several socio-environmental, situational and institutional factors acted to disempower us both. Ultimately, we were unable to overcome these barriers and we were placed in a position of '*non-participation*', characterised by Hart (1992) as '*manipulation*' ('*rung 1*'). This is the lowest level of participation where individuals have no control over their situation as activities, decisions and outcomes are prescribed to them by others. This was important for my learning, both in terms of the research but also personally, as it crystallised the social model of disability that underpins this research providing a snapshot into the challenges that Connor faces as a young man with CP. Whilst I was disempowered in terms of content that was permitted to be included on the wiki-pages, I was proud of the actions I took in terms of protecting Connor's rights as well as my duty to conduct research in an ethical manner.

Ultimately, in the final cycle Connor worked together in a collaborative manner so that he could once again achieve the highest degree of participation ('*rung 8*'). I provided Connor with opportunities to self-advocate about his future by enabling him to express his desires, hopes, aspirations and goals. Furthermore, this cycle modelled to Connor how the wiki-page could be used as a tool to 'provide him with a voice' in situations that might otherwise marginalise his voice, or circumstances that might otherwise disempower him.

Overall, this action research process highlights an important consideration. Whilst participation is often characterised as a progressively linear concept, Connor's case study highlights that this is not the case. Factors act to disempower or empower individuals and the result is that they can fluctuate in an erratic manner between non-participation and high degrees of participation. Furthermore, one final observation is that institutional barriers to participation and SA, may be more challenging to overcome than personal factors, such as impairment which can often be remediated by adaptations to practice.

## **4.8. Thematic analysis**

### **4.8.1. Interviews and data collection**

Two separate interviews were conducted with the parent(s)/carer(s) of the participants after the completion of the AR process. One participant's carer(s) did not take part in this phase of the research, although several attempts were made to interview them. However, in this instance, the participant's receptive and expressive language skills were deemed competent enough to provide feedback suitable for TA. Consequently, he was empowered further in the research design by being provided with the opportunity to give his perspective in the absence of his carer(s). Finally, three interviews were conducted with two separate facilitator(s), resulting in a total of six interviews.

### **4.8.2. Justification for the use of TA**

TA was used as a method to rigorously explore the central issues related to MMSA tools, in this case the RIX wiki-page, as well as SA in general. This sought to serve two functions: Firstly, to triangulate and potentially validate findings from the AR process; secondly, to provide further insight and understanding in relation to the important issues in this area of research from the perspective of those who have 'first-hand' experience and knowledge.

### **4.8.3. Process**

This section provides a brief overview of the research process that followed the six-stage model prescribed by Braun and Clarke (2006) outlined in *Chapter 3*. Evidence is provided to illustrate how the researcher adhered to the guidelines for achieving reliable and valid analysis. It culminates with a brief synopsis of the findings.

#### ***Step 1: Familiarisation with the dataset.***

The TA process began with verbatim transcription of the six audio-recorded interviews. During this stage pseudonyms were used to ensure anonymity. The pseudonyms selected by the researcher were relevant to the context that the research was conducted in. Complete transcripts of all the interviews can be found on the Flash-drive that was submitted with this thesis.

#### ***Step 2: Generating initial codes***

Each line of the transcript was scrutinised to determine initial codes, which were collated in codebooks. An extract from Pauline's codebook illustrates this in *Table 4.8.3*. The complete codebook for Pauline can be found in *Appendix J* and codebooks for the other participants can be accessed via the flash drive provided. There was no intention of interpreting the data at this

point and coding was focussed on the semantic level to reflect their views of the interviewees. Annotations were added to the data segments throughout the coding process and coloured highlighters were used to identify frequently occurring patterns (see *Figure 4.8.3*). In this instance, **green** signify benefits, **pink** represent barriers and **yellow** are facilitators. Data was then organised into meaningful groups in preparation for the initial theme generation.

<b>Pauline Codebook</b>
Ability to share information with others
Access to skilled support
Access to specialist equipment
Adaptations/changes to professional practice
Checking decisions/collaborating with individual
Collaboration between professionals
Difficulties with speech, language and communication
Disengagement
Familiarity/knowledge of individual needs
Fatigue
Increase in positive emotional states
Increased agency
Increased autonomy
Increased collaboration between professionals
Increased communication between parents and professionals
Increased motivation
Increased persistence
Independent use/access
Lack of access to skilled support
Lack of previous knowledge and understanding of individual

*Table 4.8.3: Extract from Pauline's codebook.*

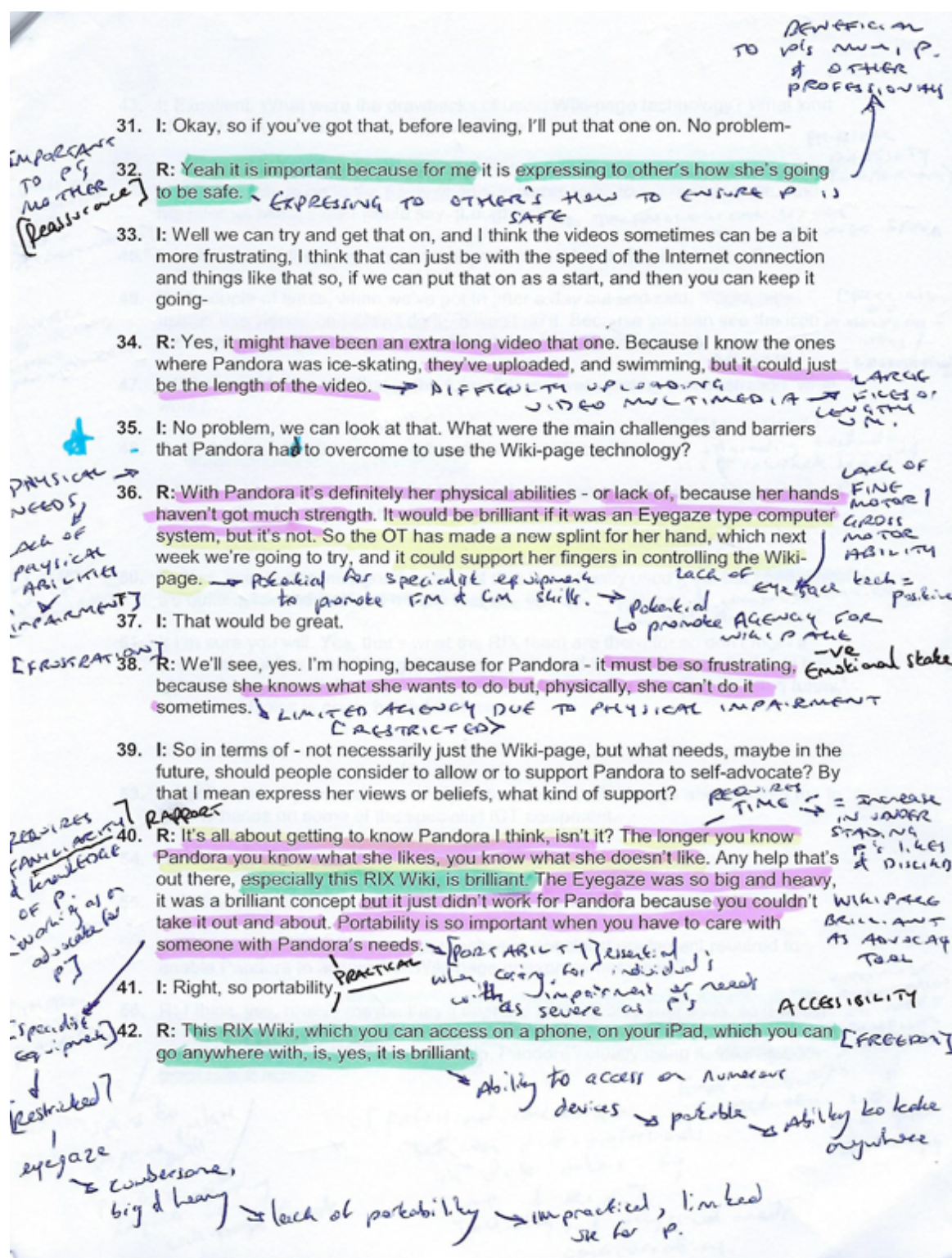
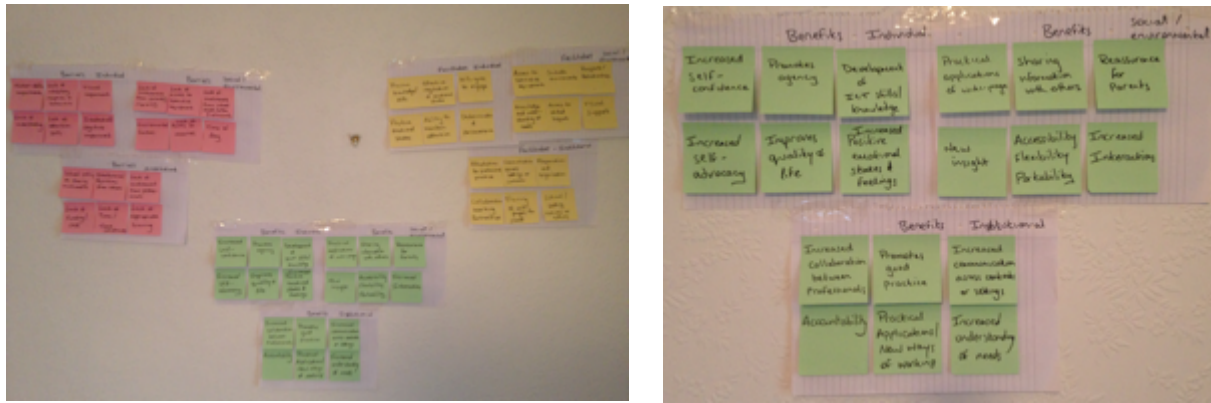


Figure 4.8.3: Example of annotations and coloured highlighters used to develop codes.

### Step 3: Searching for candidate themes

Codes were visually mapped using post-it notes (see Figure 4.8.3.1) to identify associations and relationships related to the research questions. During this step, adjustments were made to the existing codes by obtaining feedback from my supervisor in the LA. This helped to confirm the dataset and strengthen the construct validity.



**Figure 4.8.3.1: Grouping codes into initial emergent themes using coloured post-it notes.**

#### **Step 4: Recoding the dataset**

Code labels were amended to reflect the ‘language’ that is typically utilised by EPs. Initially, the researcher had adopted codes that mirrored the language used by the interviewees in an attempt to avoid placing bias on the dataset. However, during this step terms frequently utilised in EP practice were incorporated into the code (see Table 4.8.3.1).

<b>Transcript / Source of Extract</b>	<b>Transcript extract content</b>	<b>Initial code</b>	<b>Re-coding/alternative codes</b>
<b>Pauline / facilitator:</b>  <b>Extract 128.</b>	"...She will look to one side, disengage look really cheesed off... when she's not so happy and cheery... if she's a bit cheesed off and doesn't want to play ball"	Unhappy  No interest	Negative emotional state  Disengagement / lack of cooperation
<b>Charlotte / parent</b>  <b>Extract 13.</b>	"...Yes I think because of her vision as well maybe she wouldn't see all the video... with her vision the videos are probably a bit more challenging."	Difficulties associated with sight and vision	Visual impairment
<b>Connor / student</b>  <b>Extract 38.</b>	"Because it's my life and I should make choices by myself."	Able to make independent choices	Self-determination / Agency Autonomy

**Table 4.8.3.1: Examples of the re-coding process - adapting language to be consistent with EP terminology.**



Furthermore, codes were given more detail to provide a better understanding of the underlying phenomenon. For example, Table 4.8.3.2 illustrates that barrier was initially used as a broad general code but this was refined to provide more detail, enabling the generation of sub-themes. For instance, it was re-coded with increased specificity to incorporate the nature of the barrier itself.

Transcript / Source of Extract	Transcript extract content	Initial code	Re-coding/alternative codes
<b>Pauline / Parent:</b>  <b>Extract 4.</b>	"...She can't verbally communicate what she likes to people, and what she dislikes..."	Barrier	Physical impairment  Difficulties with speech, language and communication
<b>Charlotte / Facilitator:</b>  <b>Extract 6.</b>	"...And for somebody like Charlotte with her difficulties with sight..."	Barrier	Physical impairment  Visual impairment
<b>Connor / Facilitator</b>  <b>Extract 92.</b>	"... I would not think Connor would have the capacity to be able to know what is significant and what is not."	Barrier	Intellectual impairment  Lack of understanding

**Table 4.8.3.2: Examples of the re-coding process - providing increased depth and understanding to the data set.**

Organising the code in this manner provided greater richness, detail and understanding to the data set. This is appropriate for this research as the intentions of the inquiry and its communication to others are dependent upon the qualitative 'depth' of the thematic information available. In this case, the intended audience is EPs and presenting the findings at their level of understanding is a valid action to take.

### ***Step 5: Defining and naming themes and sub-themes***

After the completion of the recoding process, the data was interpreted and coded in a context that would offer insight into MMSA tools, SA and EP practice. Patterns from the dataset were used to create and develop initial themes. The data was scrutinised in the context of these themes with the intention of answering the research questions. Evidence to support each theme was reviewed and checked for consistency. Codes were then divided into three general overarching initial themes of 'benefits', 'barriers', and 'facilitators'. Tables 4.8.3.3; 4.8.3.4 & 4.8.3.5 provide evidence to support the creation of these three themes.

<b>Codes supporting the theme generation of benefits</b>
Increased collaboration between professionals
Practical applications of wiki-page
Increased self-confidence
Ability to share information with others
Reassurance to parents
Promotes good practice
Promotes opportunities for agency
Development of ICT skills/knowledge
New insight
Increased communication across contexts/settings

**Table 4.8.3.3: Examples of codes supporting theme generation of benefits**

<b>Codes supporting the theme generation of barriers</b>
Motor-skills impairment
Lack of inhibitory responses/behaviours
School policy on sharing multimedia
Interference/objections from other parents
Visual impairment
Lack of understanding
Lack of involvement from parent(s)/carer(s)
Lack of access to specialist equipment
Lack of involvement from school staff/system
Lack of attention skills

**Table 4.8.3.4: Examples of codes supporting theme generation of barriers**

<b>Codes supporting the theme generation of facilitators</b>
Access to specialist equipment
Adaptations to professional practice
Suitable environments
Communication across settings/contexts
Previous knowledge/skills
Rapport
Access to skilled support
Knowledge and understanding of needs
Preparation and organization
Effective regulation of emotional states

**Table 4.8.3.5: Examples of codes supporting theme generation of facilitators.**

### ***Step 6: Thematic maps***

The final stage involved the creation of a final thematic map summary (*Appendix J*) The thematic map exemplified three main themes (illustrated in blue) and a succinct collection of

related sub-themes (green) as well as further sub-themes (yellow). Detailed thematic maps of the individual themes were also produced to provide an increased understanding of the sub-themes (see *Appendices M; N & O*). These primarily relate to specific sub-themes generated from significant codes or frequently occurring codes (illustrated in red). These were selected to capture the depth of the phenomenon under investigation that was collected in the interview data.

#### **4.8.4. *Synopsis of the main themes***

This section provides a brief synopsis of the results of the TA by outlining the three main themes. Extracts from interviews provide the reader with context, insight, and further understanding, of the sub-themes that emerged. The findings will be explored further within the context of the discussion in *Chapter 5*.

##### **4.8.4.1. *Theme 1 – Potential benefits and positive outcomes associated with accessing multimedia self-advocacy tools***

This theme considers the potential benefits and positive outcomes associated with accessing MMSA tools. As is the case with all three of the main themes, it comprises three main sub-themes: ‘*individual*’, ‘*socio-environmental*’ and ‘*institutional*’.

##### ***Individual benefits***

The TA indicates that responses predominantly focussed on ‘*individual benefits*’, such as increased self-confidence and promoting SA. When I interviewed the facilitator in relation to Connor, I asked a more general question about the benefits for individuals with CP:

71. I: “Why do you think wiki-pages, or multimedia self-advocacy tools are particularly useful for groups of people with cerebral palsy?”
72. R: “I think for processing, for understanding, for comprehension, for limited memory. I think it helps address all those aspects... It’s a fantastic advocacy tool for them. And it’s totally personalised and bespoke within that framework. That’s just what they need.”

Connor himself felt that it had a positive impact on his QoL:

12. Connor: “Because that just makes life easier.”
34. Connor: “It’s just given me an extra thing I can do in my life.”
62. Connor: “... And show what I can do in my life.”



As did Charlotte's parent(s):

**45.** R1: "It made her feel special in class... and everyday was very important."

### ***Socio-environmental benefits***

Socio-environmental benefits also incorporated the sub-theme of QoL, but in the context of improving the QoL of other people related to the individuals. For instance, the wiki-page seemed to provide 'reassurance' for the parent(s)/carer(s) due to increased accountability, as Pauline's carer highlights:

**25.** I: "You said it's been useful for you – in what ways do you think it's been useful?"

**26.** R: "I'm going to feel secure and safe... It's passing on vital information... It's all going to be on the RIX Wiki which they can access... So they can look at it again and there's going to be no excuse for mistakes because it's there to keep looking at."

**28.** R: "It's accountability... This is Pauline's life."

**32.** R: "Yeah it is important because for me, it is expressing to others how she's going to be safe."

This was also evident for Charlotte's parents:

**165.** R1: "I think because Charlotte gains we gain. It's a win/win."

**167.** R1: "... I think that if the health people got more into it more as well you could download a video of actually how to put the splints on as well. Then at respite they would put them on properly."

Other social benefits included sub-themes such as increased communication and interactions, as well as the ability to share information with others. A key feature of the wiki-page was its practicality as Pauline's carer illustrates:

**24.** R: "I think it's very, very good... it's brilliant because it's something like her iPad, she can have it wherever she goes. She can show people anything she wants, wherever she is, so that's brilliant."

**40.** R: "...Especially this RIX Wiki... portability is so important when you have to care for someone with Pauline's needs."

**41.** I: "Right... so portability?"

**42.** "This RIX Wiki, which you can access on a phone or your iPad, which you can go anywhere with, is, yes it is brilliant"

### ***Institutional benefits***

'*Institutional benefits*' were also reported, primarily relating to new ways of working and the benefits of sharing information between systems and increased collaboration between professionals. For instance, the facilitator highlighted its potential use for EHCP meetings in the interviews for Pauline and Charlotte:

100. R: "I would love to be able to take this along... I deal a lot with social workers, they are so pushed for time... I think this would be a lot more powerful.. They can see it and you could share that page with them before they go to panel. So for me, to be able to take it to an EHCP review, I've taken one... I did actually take Pauline's into her last annual review. There is a bank of information on there, which should be shared."

77. R: "I think if you had a team of people which were Wiki-page trained and everybody was on board with the importance of it... and what you could be leaving with if you saw it used in an EHCP meeting... Personally, I'd love to see them being used and at different ages and different stages of children's education.... It would have to be another part of the culture... You know, fade out the home school book and we bring in the wiki-page book."

#### ***4.8.4.2.Theme 2 – Factors considered to be barriers for accessing multimedia self-advocacy tools and achieving self-advocacy***

This theme identifies factors considered to be barriers for YPCP accessing MMSA tools and achieving SA. Barriers to accessing MMSA tools also generated three main sub-themes: individual, socio-environmental and institutional.

### ***Individual barriers***

The TA revealed that '*individual barriers*' were reported most frequently as barriers to participation. There was an emphasis on '*physical impairment*' and '*intellectual/cognitive impairment*', such as difficulties with SLC, as the interview with Pauline's carer highlights:

4. R: "Because she can't verbally communicate what she likes to people, and what she dislikes."

58. R "... I mean Pauline can express herself by her facial expressions... You can ask Pauline a question and she can tell you, "Yes", with her right hand, "No", with a shake of her head."

Other individual barriers related to '*personal characteristics*', which are deemed modifiable through intervention. For instance, in the interview with the facilitator discussing Charlotte,

difficulties were reported in relation to her relative inability to effectively self-regulate her emotions:

15. R: "... She'd get overwhelmed, excited and would repeatedly talk about doing her wiki-page for the whole day, which would interrupt learning."

29. R: "... And verbally she can get quite transfixed on a subject and quite excited and then you need to bring her back down to help her to stay on-task."

Charlotte's parents also referred to some of these challenges, most notably a lack of inhibitory responses, or lack of patience:

35. R1. "She hasn't got the patience."

36. R2. "She hasn't. She would just keep on hitting it and hitting it, wouldn't she?"

37. R1. "Yes. You see, if that video wasn't there in two seconds flat she would be jarred off, and just get, "Is it going wrong?"

39. R2. "She doesn't really have the patience for it. If the screen doesn't move straight away after she's pressed the button."

### ***Socio-environmental barriers***

'*Socio-environmental barriers*' account for social and environmental considerations that were detrimental to the YPs' participation. This included issues such as a lack of resources, and access to specialist equipment. Charlotte's parents noted that different settings, or contexts, impacted her opportunities to access her wiki-page:

29. R1: "Yes, and I think it was fine when you and Lola were doing that there in school, because you've got the big buttons and things like that for Charlotte, but we haven't obviously got that at home."

It also incorporated social barriers, such as a lack of involvement from parents, or their inability to support the individuals due to a lack of understanding or knowledge. The facilitator highlighted this point when discussing Connor:

88. R: "...Certainly in special education the parents are quite often very protective. They might not be completely knowing and understanding of social media themselves and the benefits of technologies."

### ***Institutional barriers***

'*Institutional barriers*' relate to issues such as policies, or institutions or services, that all operate in accordance with their own systems. The facilitator reported institutional factors as being a

significant barrier, preventing Connor from self-advocating about topics that he was passionate about, such as his friendships:

14. R: “We’ve had conversations about the other friends and we’ve said that if those parents have not given permission then he cannot upload those photographs, because he’s not allowed to. That’s partly because of the school setting obviously has child protection concerns. Even though those students may have been over 18, we still have to work under the parental permissions.”

94. R: “I think the setting has its limitations because we’re working within quite a tight remit for different reasons. Perhaps he might have had more freer opportunities to upload in a mainstream setting.”

#### ***4.8.4.3.Theme 3 – Factors considered to be facilitators for accessing multimedia self-advocacy tools and achieving self-advocacy***

Once again, facilitators for accessing MMSA tools and achieving SA were organised into three main sub-themes: individual, socio-environmental and institutional.

##### ***Individual facilitators***

‘Individual facilitators’ focussed two main sub-themes of intellectual/cognitive ability and personal characteristics, although these themes were not reported as frequently as they were in the context of barriers. Intellectual, or cognitive factors, also considered variables such as previous knowledge, understanding and skills as Connor indicated:

40. Connor: “Well, first of all, it’s getting to know how to use it but apart from that, I’m a whizz at it now.”

Other individual factors related to cognitive skills included attention, which was particularly relevant for Charlotte as highlighted by the facilitator:

17. R: “... Equally she would listen to direction and follow instructions.”

41. R: “I think the level of concentration. When I fed back to Jasmine, she was just absolutely amazed that she had worked for that level of time.”

##### ***Socio-environmental facilitators***

Socio-environmental factors encapsulated a range of facilitators, such as adaptations to practice, as well as adaptations to equipment. Social factors, such as good rapport with the individual, as well as relationships more generally, were also recurrent themes. Previous knowledge, and understanding of the individuals, were perceived as central facilitating factors. The interview

with the facilitator highlights that a range of socio-environmental factors were important for facilitating participation, particularly for Pauline, due to her difficulties with SLC:

**14.** R: “I think you needed to know Pauline, how she communicated to begin with. The room had to be quiet... There’d be a lot of preparation going in.”

**16.** R: “... Because I know Pauline relatively well, so that did help. I have a background relationship with her.”

Pauline’s carer also reported that these were significant factors that helped to facilitate Pauline’s participation:

**4.** R: “... So people need to know what she likes and what she doesn’t like.”

**40.** R: “It’s all about getting to know Pauline I think isn’t it? The longer you know Pauline, you know what she likes, you know what she doesn’t like.”

### ***Institutional facilitators***

Institutional facilitators considered factors that were related to the various systems and policies that promoted participation. Communication and collaboration between distinct systems, as well as the professionals situated in these institutions, were recurrent themes that were widely regarded as a central component to positive outcomes for all three individuals. Pauline’s carer reflected on this issue:

**150.** R: “You worked with Lola didn’t you?... I’ve got Lola’s e-mail, I’ve got your e-mail, I’ve got your phone number, I’ve got the school’s phone number. You showed me how to use it, so yes, it’s all worked out really well.”

Charlotte’s parents also focussed on the importance of collaborative working partnerships between professionals:

**197.** R1: “I think you liaising with the staff. Because of course they know the children better, so they know the important stuff... The key thing is to find out from the teachers.”

Finally, the facilitator also highlighted the importance of communication between institutions for facilitating Connor’s ability to self-advocate:

**66.** R: “Certainly everyone who is involved with him professionally. I think that would be really important... He’s talking about wanting to go into supported living in the next year or so... Anybody who would be involved with him care-wise... I think that will be vital.”

#### **4.9. *Summary of chapter***

This chapter outlined the preparatory work undertaken prior to initiating the AR, and the data collection process followed. Three case studies demonstrate how the research was conducted, and how outcomes were analysed simultaneously. Comprehensive reflections, adaptations to practice, and an overview of the unique AR process undertaken for each individual case study are provided. The details of the interviews, steps taken to analyse the data, and results from the subsequent TA were then illustrated using a brief synopsis.

## Chapter 5: Discussion

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### 5.1. *Introduction to chapter*

This chapter answers the research questions by synthesising the findings from AR and results of the TA to form an analytic narrative. The design is critiqued in relation to the methodology, adaptations to practice and research process. Details of the distribution of findings to key stakeholders are outlined, and implications are considered in the context of relevant legislation. Potential areas for future research are considered. The chapter culminates with reflections and conclusions from the research journey.

### 5.2. *Discussion of the findings*

The findings are discussed in relation to the four research questions outlined in *Chapter 2*. Together with the conclusions formulated from the AR process, these form an analytic discussion, which provides a synthesis between the AR and the interviews that form the evidence base of the TA.

#### 5.2.1. *What are the potential benefits for young people with cerebral palsy being able to access multimedia self-advocacy tools?*

Providing YPCP opportunities to access MMSA tools, such as wiki-pages, appears to have a wide range of potential benefits. Most notably, they offer individual benefits to the YPCP, providing increased opportunities for SA. This finding is significant, as previous research by Shikako-Thomas et al. (2009) suggests that opportunities to self-advocate are associated with positive perceptions of QoL, and are crucial for adolescent well-being. They state that it is fundamental that YPCP are able to pursue, and participate, in a broad range of activities of individual interest. MMSA tools can promote these aspirations by providing a platform to achieve SA. This could have considerable implications, since well-being has been reported to be lower among YPCP when compared with normative representative samples (Livingston et al., 2007).

In the most part QoL is not associated with impairment, but largely determined by socio-environmental factors (Dickinson et al., 2007; Rosenbaum et al. 2007; Arnaud et al., 2010). MMSA tools can be effective as they remove physical and socio-environmental factors that have been reported as significant barriers to participation in previous research (Lawlor et al. 2006). It is also reported that YPCP may encounter increased barriers to social inclusion, with a tendency to participate in activities alone (Imms et al. 2008). The ability for YPCP to share information

with others is a key feature of MMSA tools, and is crucial in reducing social isolation. Furthermore, MMSA tools may reduce the reliance on family members, commonly reported in research (Lawlor et al. 2006; Imms et al. 2008; Shikako-Thomas et al., 2012). In doing so, MMSA may mitigate many socio-environmental factors that are believed to be significant determinants of lower QoL for YPCP.

The use of MMSA tools can promote independent choice behaviours, which complements the findings of Stasolla et al., (2013). The use of technology, not only promoted the ability of the YPCP to make choices, but also appeared to increase levels of engagement and positive emotional states, such as happiness. Furthermore, MMSA tools promoted skill development, as well as knowledge and understanding, in relation to ICT. As technologies continue to advance in the future, this could lead to increased opportunities and additional benefits for these individuals. Availability of these kind of interventions, signifies a potential change for YPCP, shifting them from a position of relative passivity, to a condition of self-determination and personal control (Flad et al., 2011; Munger, 2011; Stasolla et al., 2013). By promoting opportunities for self-determination, MMSA tools may enable YPCP to foster a positive self-image (Shikako-Thomas et al., 2009).

The practical applications of this technology present real opportunities for parents, professionals, and institutions to empower YPCP. Social and educational policies need to reflect this, by ensuring that individuals with CP have their rights considered, and are able to participate fully in society in accordance with the UNCRPD (2006), as well as the Children's and Families Act (2014).

#### ***5.2.2. What are the challenges of using multimedia self-advocacy tools with young people with cerebral palsy and what barriers must they overcome to be able to self-advocate effectively?***

Individuals with CP present a wide-range of unique needs that need to be carefully identified and considered before they can access MMSA tools. Physical and intellectual impairments are particularly important to consider, due to the variability of function apparent within individuals with CP. The nature, and severity, of these impairments can present significant barriers for YPCP accessing MMSA tools. Impairments include difficulties with SLC, VI, motor-control difficulties, and a range of cognitive difficulties, such as lack of flexibility in thinking and difficulties with attention. These impairments present challenges that can have a significant impact on the YPCP's level of participation. This is consistent with previous research that



suggests severity of impairment, or the functional ability of individual's with CP, is associated with reduced levels of participation (Imms et al., 2008; Shikako-Thomas et al., 2013). Personal characteristics, or features that are deemed modifiable through intervention, include factors, such as motivation and willingness to engage. These also impact on participation, and may present significant challenges when using MMSA tools with YPCP. Indeed, it has been established that personal factors and individual differences can impact access to technologies for some individuals with CP (Stasolla et al. 2013).

Socio-environmental factors, such as the family environment or school setting, also appear to have a significant influence on participation (Longo et al. 2012; Shimmell et. al, 2012). These factors can result in variance for the support that YPCP receives when seeking equipment such as MMSA tools, as well as the availability of adaptations. Therefore, with this social model of disability, these factors may compound impairments by limiting opportunities for participation (Lawlor et al. 2006; Fauconnier et al. 2009; Longo et al. 2013; Shikako-Thomas et al. 2012; Shimmell et al., 2012).

Disempowerment through societal structures is another significant challenge that YPCP encounter when accessing MMSA tools. Institutions can present significant barriers to participation and the ability for YPCP to have autonomy, control or self-determination over their lives. This ultimately can result in reduced opportunities for SA (Lawlor et al. 2006). These factors are influenced not only by the attitudes of individuals, but the ingrained approaches of institutions, evident in systems and policies that often disempower and marginalise groups of people (Lawlor et al. 2006). Institutional barriers can ultimately undermine basic human rights and YPCP are at particular risk (UNCRC, 1989; UNCRPD, 2006).

Overall, individual barriers, even those that may initially seem very significant, can be overcome to some extent with adaptations. Overcoming socio-environmental and institutional barriers, however, can be significantly more challenging. This is due to the lack of control, or agency, that the YPCP may have over these factors, and their inability to change them (Shikako-Thomas et al., 2009; Flad et al., 2011; Munger, 2011).

### ***5.2.3. What adaptations to professional practice are necessary to facilitate the participation of young people with cerebral palsy so that they can access multimedia self-advocacy tools?***

Participation is a multi-faceted construct that is punctuated by a dynamic interplay between intrinsic and extrinsic factors (Shikako-Thomas., 2012; Shikako-Thomas., 2013). Fauconnier et al. (2009) believe that an increased awareness of these factors may result in strategic planning and changes to policy that promote health and well-being. Exploration of these interactions may provide insight into effective changes, or adaptations, which can be made to promote participation of YPCP and improve access to MMSA tools. Consequently, the adoption of a systems-based approach towards YPCP, which captures the multiple-levels of interactions, may be beneficial for directing effective interventions (Shikako-Thomas et al., 2012).

This seems to require the implementation of practice-based evidence. EPs have the necessary skills and knowledge to identify individual barriers to participation, and provide access to specialist equipment (Lawlor et al., 2006; Shimmell et. al., 2012). Indeed, it is possible for professionals to empower YPCP to transform social structures that constrain their lives, and this can be further facilitated by innovative technologies, for example MMSA tools. In addition, EPs can make appropriate adaptations to such technologies to further promote participation. These interventions can enable YPCP to make choices with adapted technology, such as a specialised mouse that reduces the impact of fine-motor impairments, or AAC devices that support SLC difficulties. This is encouraging as solutions for more accessible assistive technology, and adaptations to practice, are also reported to be facilitators of participation (Flad et al., 2011; Stasolla et al. 2013). Consequently, by providing MMSA tools, and making appropriate adaptations as required, EPs can provide YPCP with facilitators that promote participation.

A systems-based approach can also be framed within the social model of disability (Flad et al. 2011, Munger, 2011 Shikako-Thomas, et al., 2009). Adaptations to professional practice to promote access to MMSA tools should focus on facilitating socio-environmental factors that remediate barriers and increase participation. These adaptations should consider the individual needs of the YPCP, resulting in unique strategies and solutions (Flad et al., 2011; Munger, 2011; Stasolla et al., 2013). Indeed, even individual characteristics, such as motivation, may be modifiable through specific intervention strategies. Professionals need to actively participate to ensure healthy development of YPCP by informing families about the potential intrinsic and extrinsic characteristics, which may contribute to greater participation (Shikako-Thomas et al., 2012).

Lawlor et al. (2006) found that professionals providing advocacy for parents when seeking equipment and services for their children is a significant facilitating factor for participation. Therefore, EPs should also focus on effective strategies to support an individual's physical needs. By promoting access to specialised equipment, such as MMSA tools, the professional can facilitate independence of participation and reduce the level of support, and supervision required. This is significant, as research suggests that YPCP are often reliant on the commitment and support of adults to participate, usually their parents (Lawlor et al., 2006; Imms et al., 2008). By adapting their professional practice, EPs can empower YP and their families by providing increased support and assistance to facilitate opportunities, enabling individuals with CP to increase their level of participation whilst accessing MMSA tools.

In summary, professionals and service providers can promote participation in YPCP so that they can access MMSA tools by making adaptations to professional practice that positively influence personal, and environmental, interactions and the inter-related processes between the two (Shimmell et al. 2012). With strategic planning and changes to practice, it may be possible to elevate participation, and in doing so improve psychosocial health, promote general well-being, and increase QoL (Munger, 2011).

**5.2.4. *What are the implications for my own practice, and other Educational Psychologists, who work with and conduct research with individuals presenting similar impairments or needs?***

This research adds valuable insight to an emerging, and relatively under investigated, area of study. The results complement previous findings by illustrating that assistive technology, in this instance MMSA tools, can increase the degree of participation for YPCP so that they can effectively self-advocate (Stasolla et al. (2013). It also expands on the existing knowledge base by successfully incorporating three key recommendations that Stasolla et al. (2013) prescribed for future research: Firstly, the researcher adapted the MMSA tools to ensure they were easier to access and use within the educational context; secondly, check-back procedures were conducted throughout the research to verify participant satisfaction in relation to the technology, as well as adaptations implemented; finally, adaptations were validated with parents, caregivers and professionals, to determine the impact of MMSA tools. Overall, it explored new solutions to accessible assistive technology, and the necessary adaptations required to increase participation for YPCP. The MMSA tools appear to offer significant opportunities for YPCP to effectively SA, with a wide range of potential applications. Furthermore, the nature of the on-

line inter-face eliminates many of the restrictions, and socio-environmental barriers, which often accompany alternative methods. However, given the prevalence of CP, and the varied nature of its associated impairments, further research is required in this area.

The research complements other studies by adopting, and adhering to, the social model of disability that is underpinned by emancipatory values. In this AR context, the researcher empowered the participants to share their experiences, and in doing so, created knowledge within his own professional discourse. This not only empowered the YP to have a voice in the academic arena, but enabled the researcher to undertake an active role in finding solutions to overcome the challenges this posed, promoting improved professional practice. Research that produces new knowledge, firmly rooted in experience and located in the prevailing socio-environmental context, requires clear goals and ongoing assessment. Furthermore, the adoption of AR in an emancipatory framework requires unconventional techniques, such as self-reflective practice. (Flad et al., 2011). The audit trail that represents the evidence base for this research highlights that the researcher was comfortable adhering to these requirements.

This experience has developed the researcher's awareness, that EPs acquire many skills during their training, augmented through their daily practice, which are well-suited to AR. These include: Empathy and the ability to build relationships/rapport; the ability to identify needs and impairments; an understanding of how complex and inter-related factors impact upon individuals; and psychological/theoretical understanding. In addition, EPs have a knowledge of legislation, institutions and different professions that are located in varied, often fragmented systems, as well as access to services. As such, there appear to be compelling reasons that indicate how EPs are uniquely positioned to design, conduct, assess and report emancipatory AR within the social model of disability. Furthermore, the researcher feels that the emancipatory value inherent to AR - that the primary obligation should always be to the people studied - should also be the core value and principle upheld in daily EP practice.

It is apparent that there are significant implications for the professional practice of EPs, in relation to future directions of practice-based evidence. AR approaches can make experiences more accessible to professionals so that they can advance the agenda for adopting a social model of disability, which facilitates equal access to opportunities (Munger, 2011). Increased EP involvement may result in improved strategic planning and changes to policy that promote health and well-being for YPCP (Fauconnier et al., 2009). In this way, they not only advocate for the increased rights of marginalised and vulnerable YPCP, but also challenge unethical

practice imposed by institutions to ensure that they adhere to legislation, created with the purpose of protecting these rights (UNCRC, 1989; UNCRPD, 2006; Children and Families Act, 2014). In doing this they not only improve their personal professional practice, as well as the practice of the wider EP community, but simultaneously advance real-world change in the institutions they are located; communities, the education system and wider-society more generally. Overall, there is good reason to believe that EPs are uniquely positioned to potentially provide a ‘gold-standard’ for robust, insightful real-world practice.

### **5.3. *Critique research design***

Three main areas are focussed on to evaluate the research; the methodology, adaptations to practice, and the research process.

#### **5.3.1. *Methodology***

As part of the AR methodology, five cycles were conducted with each individual. 15 AR cycles were completed in total over the course of the research project. After the completion of the AR process, six interviews were conducted. This is not representative of an EP’s typical remit. Within a LA it would be very unusual to dedicate this amount of time to a single endeavour, however, significant input was required for this research.

##### **5.3.1.1. *Action Research***

The AR methodology adopted in this research has historically been dismissed by researchers from the ‘traditional’ post-positivist approach. This approach tends to seek strict rigidity in research design so that findings can be replicated, serving as the ‘gold standard’ for research reliability. A distinct feature of AR, however, is its flexibility. The process is fluid, enabling and actively encouraging the research to take new directions, not just prior to the research commencing, but also whilst the research is being conducted. As McNiff and Whitehead (2011) note, conducting research in this way can be both ‘exciting and risky’. A practitioner must allow himself/herself, “to experience surprise, puzzlement, or confusion in a situation” (Schön 1983, p.63). The author found the uncertainty that accompanies AR to be a liberating experience, as it provided opportunity to employ creativity for the purpose of research. This epitomizes the sentiments of Lyotard (1984) who stated that knowledge, as a living and evolving process, is in a sense, a work of art.

In the context of professional practice, the author believes AR to be compatible with the assessment of quality in the field of education, particularly for EPs. An action researcher is

constantly re-evaluating what he/she knows, and using this to plan further action. Likewise, the practice of EPs requires constant reflection. It seems logical, therefore, that professionals in this area should seek to adopt an AR methodology, which complements and promotes these skills.

#### **5.3.1.2. *Individual sessions***

The YPCP in this research benefited from working individually with the support of one or two adults. It could be argued that this would be prohibitively costly in an educational setting. For this research design there are several justifications to validate this approach. Firstly, the nature and significance of the participants' needs meant that they required intensive support from the researcher/facilitator to access their wiki-pages. Secondly, the individualised adaptations to practice necessary to facilitate effective access would not have been feasible in a group context. There is the argument that Connor might have potentially benefitted from being able to work in a group setting, engaging in collaborative learning processes and sharing ideas with peers. However, this research explored personal and emotive topics, neither suitable, nor appropriate to conduct in a group format. Finally, the content and direction of the wiki-pages was tailored to the individual due to the values and concepts underpinning the research. SA is personal to the individual in terms of what he/she want to express and how he/she wish to achieve this. Overall, working individually with the YPCP enabled the author to develop better rapport and gain a deeper understanding of their individual needs.

#### **5.3.1.3. *Use of a facilitator***

As the intention of AR is to focus on individual practice, the inclusion of the facilitator may be questionable. Whilst providing a safe-guarding measure for the YPCP and author, there were other additional benefits to this component of the research design. Having someone that the YPCP trusted and were familiar with, assisted the author to develop rapport. The facilitator offered unique insight into the YPCP's personalities and individual needs. For instance, it would not have been possible to communicate with Pauline using AAC devices, such as the eye-gaze technology, without the prior skills and experience of the facilitator. Furthermore, it would have been challenging to manage the practical issues, such as manoeuvring specialist equipment, without this support.

The facilitator also provided collaborative learning opportunities, playing an important role in the discussions and reflections. For instance, the case studies of Pauline and Charlotte highlight the significant role that the facilitator played in making adaptations to practice and ensuring successful outcomes. Working in this manner meant remaining mindful of potential power

imbalances developing, but the relationship fostered seemed to mitigate this issue. This was underpinned by an agreement to position ourselves as equal partners, with the shared aim of promoting opportunities for the YPCP. Finally, empowering the facilitator provided the YPCP with a skilled individual that could support them in the future after the conclusion of the research.

#### **5.3.1.4. *Video recording***

The video cameras utilised to record the sessions did not appear to impact the YPCP's behaviour. Indeed, the YPCP used various technologies throughout the process, often taking videos or photographs of themselves or favourite activities. Two video cameras were used in each session, allowing two data sets to be captured that could be mapped onto one another. The first camera was positioned at the back of the room to capture data of their wiki-page. The second was positioned in front, or to the side, facing the participant to capture their behaviour. These two data sets could be mapped onto one another to provide a complete picture so that when they were analysed simultaneously they captured and informed the impact of adaptations to practice.

The purpose of the video cameras was to capture both verbal and non-verbal interactions. The main advantage of using a video camera was the increased opportunities for reflection after the sessions. It provided richer data than traditional notes and less information was 'overlooked', 'missed' or 'lost'. For instance, the nuances of subtle behaviours, such as body positioning or posture, were typically only discovered when reviewing the video data after the completion of the sessions. The quality of data that was captured using this method is evident in the detail and depth of the extracts provided in the case studies.

The use of video-recorded data, however, did have implications for reviewing the data with peers due to the need to uphold confidentiality and anonymity. Subsequently, written extracts and the reflective journal were used to inform discussions and provide validity for intended actions in subsequent cycles.

#### **5.3.1.5. *Informed consent***

Consent was initially gained from the Head Teacher of the educational setting and the YPCP's parent(s)/carer(s). Following on from this, informed consent was also obtained from the YPCP. This raises an ethical issue. As adults over 18 years old, they have the legal right to make an autonomous decision to participate in a research study if they provide informed consent. The fact that parent(s)/carer(s) ultimately decided if they participated, contradicts the fundamental

aims and values that underpinned the research, and the topic of investigation, SA. The author was aware of this ethical conundrum but also of the legal guidance that needed to be adhered to. Ultimately, control over this decision rested with the research ethics committee at the UEL. They decided parental consent was necessary to grant approval. However, it is an interesting debate and researchers in the future might seek to incorporate an assessment of mental capacity, which could empower adult participants to make decisions independently, further promoting the concept of SA and emancipatory research.

#### **5.3.1.6. Interviews**

Although the author intended to uphold emancipatory values by including all the YPCP in the interview process, this was not possible, with the exception of Connor, due to SLC difficulties exhibited by the YPCP.

#### **5.3.2. Adaptations to practice**

The case studies highlight the variety of approaches, adaptations and strategies that were undertaken during the research. Adaptation was guided by the values and principles that underpin the research to ensure ‘participation’, increased access to the wiki-pages, and opportunities to self-advocate. Adaptations were not implemented in a uniform manner, but were unique to each participant, dependent on individual needs. Adaptations primarily focussed on reducing the impact of barriers related to impairment, and many utilised specialist equipment. Adaptations were initially led by the author, however, practice that considered the views of the YPCP through a process of collaboration also led to positive outcomes and significantly increased participation.

##### **5.3.2.1. Validity of adaptations**

It is often argued that findings from AR are only valid for the specific context that the phenomenon occurred, applicable to that researcher, with those participants, in that specific situation. However, findings can be valid and robust as AR is a systematic enquiry that tests the validity of claims to the knowledge (McNiff & Whitehead, 2011). This living theory of practice was created through detailed accounts that outlined the actions taken and the processes followed. The reflections at the conclusion of each cycle provide explanations of proposed actions for the subsequent cycle, as well as the rationale and justifications for proposing that action. The written records, reflections and explanations as to how and why the AR was conducted ensures that the research has a strong legitimacy. As extracts from the AR process highlight, decisions were not taken without the evidence to justify such decisions. This resulted in clearly identifiable cycles



outlining: what actions had been taken; what the actions achieved; proposed actions for the next cycle; the reasoning behind this proposed action; and the intended aims of that action. Additionally, the adapted ladder of participation (Hart, 1992) was used to evaluate the outcomes of adaptations in relation to '*participation*'. This provided a framework, which ensured actions had a clear purpose that emanated from the research aims and fostered collaborative, equal partnerships with the YPCP.

The researcher wishes to highlight the misconception that participation is a linear process (Wright, Turner, Clay, & Mills, 2006). This does not accurately represent the reality of Hart's (1992) ladder of participation when applied to 'real-world' situations. (Hafford-Letchfield, Leonard, Begum & Chick, 2008). The rungs of the ladder do not necessarily represent linear or chronological progression, but rather, are intended to add clarity to the complex set of interactions (Laverack, 2007; Hafford-Letchfield et al., 2008). Indeed, participation tends to be organic, and therefore unpredictable, as this research demonstrated. As a consequence, different elements of the ladder may be applicable depending on the specific environment and culture it is located. As Wright et al. (2006) note, it should not necessarily be considered as a hierarchical construct, where the aim is to reach the top of the ladder. Rather, different levels of participation may be equally valid for different individuals or groups depending on the intended purpose, aims, and outcomes of its implementation.

### **5.3.3. *Research process***

#### **5.3.3.1. *Recruitment***

Purposeful sampling was utilised to recruit participants from a specific group of people. The individuals that took part in the research did not represent a homogenous sample. This was not surprising due to the wide variability of function, both physical and intellectual, associated with CP. Indeed, this lack of homogeneity was a primary reason that YPCP were recruited. It resulted in a variety of case studies that challenged the author to adapt practice in several areas, informed learning, and developed skills in a range of domains. This highlights to other professionals working with YPCP that consideration of needs is required at an individual level, and offers insight for those experiencing similar challenges and difficulties.

#### **5.3.3.2. *Analysis of data***

The premise for this research was the author's desire to develop skills and knowledge, both as an EP practitioner and an action researcher. The data collected was sourced through a variety of different formats. Data was primarily obtained from the responses to the adaptations

implemented. Responses ranged from non-verbal gestures or behavioural cues to verbal feedback, depending on the communication ability of the participant. Further data was obtained from discussions with the facilitator and the feedback they provided. Analyses of these data sets provided information that directed further adaptations to practice, depending on the data received. Other data sets came directly from the YPCP, empowering them to dictate alterations or adaptations to the author's practice. The wiki-pages also constitute part of the data as it was possible to analyse the various adaptations and map these against the YPCP's ability to access the platform in accordance with the adapted ladder of participation (Hart, 1992).

It is usually possible to code qualitative data to identify themes. Typically, these are discussed with colleagues or returned to the participant to gain clarification or consensus. During the AR cycles, it was not possible for data to be scrutinised in this manner due to collection and analysis occurring simultaneously. To ensure integrity in terms of the analysis, video data of individual sessions was reviewed and my reflections or interpretations of the data were discussed with my supervisor in the LA. Furthermore, during the sessions themselves discussions with the facilitator ensured that adaptations to practice were valid, as well as beneficial to the YPCP.

A final source of information was obtained from the interviews. This provided additional data sets that reflect several different perspectives and experiences. The data was analysed using TA to determine if the emergent themes reflected the conclusions of the AR process, providing a form of triangulation of the findings. The TA was conducted with a clear audit trail that followed the six-stage model as prescribed by Braun and Clarke (1996).

Upon reflection, IPA could arguably have been a more suitable form of analysis due to the small sample size. Although there was a lack of homogeneity between participants the researcher does not believe that this would have had an impact on the outcomes of IPA analysis. Whilst the researcher anticipated that TA was a useful technique for obtaining general findings across the participants, IPA may have provided greater detail and depth in relation to themes for each individual participant. In contrast, TA focuses mainly on patterning of meaning across participants, IPA has a dual focus on the unique characteristics of individual participants and on patterning of meaning across participants (Larkin et al., 2006; Smith et al., 2009). This could potentially have resulted in a lot more emergent themes being generated from IPA compared to the number of themes generated from the TA, as well as a greater focus on the unique characteristics of each individual participant. The researcher, however, feels that the TA does fulfil its fundamental aim of providing a framework for other practitioners who may wish to

generalise the findings to other YPCP or even or groups of people with similar needs, as well as providing triangulation to the findings of the AR. Certainly, if the sample size had been larger, TA might have represented a more suitable method of analysis.

Overall, the TA does provide some insight into this new area of research for others to adapt and improve. This research, however, does not necessarily benefit from the TA aspect due to the lack of detail that the author was able to include and explore in the write-up, within the restrictions of writing a doctorate thesis. In hindsight, a greater focus on the AR aspect, and perhaps omitting the TA, could have been beneficial for this particular piece of research.

#### **5.4. *Feedback to stakeholders***

Although the primary aim was to develop the author's knowledge and skills, the emancipatory nature of the research, along with the study's collaborative nature and design, resulted in several other 'stakeholders'. These included; YPCP and their families, the facilitator and the school, LA, UEL, and the RIX Centre.

##### **5.4.1. *Young people and their families***

The YPCP were stakeholders due to their participation as collaborative contributors to the development of the research process. They were not only consulted on adaptations to practice, but also had an active role in devising adaptations that increased ability to access their wiki-pages. This resulted in a high level of active participation, the development of knowledge and skills, and increased opportunities for SA.

After the conclusion of the interviews the author returned to the school and met with the YPCP individually for debriefing of the research. This was adapted to their level of need and provided them with an opportunity to ask questions. Their wiki-pages were reflected upon and discussions centred on how the YPCP might continue to use it in the future, and who might support them to do this. Furthermore, they each received a letter thanking them for their participation (*see Appendix O*).

The author also met with their parent(s)/carer(s) and addressed any concerns or questions they had. The author directed them to Gosia Kwiatowska at the RIX Centre who had agreed to provide on-going support with technical aspects of the wiki-pages. Finally, permission was gained from the YPCP, as well as their parent(s)/carer(s), to share aspects of their wiki-pages with relevant professionals, including school staff and EPs.

#### **5.4.2. *Educational setting***

The author considered the school that the YPCP attended to be a stakeholder. Key aspects of the research were shared with the Head Teacher and members of senior management. They were grateful for this insight and overall very positive about the wiki-page platform, recognising the potential applications and increased opportunities for SA that it can provide for YPCP. Furthermore, they felt that wiki-pages could be potentially beneficial for other YPCP of different ages and needs. They also noted the opportunities the author provided the YPCP for participation in the decision-making process and stated it could lead to better practice, which could ultimately support the needs of the YPCP more effectively.

Finally, the author also met with the facilitator who had been central to the research during the collaborative journey. The author suggested relevant professionals who could provide support in the future, and agreement was made to share findings that specifically focussed on the facilitator's professional practice.

#### **5.4.3. *Local authority***

The author gave feedback to a group of EPs at a regional conference in the LA. They felt that wiki-pages potentially offered a better tool than the current One-Page profiles, and that this could be invaluable in relation to the Children and Families Act (2014). EPs were also granted the opportunity to practically engage with the wiki-page platform, using the author's account. In general attendees were receptive to the potential benefits.

#### **5.4.4. *University of East London***

The author provided feedback of the initial findings to trainee EPs at the UEL. This focussed on the challenges of the research process such as recruitment, difficulties of working in SEN environments and practical issues including time constraints. This was achieved using a wiki-page presentation to increase awareness and understanding of the platform (see *Appendix P*)

#### **5.4.5. *RIX Centre***

It is the author's intention to meet up with Gosia Kwiatowska to provide feedback regarding the use of the wiki-pages with these particular individuals. The intention is to illustrate the potential barriers to participation as well as some of the adaptations to practice that seemed to overcome these challenges. It will also provide the opportunity to provide insight regarding the wiki-page platform, and potential areas for improvement in the future.

## **5.5. *Implications for practice***

This research has direct implications for the author as a researcher. Potentially, it can inform the wider community of EPs in relation to professional practice, as well as others working within education. There are also ethical implications to consider in relation to YPCP, particularly the participants of the research. Finally, institutions can use the findings to improve strategic approaches and policies, to further align them with current legislation.

### **5.5.1. *Implications for the author's practice***

This experience has improved the author's knowledge and skills relating to research. Adopting AR has led to increased understanding of '*living theories*' and this has been synthesised into the author's professional practice, with an increasing awareness of the need to conduct work in this manner. Every individual presents unique needs so this is an area of expertise that can be continually developed and improved. The author now perceives '*knowledge*' as living theories and will continue to develop the theories cultivated during the research process.

Relatively few professionals are aware of wiki-pages, or possess the necessary skills or knowledge to use them. The author therefore possesses unique skills and knowledge and it is his responsibility to share this with others. The author hopes to support other professionals to utilise these tools in the future, particularly in situations that present similar challenges.

### **5.5.2. *Implications for the practice of EPs and other professionals***

This research highlights the importance of EPs remaining reflective practitioners. EPs should aspire to continue their professional development through a constant process of examining and evaluating their practice to improve its quality. If EPs do not reflect on their professional practice, then there is the increased risk that they will deliver poor work that lacks the development of new ideas or innovative systems. Practice-based evidence is an approach that provides an effective framework to formally evaluate work and highlight areas for improvement. Encouragingly, recent research suggests EPs seem to be increasingly adopting this method (Zambo, 2007).

AR epitomises this approach as it provides the necessary tools to evaluate practice and the methods adopted. McNiff and Whitehead (2011) purport that AR is a relatively 'new scholarship' that represents a systematic, high-level study of professional practice. Action researchers can justify claims to knowledge by producing authenticated evidence that

emphasises the evaluative elements in the research process with valid findings contributing to an ever-expanding evidence base (Mertons, 2005; McNiff & Whitehead, 2011).

Practice-based evidence promotes on-going discussions amongst practitioners. AR is an important tool for practitioners to evaluate practice-based evidence. EPs can adopt AR to challenge current ways of working by exploring and evaluating potential improvements in practice.

In summary, AR appears to be useful for EP practitioners seeking to conduct research. It is particularly applicable to the range of skills, talents and experience that they have acquired over many years of training, and allows for collaboration with other professionals.

### ***5.5.3. Implications for young people with cerebral palsy***

Far too often young people with disabilities are asked if they like, or dislike a situation or experience, without being consulted on how they would prefer the situation to be, or what changes are necessary. This research indicates that YPCP considered to have significant or severe impairments were able to direct and provide feedback on adaptations to practice if their views are considered, and the appropriate resources or communication methods are made available.

From this experience of the research, perhaps the YP directly involved in the research will feel empowered to voice their views and opinions in other situations in the future. In a broader context it is hoped that wiki-page tools can promote SA for YPCP generally, particularly those with CP.

### ***5.5.4. Implications for institutions, policy and legislation***

The Children and Families Act (2014) places great emphasis on the need for participation of CYP and their families in decision-making processes. Consequently, national policy is now arguably more in line with the United Nations Convention on the Rights of the Child (UNCRC, 1989), which empowers CYP with the basic right to have their views given due weight in all matters affecting them. Within real world institutions, however, reality often falls well short of this ideal. The ingrained approaches of institutions, evident in systems and policies, often disempower and marginalise groups of people (Lawlor et al. 2006). Institutional barriers can ultimately undermine basic human rights and YPCP are at particular risk. This is due to the lack

of control that the YPCP may have over these institutions, in addition to their ability to change them (Shikako-Thomas et al., 2009; Flad et al., 2011; Munger, 2011).

Revisions to the education system in the UK have resulted in national mandates that have placed an increasing emphasis on CYP being more involved in decision-making processes. For instance, the Education Acts (1993; 1996) have provided pupils with increased rights that are protected by law. However, within school institutions, especially SEN environments, the students remain disempowered, and are rarely given the opportunity to participate in decision making in a meaningful way to influence policy. For instance, the fact that consent for participation in this research project was ultimately that of the Head Teacher and parents/carers, not of the YPCP, who were of legal adult age. The author does not doubt that good intentions underpin such approaches, but this is clearly at the expense of SA. By adopting an AR approach, and making adaptations to promote participation, SEN environments, and schools in general, could benefit from improved policy outcomes that support the needs of the students more effectively.

Currently, the use of One-Page profiles in LAs falls well short of the principles outlined in the Children and Families Act (2014). Wiki-pages potentially provide a superior tool, enabling YPCP to share health, educational and personal information with a range of professionals, so that their needs in these areas can be met more effectively. More generally, MMSA tools could provide a useful method for LAs, and the professionals located within them, to have increased collaboration, and improved policy outcomes.

Although legislative progress has been made in recent times, it is still drafted within an environment consistent with the medical model of disability. In contrast, by embracing an AR approach, the government could advance the agenda for the adoption of a social model of disability (Munger, 2011). The author suggests that with adaptations to promote the meaningful inclusion of YPCP within the decision-making process at a national level, legislation could be further improved.

In summary, the use of AR could lead to greater participation of YPCP in the institutions in which they are located, including; schools, LAs and wider-society in general. This could promote ‘real-world’ change, with the promise of recent legislation perhaps being fulfilled.

## **5.6. *Further research***

This work has highlighted that the concept defined as SA is significantly under-researched for individuals with CP, particularly YPCP aged 16 – 25 years. The research was therefore deliberately designed within an exploratory and emancipatory framework, to develop understanding of using MMSA tools with YPCP. It illustrates that qualitative research methods, such as AR, can be used effectively to provide practice-based evidence. It was always the author's intention that this research would provide a primary platform from which further study could be undertaken. The author hopes others might adopt, refine and improve similar methodologies in the future. Moving forwards, researchers might focus on assessing the efficacy of MMSA tools in comparison to traditional methods of achieving SA. It could also be interesting if research was undertaken, to determine if different challenges or barriers present in mainstream educational settings. Finally, the use of larger sample sizes is necessary to improve validity and reliability.

## **5.7. *Reflections and conclusions from the research***

Throughout this research reflexivity was a central component of the design and outcomes. The reflective journal was crucial for expanding the author's understanding of the research process and developing an increased awareness of learning.

### **5.7.1. *Roles assumed in the research***

In the process of this journey the author undertook several different roles depending on the situation or context. These roles included researcher, practitioner, and advocate. The primary aim was to adopt the role of an action researcher with the intention of developing professional practice, in addition to informing the wider EP community. The author succeeded in making adaptations and changes to his practice, and was able to share these 'living theories' and the experiences they encapsulated, with the intention of inspiring others to make similar changes. As a practitioner, the author utilised prior experience and skills working within SEN provisions to provide the YPCP with increased opportunities for participation. There were also times that the author assumed the role of an advocate for the YPCP, attempting to uphold their legal rights when they appeared at risk of violation.

### **5.7.2. *Reflections of research journey***

Although the author has previously conducted qualitative research for a Master's degree, this was a new experience of using an AR methodology. It has developed understanding of the importance of continuous reflection and reviewing practice as an EP. This journey has been



punctuated by uncertainty. There was little research in the area of SA in relation to YPCP, and wiki-pages are an emerging technology with a limited evidence base. Whilst there is a lack of research to support the efficacy of wiki-pages, they appear to have significant potential to overcome barriers that often 'disable' YPCP from achieving SA. The author focussed on identifying potential barriers and developing adaptations, reducing or removing these barriers, to promote participation and make the wiki-pages accessible. To do so, the author gained the views of the YPCP. This process resulted in collaborative decision-making processes that fostered good rapport and trusting relationships with the YPCP. They demonstrated determination and perseverance whilst they learnt about the wiki-page platforms, as well as the various methods or adaptations that we trialled to empower them.

The skills acquired and developed as an action researcher has made the author more determined to improve his professional practice. The values that underpin the research have highlighted that part of the role of an EP is to ensure that the YPCP involved have opportunities to self-advocate, and in doing so contribute to the author's ongoing professional development. The author has gained confidence in his ability to make informed decisions, as well as being able to provide justification and rationale to support those decisions. The aim is to continue to use practice-based evidence to develop innovative ways of working with emerging technologies, in the hope that they can remove the barriers emanating from a social model of disability.

## **5.8. Conclusions**

The author adopted AR with a desire to understand his own practice and the intention to question, critique, and improve it (McAteer, 2013). The significance of this research is that by generating and testing living theories it has resulted in the improvement of the author's practice, evident in a clear and identifiable process (McNiff & Whitehead, 2011). The research demonstrates that MMSA tools can be beneficial for YPCP, and establishes adaptations that successfully increased participation, highlighting that with appropriate support they can access MMSA tools and achieve SA. Indeed, the participants in the research were perceived as collaborators and co-creators of knowledge, with their views being considered and acted upon.

Having completed the research and reflected on the findings it is evident that the author is in a position to answer the four research questions. The *benefits* of using MMSA tools with YPCP has been investigated, with focus on increased participation and an increased ability to self-advocate. Through sharing this knowledge with the EP community, the hope is that colleagues will feel confident to use MMSA tools with YPCP presenting a wide range of needs. The

*Challenges* of using MMSA tools with YPCP have been identified, and barriers to participation categorised into three groups; individual, socio-environmental and institutional. Socio-environmental and institutional barriers can be particularly problematic to overcome, and act to disempower individuals with CP in a way consistent with a social model of disability. The *adaptations* to practice have been highlighted, and it has been demonstrated how these were developed and implemented to ensure that challenges were minimised or overcome. Examples include adaptations to ICT equipment and implementation of a variety of different communication methods. Finally, the *implications* of the research have been explored in the context of the effects on the author's own professional practice and that of the wider EP community. This has highlighted the importance of acknowledging the views and desires of the YPCP, and developing new ways of working in collaboration with that individual, along with parents/carers, and other professionals.

More research is required in this area to increase the opportunities for YPCP to self-advocate. There is the need for the production of case stories to show how researchers improve both situations and their own learning, so that the wider EP community can benefit from the data. The more case studies that appear, the more powerful the body of knowledge will become, with action research constituting a form of learning that may have profound implications for future society (McNiff 2010). Certainly, the author's intention is that his living theories will continue to grow and develop through professional practice. The essence of this sentiment is captured eloquently by McNiff and Whitehead:

*"Never believe that your knowledge is complete or there is no more to learn."* (McNiff & Whitehead, 2011 p.256).

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## **Appendices**

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*Appendix A* – Examples of One-Page profiles

*Appendix B* – Extract from research journal

*Appendix C* – Information sheet for parent(s)/carer(s)

*Appendix D* – Consent form for parent(s)/carer(s)

*Appendix E* – Pen portraits of participants

*Appendix F* – Assessment of participants needs

*Appendix G* – Ethics approval from University of East London

*Appendix H* – Adapted information sheet for participants

*Appendix I* – Adapted consent forms for participants

*Appendix J* – Pauline's codebook

*Appendix K* – Thematic map

*Appendix L* – Thematic map of benefits of MMSA tools

*Appendix M* – Thematic map of the barriers to accessing MMSA tools

*Appendix N* – Thematic map of the facilitators of accessing MMSA tools

*Appendix O* – Letter of thanks sent to participants

*Appendix P* – Wiki-page used to present preliminary findings to colleagues at UEL

## Appendix A

### What Others Admire about Me

- Kind
- Caring
- Good friend
- Good with children
- Determined
- Good morals
- A leader

### What is Important to Me

Getting to know the school quickly

Knowing where to go if I need help

Having time to be with friends and just relax

Access to a telephone when stressed

Taking classes that are fun but also help me work toward a career in childcare

Getting through compulsory courses

Help with Math when I need it

Staying away from situations where I might be influenced to make poor choices

That both of my parents are involved in my education

A consistent person to go to for emotional, stress management

Learning good study habits

### VISION

- Work toward a career in childcare
- Yearbook club
- Volleyball
- Meeting new friends and hanging out
- Making good choices
- Going on school trips (Stratford)

### How to Support Me Best

I don't like to ask for help, please offer it to me if you feel I need it.

After a visit to my dad's house I have a hard time getting back into the swing of things, be patient and offer your support

If I get overwhelmed I tend to give up, please encourage me to stay on track

I like to write stories or journal when I am frustrated or sad, sometimes I need freedom to do this

I like to be a leader but sometimes get caught up in the drama of situations; I might need a motivational reminder

In elementary school I did not have a lot of homework or studying, I had mostly one on one due to small classes, this will be a huge adjustment for me, support me in developing good strategies

Stress is not my friend, my anxiety level raises and I need reassurance or comfort from someone I love or am comfortable with

Public speaking makes me physically ill, my anxiety level rises until I am sick and cannot function. Please limit this when possible.

### Great Things about Jack:

Jack has a very good sense of humour and enjoys jokes and teasing around. He is a great fun and likes to pull funny faces, the enjoy cooking and eating food he has created, as well as cooking for others.

Jack is a daredevil and likes to engage in risky activities like motorcycle riding, skate park scootering and trampolining. He is an exceptional BMX rider and races for the Shepparton BMX club.

Jack loves star wars and has a fabulous knowledge of all things related. He enjoys drawing, particularly when it is related to his interests. He will use drawing to create elaborate plans of things he would like to construct out of Lego or wood. He can make amazing constructions out of Lego and works well with timber, creating his own ramps and jumps for the bike and scooter. Jack also works well with tools and can use a compass drill, screw driver, hammer and like tools with competence.

### Important To Jack:

Time with Dad first thing in the morning - having a ride and a chat about things that are coming up, things that are going on - being able to get up early to make sure he doesn't miss Dad.

Knowing what's happening moment by moment, and ideally feeling clear about what's happening about a week in advance. To not have plans change, especially at short notice.

People understanding what he's trying to say, taking notice and acknowledging him.

Topics being presented to him in small steps, with visuals in the form of lists to help him stay focused. He likes it when interest is shown in what he is doing, and support is offered, even if he declines.

People taking time to talk to Jack about the things he's interested in - eg. Star Wars, BMX, Scooters, Cruddy Demons.

Time for doing things with his hands for at least half an hour every day - eg. Building things - legs, making things with wood, drawing, putting things apart and putting them back together again.

Not being late - having time to feel prepared, organised and ready for what's happening next - never having to rush.

Having his own space - not having anyone close enough that he'll feel them breathing on him (unless he's initiated it himself).

Having something to hold in his hands & fiddle with, to help calm himself and feel focused.

### How to Best Support Jack

Know that Jack's mind is like a computer database running all the time - eg. he may have all the answers that he's never even registered in his head - especially if someone's giving him instructions and he doesn't understand. He will often miss things that are said as a result. Always check that he has understood, that he knows what is expected of him and what's going to happen.

Jack doesn't mean to be rude when he talks over others. Giving him a visual signal that you and he understood will help him to remember to wait for a turn in conversation.

Provide a schedule with times listed on it indicating when things are going to occur, so that he can keep track of things and know what is coming up next.

It's very difficult for Jack to understand instructions that don't build on any existing knowledge or experience that he already has.

If there have been changes to plans, reassure Jack that it will be ok. Talk through the plan with him, then redirect his attention to something good that's happened or about to happen in his day.

Plan ahead with great activities to support Jack to have a way to maintain his own boundaries as others aren't in his space - eg. his own cushion to sit on or a mat, or if you can, remind the whole group by asking them to sit in a circle but making out their own space first. Avoid situations where he has to hold other people's hands. Encourage him to be, but you him and if he doesn't want to.

### What's Important to Mel at school

- To do R.E. at school and go to Mass. Mel's faith is very important to her.
- To be included and a part of things, Mel likes to join school clubs and activities
- To know what the rules are to follow them, this helps Mel feel safe
- To be around people who also follow the rules and don't tell lies
- To do science and art, Mel likes lessons where she can do practical things. She really likes drawing and painting
- Not to have people bullying her or being mean
- To play with Sophie at playtime, Mel's favourite games are pretending ones
- Not to have to copy down lots of writing in literacy
- To be in a calm environment. People who talk too much in lessons puts her off and if people are very loud and angry this worries Mel a lot
- To sit near the front of the classroom
- To know people are listening to her and to have time to answer questions and not be rushed
- To know what is happening during the day, but to have this in small chunks
- To be told when she is doing something well and to have lots of opportunities to do well
- To have a feelings chart to fill in and talk about at playtime, lunch time and at the end of the day
- To know where she needs to go and to know what she needs for each lesson in her new school
- To know who to go to if she is worried about something. Mel might write a letter to explain what is the matter

### Things we like about Mel

Mel is gentle and calm. She tries really hard and is very enthusiastic. Mel is funny and makes me laugh. She is lovely.

### How Best to Support Mel

- Understand that being included is very important to Mel. Try to think of activities she may enjoy and let her know how to get involved.
- Mel needs to know the rules and finds it hard if other are not following them. It worries Mel a lot if others are loud and angry in class. Support her by guiding her out of the situation and room as soon as you can and reassuring her.
- Know that Mel enjoys practical tasks and finds some lessons harder. Mel particularly finds it difficult to have to copy things down in Literacy. It would help Mel a lot to have things like dates or tables prepared for her or by having a date stamp she can use.
- Know that Mel always gives 100%. Support Mel by giving her every opportunity to do well by offering her practical tasks to do and always noticing when she has done well. Remember that she always tries very hard.
- Mel is a trusting girl and occasionally people can be mean to her without her realising this. Support her by being aware of this and stepping in if people are unkind. Sometimes Mel will say someone has been mean but it is something else that is worrying her more, check this with her.
- It is important that Mel knows where she needs to be and what she needs for her lessons. Too much information at once won't work for her. Support her by giving her any instructions that she needs to remember in short bursts and giving her information in ways that work for her. Colour coding of rooms, lessons on her timetable and the list of things she needs for each one may help, as well as pointing out another child who is going to the same place.
- If Mel doesn't understand what she needs to do she may look out for cues by watching the other children. Mel doesn't usually say if she is struggling. You may notice that she is repeating the last word you say or not picking up her pen to start. Be on the lookout for this and be ready to offer her some help. It may work for Mel if you agree with a way of her letting you know she is stuck before the lesson starts. If you ask Mel if she has enjoyed a lesson and she says no, she might not have understood it so this is a good way to check.
- Mel needs time to think before answering questions. Give her this time and don't keep asking her, as this makes it harder to think. Saying her name when you ask her a question may help.
- Be aware that Mel needs to know who to go to for help. Make sure she knows who this is and remember that she sometimes finds it easier to write a note rather than explain what is wrong. Mel is very keen to have a feelings chart that she can talk about each day. Support her by making sure she has this opportunity.

Mel does brilliantly well

### Like and admire about me

I am good at Rhythms

I am good at guitar

you are good at

Mathematics

you always smile

you are good at drawing

you are a great friend

you are given a football

you are nice and you are clever

you are good at swimming

I am good at art

I am good at Lego

### Important to me

My Family

Squiggles and Fittos (my guinea pig)

And my Fish and

my friends

LEGO

Food

Minecraft

Mossy

### What my teacher needs to know to support me

- Needs specific instructions
- Doesn't respond well to vague/voluntary tasks
- Needs encouragement to put himself forward for things
- Needs reminding to stay on task
- I like ICT
- I like tests
- I like homework
- I enjoy projects
- I know my times table



Thursday 17th September 2015  
Session - 1: P

Arrived - child protection issue  
No facilitator. Meeting room unavailable.  
Went ahead with session regardless with  
another member of staff.

Problems:

Lack of preparation. Facilitator - lack of  
knowledge of the aims and wiki-page  
platform.

Lack of ability to communicate with  
Participant - Non-verbal. = Lack of  
ability to make intentions known and  
∴ make choices

Lack of motor - skills. / lack of resources

Considerations for next session

- Ensure facilitator is available and  
reiterate to school, will not be able  
to undertake research unless room is  
available

- Resources / Adaptations

- \* Find more effective communication method
- \* Adaptations to reduce motor impairment

Reflections

Frustrations, quality of work should not  
be compromised

- \* Need for rapport w/ facilitator

**Information Sheet for Parents**

**Exploring the potential challenges and benefits of using multimedia self-advocacy tools for young people with cerebral palsy aged 16 – 25 years.**

**MY NAME IS RICHARD WESTERMAN AND I WORK WITH CHILDREN AND YOUNG PEOPLE IN ESSEX. I AM CURRENTLY TRAINING TO BECOME AN EDUCATIONAL PSYCHOLOGIST AT THE UNIVERSITY OF EAST LONDON AND AS PART OF THE COURSE I AM DOING A RESEARCH PROJECT THAT PUTS THE VIEWS OF YOUNG PEOPLE WITH CEREBRAL PALSY AGED 16 – 25 AT THE CENTRE OF THE RESEARCH.**

*WHY IS THIS RESEARCH BEING DONE?*

**AT THE MOMENT THERE APPEARS TO BE A LACK OF RESEARCH THAT FOCUSES ON ISSUES OF EMPOWERMENT AND SELF-ADVOCACY (SEE GLOSSARY OF TERMS) FOR INDIVIDUALS WITH CEREBRAL PALSY. IN PARTICULAR THERE ARE FEW RESEARCH PROJECTS THAT REPORT THE VIEWS OF THE INDIVIDUALS THEMSELVES, ESPECIALLY FOR CHILDREN AND YOUNG PEOPLE.**

**I IDENTIFIED THIS AS AN ORIGINAL AND IMPORTANT AND AREA OF RESEARCH IN LIGHT OF THE RECENT INTRODUCTION OF THE CHILDREN AND FAMILIES ACT (SEPTEMBER 2014) THAT STATES THAT EDUCATIONAL PSYCHOLOGISTS WILL NOW BE WORKING WITH YOUNG PEOPLE AGED 16 – 25.**

**BY TAKING AN EMANCIPATORY APPROACH (SEE GLOSSARY OF TERMS) AND INVOLVING THE INDIVIDUALS' IN THE RESEARCH, IT IS HOPED THAT THIS CAN ACT TO EMPOWER THESE PARTICULAR YOUNG PEOPLE. EACH YOUNG PERSON WILL HAVE OPPORTUNITIES TO ACTIVELY CONTRIBUTE AND GUIDE THE DIRECTION OF THE PROJECT. THEY WILL ALSO HAVE THE OPPORTUNITY DURING THE PROJECT TO DEVELOP THEIR OWN PERSONAL WIKI-PAGE (SEE GLOSSARY OF TERMS).**

*WHICH YOUNG PEOPLE WILL BE INVOLVED?*

**A PURPOSEFUL (SELECTIVE) SAMPLING PROCESS WILL BE USED, WHEREBY VOLUNTEERS WILL BE SOUGHT WHO FIT THE CRITERIA OF BEING AGED BETWEEN 16 AND 25 AND WHO HAVE CEREBRAL PALSY. THESE ARE THE ONLY CRITERIA AS THERE IS NO INTENTION OF DIFFERENTIATING BETWEEN DIFFERENT 'TYPES' OR 'SEVERITY' OF CEREBRAL PALSY IN THIS RESEARCH PROJECT.**

*WHAT DOES THE STUDY INVOLVE?*

- 1). INITIALLY I WILL MAKE ARRANGEMENTS TO COME AND TALK TO POTENTIAL PARTICIPANTS ABOUT THE STUDY IN MORE DEPTH. I WILL ANSWER ANY QUESTIONS THAT YOU, THE YOUNG PERSON, OR THE YOUNG PERSON'S PARENTS/CAREGIVER MAY HAVE. IF THE YOUNG PERSON IS HAPPY TO BE PART OF MY PROJECT AFTER THIS, THEY WILL BE INVITED TO BE INVOLVED IN THE STUDY WITH SEVEN OTHER YOUNG PEOPLE WHO ARE DEEMED APPROPRIATE FOR THIS RESEARCH PROJECT. AT THIS POINT I WILL OBTAIN INFORMED CONSENT IN WRITING FROM THE YOUNG PERSON AND ALSO THE PARENT(S)/CAREGIVERS IF APPROPRIATE. I WILL ALSO TAKE THIS OPPORTUNITY TO FIND OUT FROM THE YOUNG PERSON IF THERE ARE ANY SPECIFIC RESOURCES OR STRATEGIES THAT THEY MAY REQUIRE, OR I SHOULD CONSIDER, TO ENABLE THEM TO PARTICIPATE FULLY IN A GROUP DISCUSSION AND ALLOW THEM TO HAVE THEIR VIEWS HEARD DURING THE ENTIRE PROJECT.**
- 2). IF THE YOUNG PERSON IS STILL HAPPY TO CONTINUE TO BE PART OF MY PROJECT AFTER THE INITIAL PLANNING STAGE, I WILL ARRANGE A GOOD TIME TO MEET WITH THEM AGAIN INDIVIDUALLY. I WILL ASSIST THEM WITH**

CREATING A **WIKI-PAGE** (SEE GLOSSARY OF TERMS) OVER SIX SESSIONS. ALL OF THE SESSIONS WILL BE VIDEO RECORDED.

3). AFTER THE CREATION OF THE WIKI-PAGE YOU ARE WELCOME TO BE PART OF THE INTERVIEW PROCESS. THIS IS YOUR CHOICE. WHILST IT IS NOT CENTRAL TO THE RESEARCH, IT WOULD BE VERY USEFUL TO GAIN YOUR VIEWS AND LEARN FROM YOUR EXPERIENCES. QUESTIONS WILL BE SIMILAR TO THESE EXAMPLES:

- **WHAT DID ... LIKE BEST ABOUT THEIR WIKI-PAGE? WHY DO YOU THINK THEY PARTICULARLY LIKED THAT?**
- **WHAT HAS YOUR CHILD FOUND MOST ABOUT THE WIKI-PAGE PROJECT?**

THIS CONVERSATION, OR INFORMAL INDIVIDUAL, INTERVIEW WILL LAST APPROXIMATELY 1-HOUR WITH NO CONVERSATIONS LASTING MORE THAN 90 MINUTES IN TOTAL.

#### *CONFIDENTIALITY*

WHEN THE YOUNG PEOPLE ARE HAVING CONVERSATIONS DURING THE GROUP DISCUSSIONS, I WILL RECORD WHAT THEY SAY USING A TAPE RECORDER TO ENSURE THAT THEIR THOUGHTS ARE RECORDED ACCURATELY. WHAT THEY SAY WILL BE KEPT BETWEEN MYSELF AND THE OTHER YOUNG PEOPLE. FURTHERMORE, WHEN I AM TALKING TO THE YOUNG PERSON INDIVIDUALLY IN MORE DETAIL DURING THE INTERVIEWS, I WILL ALSO RECORD WHAT THEY SAY USING A TAPE RECORDER TO ENSURE THAT THEIR THOUGHTS ARE RECORDED ACCURATELY. WHAT THEY SAY WILL BE KEPT STRICTLY BETWEEN THE YOUNG PERSON AND MYSELF. THE ONLY TIME I WOULD BREAK CONFIDENTIALITY IS IF THEY DISCLOSED SOMETHING THAT MEANT EITHER THEMSELVES OR SOMEBODY ELSE WAS IN DANGER. THESE RECORDINGS WILL BE KEPT IN A SECURE, LOCKED CABINET UNTIL TRANSCRIBED. AT THIS POINT THE RECORDINGS WILL BE DESTROYED AND THE TRANSCRIPTIONS WILL NOT HAVE ANY IDENTIFYING MARKERS ASIDE FROM THE I.D NUMBER ALLOCATED BY THE RESEARCH. I.D NUMBERS WILL BE KEPT SEPARATE FROM RAW DATA AND TRANSCRIPTIONS IN A SECURE, LOCKED CABINET.

WHEN I HAVE GATHERED THE YOUNG PERSONS' THOUGHTS VIA THE GROUP DISCUSSION AND THE INDIVIDUAL INTERVIEWS, I WILL WRITE ABOUT WHAT I HAVE FOUND OUT. HOWEVER, I WILL NOT USE THEIR NAME AND I WILL ALSO MAKE SURE THAT NOBODY CAN WORK OUT WHO SAID WHAT. THE YOUNG PERSON'S RESPONSES WILL NOT BE LINKED TO THEIR NAME, SCHOOL OR ANY PERSONAL DETAILS, AS THEY WILL HAVE BEEN COMPLETELY ANONYMISED. ALL RAW DATA INCLUDING THE TRANSCRIPTIONS AND RESEARCHER NOTES WILL BE COMPLETELY DESTROYED ONCE THE WRITE-UP HAS BEEN COMPLETED AND ACCEPTED POST VIVA VOCE.

*WHAT IF YOU WOULD LIKE TO FIND OUT MORE ABOUT THIS STUDY?*

IF YOU HAVE ANY QUESTIONS ABOUT THE STUDY OR IF YOU WOULD LIKE TO DISCUSS THIS FURTHER, PLEASE DO NOT HESITATE TO CONTACT ME: -

EMAIL: RICHARD.WESTERMAN@

CONTACT TELEPHONE NUMBER: +44 3330 138 576

*THANK YOU FOR TAKING THE TIME TO CONSIDER THIS STUDY*

KIND REGARDS,

RICHARD WESTERMAN

### Consent Form

**‘Exploring the potential benefits and challenges of using multimedia self-advocacy with young people with cerebral palsy aged 16 – 25 years.’**

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**Primary Researcher:**

Richard Westerman  
Trainee Educational Psychologist  
University of East London & Educational Psychology Service  
Richard.westerman@  
07938561353

**Faculty Supervisor:**

Dr Mark Fox  
Director of Educational Psychology Training Programme  
University of East London  
020 8223 4680  
[m.d.fox@uel.ac.uk](mailto:m.d.fox@uel.ac.uk)

**Placement Supervisor:**

Paul Hammond  
Senior Specialist Educational Psychologist  
Educational Psychology Service  
Paul.hammond@

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Dear Sir/Madam

First of all please allow me to take this opportunity to thank you for showing interest in this research project. Having spent considerable time providing care for children with a range of disabilities I have decided to devote my thesis research to exploring how young people with cerebral palsy can express their views, beliefs, hopes and aspirations.

In doing so, I not only hope to add to the growing literature in this critical area of research but also use this as a pilot study to test the techniques in an effort to enrich and improve young people's lives as well as informing professionals who work in this area how they might be able to improve their practice.

### Procedure

If you agree to allow your child to participate in this study, I will assist your child to create their own Wiki-page over 6 sessions at school. Following the completion of their Wiki-page I would like to have a discussion (maximum 1 hour) to find out about what they chose to share and how. All sessions will be recorded with a digital camcorder. I would also like you to have a 'say' in the research so it would be great if we could have a discussion about the Wiki-page for approximately 1 hour at a time convenient for you. This conversation will be recorded using a Dictaphone but it is your choice whether or not you wish to be involved as it is not central to the research.



### Confidentiality

The privacy and confidentiality of your child are very important and will be the primary concern throughout the study. Anything that is recorded by the researcher will be strictly confidential and any identifying information will be coded in order to assure your child's anonymity. All materials (video recordings, voice recordings and transcripts) will be stored securely and will only be accessed by the primary researcher. Pseudonyms will be used in order to protect the privacy of your child and only non-identifying information will be reported in the final project. Upon completion of the project, any identifying information and raw data will be completely destroyed.

The participation of your child in this study is completely voluntary and you have the right to withdraw your child at any time (this includes post data collection). In the case that you do choose to withdraw your child, any information that you have provided or has been collected will not be used for research purposes and will be destroyed. Furthermore, you are under no obligation to be involved in the interviews if you choose not to be involved.

### Additional Information

The benefits of participating in this study include the opportunity to reflect on your experiences as well as those of your child. I also seek to use the research to enrich the lives of those who participate in the research and the young person will be able to keep their wiki-page and adapt it to meet their needs in whatever manner they choose in the future. The risks involved in this study are minimal. However, I acknowledge that talking about past life experiences can be distressing or traumatic if it brings up painful memories. If you experience any discomfort you are free to terminate the interview at any time and I could advise you where you can seek additional support if you feel this is necessary.

### Contact

If you have any questions regarding your child's participation in this study, or are interested in the results of the study (which should be available by September 2016), please feel free to contact me (Richard Westerman).

If you have any further questions about the ethical issues involved in the project you may contact myself, The University of East London or my supervisor (Dr Mark Fox).

Furthermore, I am more than willing to discuss the study with you personally in further detail if you feel that you require further information or additional details.

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*I have read the description of the study, I understand the requirements involved and I willingly consent my child to participate in this study.*

*I have understood that I have the right to withdraw my child from the study at any time and for any reason.*

Name of child: \_\_\_\_\_

Parental/guardian signature: \_\_\_\_\_ Date: \_\_\_\_\_

## ***Appendix E***

### **Participant profiles: Summary of individual needs and general level of support required.**

Prior to commencing the practical aspects of creating the individual wiki-pages, a skills and support profile assessment was conducted for each participant. This was assisted by a keyworker who was familiar with the abilities and needs of the individuals and who would also be collaborating/assisting with the creation of the wiki-pages during the research process. It was further facilitated through the use of a participant profile assessment form (See Appendix F) provided by The RIX Centre that was developed for the purpose of a previous research project called the Symbol Surfing Project.

Although there is reference to the traditional categorisation of CP, as well as some diagnostic information or references to medical diagnoses, the aim of the pen portraits is to build up a rich picture of the individual's needs as opposed to presenting statistical information that standardised assessments offer.

### **Pauline**

#### **Broad overview of CP classification impairment**

Pauline is a young adult female who is 18 years of age. She has a diagnosis of hypotonic quadriplegic (or tetraplegic) CP that is characterised by decreased muscle tone, resulting in loose, floppy limbs. The result is the consequence of sensory and motor impairment, which means that both sensation and control are compromised or lost completely. This is generally considered the most 'debilitating' of CP types as it results in the partial or total loss of use of all four limbs and torso, in addition to giving rise to several associated impairments.

#### **Physical needs, motor skills and necessary support for limiting impairment**

Due to the nature of quadriplegic CP, Pauline has significant impairments in terms of gross and fine motor skills. In terms of functional ability, Pauline has limited use of her left hand/arm. She has the ability to extend and slightly move her fingers on her left hand and indicate 'yes' with physical gesture of her hand by shaking it vertically. Furthermore, she can use her left hand to grasp small, light objects with some additional support from another person.

She can also rotate her head right and left although she requires a head rest for support to maintain head position/posture, which can also act to further restrict lateral movement.

In terms of mobility, Pauline uses a wheelchair with the support of an adult. In addition to this, to assist with Pauline's gross motor and mobility needs she also has access to leg splints and arm splints to support her posture and maintain her positioning. She also has specialist equipment such as a standing frame and an adapted tricycle.

#### **Communication skills and communication needs**

Due to the associated difficulties that can often accompany quadriplegic CP, Pauline exhibits significant and severe difficulties with communication. Although she is nonverbal she can produce vocalisations. Communication is mainly through body language, facial expression, eye contact/gaze, gesture, vocal response or laughter.

Pauline can communicate through pictures/symbols by selecting from a choice of 4 – 6 items. Pauline is also able to point at objects and can use objects of reference to communicate, although this can be extremely tiring and can lead to fatigue. More recently she has developed skills in using eye gaze technology through extensive training although it is reported that the technology

can be problematic and can also be dependent on Pauline's emotional state, motivation or willingness to engage. Fatigue, as well as environmental factors, such as movement or noise also impact its effectiveness.

It is reported that the following considerations can promote effective communication with Pauline. Individuals should use facial expressions, signs and gestures, objects of reference, graphic symbols, photographs and pictures. It can also be beneficial to have an adult who is familiar with her communication traits, such as a parent, or member of staff who works frequently with her. Pauline is supported by enthusiastic support staff whose intimate knowledge of Pauline's facial expressions and communicative gestures are central to her involvement in social and learning activities. It is also important to use short, simple sentences with several key words.

### **Cognitive skills, intellectual function and literacy ability**

Pauline exhibits significant difficulties with learning (SLD). However, due to her significant difficulties with communication, in addition to her extensive physical impairment, it can be challenging to determine and evidence her ability.

Pauline exhibits some difficulties with maintaining her attention during learning activities, which is further impacted by the immediate environment in terms of sound and movement. She generally needs to look in the direction of the stimulus, or person communicating to her to effectively process information.

In terms of Pauline's literacy skills, it is reported that there is no known or observed ability to read or write. However, Pauline has good receptive listening skills and demonstrates her understanding by responding to closed questions, selecting from a choice of photographs, pictures and symbols.

### **Additional considerations**

- Pauline has limited ICT skills and seldom had the opportunity to engage in ICT activities, aside from her ability to operate eye gaze technology.
- She is gastro fed through a peg with adult support. She also requires support for aspects of personal care and other factors that limit her independence.
- Pauline is in permanent foster care.

## **Charlotte**

### **Broad overview of CP classification and impairment**

Charlotte is a young adult female who is 19 years of age. She has a diagnosis of ataxic hemiplegic CP. Ataxic CP originates from damage to the developing brain's motor control centres that causes an interruption of muscle control in the arms and legs, resulting in a lack of balance and coordination. This is the case for the left side of her body but she also has difficulties in coordinating movements in a general sense. Ataxic CP can affect the hands, arms, legs, feet, eyes and even speech, which is the case to some extent for Charlotte. She exhibits significant visual impairment (VI) and some difficulties with aspects of expressive/receptive communication. In addition to this, Charlotte has also been diagnosed with autism spectrum disorder (ASD).

### **Physical needs, motor skills and necessary support for limiting impairment**

Ataxic CP is characterised by clumsiness, imprecision, or instability. Consequently, movements are not smooth and may appear disorganised or jerky. Charlotte generally uses a walking support in the home and educational contexts but will use a wheel chair for increased mobility when she

is required to travel long distances. It is possible for her to walk small distances independently (without a walking support) but will generally have to hold onto other people, rails or objects, such as tables, to promote her confidence, posture and balance. This ability is also improved through the use of leg splints that Charlotte wears daily.

Generally, the lack of coordination seen with ataxia is most notable when a person attempts to perform voluntary movements, such as walking or picking up objects. Furthermore, individuals with ataxic CP appear to struggle with precise movements, such as writing and grasping small objects. Although Charlotte can find the coordination of movements challenging, she is able to use both hands to grasp something or pick up items of various sizes and move them. Charlotte can perform several different fine-motor tasks but may require encouragement and support to motivate her to stay on task.

### **Communication skills and communication needs**

It is reported that Charlotte has relative strengths in verbal communication skills and the content of her expressive language is generally accurate. She therefore generally communicates verbally but there are times when she uses additional signing, gestures or pointing at photographs, pictures or symbols when necessary. It should be noted that Charlotte's speech can sometimes be hard to decipher, particularly if people are not familiar with her communicative style or she is in a heightened emotional state, such as when she is frustrated, upset or excited.

Charlotte can answer open ended questions but it is important to use short, simple sentences with several key words. However, depending on the complexity of sentence structure and the concepts being referred to, she may need additional support/assistance to prompt or break information down into manageable chunks to achieve this. Communication with Charlotte can be promoted if objects of reference are used. Furthermore, she benefits from adults (either parents or staff) who understand her communication and emotional needs.

### **Cognitive/intellectual function and literacy skills**

Aside from her fine motor difficulties, Charlotte finds literacy challenging due to her significant visual impairment. In addition to ocular damage resulting in poor eye sight, Charlotte exhibits cortical visual impairment (CVI).

CVI is a term used to describe visual impairment that occurs due to brain injury. CVI is caused by damage to the visual centres of the brain, which interferes with communication between the brain and the eyes. Consequently, the eyes can 'see', but the brain is not interpreting what is being seen.

In addition to these physical impairments, Charlotte also has significant learning difficulties (SLD) that impacts her learning outcomes. She can find it challenging to effectively engage, deploy, maintain and disengage her attention. It requires additional adult support to help mediate these difficulties and is necessary to keep her on task.

In terms of literacy skills, Charlotte engages in some social sight reading activities, uses pictorial support and can write her own name and copy letters and words.

### **Additional considerations**

- Charlotte may at times require support to assist her to manage her emotional needs. In particular, she can find it challenging to effectively self-regulate intense emotional states such as overexcitement, frustration or anger. This can have a significant impact on her motivation levels, as well as the clarity and quality of her communication.

- Charlotte's ASD diagnosis relates to a relative lack of flexibility in thinking skills and self-directed behaviours. She can find it particularly challenging to demonstrate inhibitory behaviours or responses, which can impact her ability to follow instructions.
- Charlotte has had some opportunities to access ICT technologies with some support but has limited ICT knowledge and skills.

### **Connor**

#### **Broad overview of CP classification and impairment**

Connor is a young adult male who is 19 years of age. He has a diagnosis of spastic hemiplegic CP, which limits some aspects of movement and coordination of his leg, arm and hand on the left hemisphere of his body. This condition is often characterised by tense muscles and spasms in the affected regions. In addition to this, Connor has also been diagnosed autism spectrum disorder (ASD).

#### **Physical needs, motor skills and necessary support for limiting impairment**

Connor appears to have good balance and coordination skills in both fine and gross motor activities. This is reflected in his ability to ride a bicycle competently. He is also able to write with precision and can manipulate ICT equipment, such as a mouse and keyboard independently. It is reported that Connor's impairments do not significantly impact his ability to effectively interact with ICT hardware devices or software platforms.

In terms of Connor's motor skills, he can walk independently; is able to use his arms/hands to grasp objects; is able to pick up items and move them and is competent at performing fine motor tasks.

#### **Communication skills and communication needs**

Connor is competent at articulating and expressing himself verbally. His speech is clear and understandable, regardless of people's familiarity with him. He generally engages in open and interactive two-way conversations and is proficient at answering open-ended questions. However, Connor sometimes needs some assistance to break down large quantities of information into manageable 'chunks'.

Overall, Connor's communication is predominantly through word combinations that utilise speech due to his strength in expressive language skills. This means that no additional resources, support or adapted techniques are generally necessary to communicate effectively with Connor, although visual support (such as pictures or demonstrations) can promote his understanding if concepts are abstract or complicated in nature.

#### **Cognitive skills, intellectual function and literacy ability**

Although Connor exhibits moderate/severe learning difficulties he can read and write, although he often needs support with aspects of spelling. With regards to his literacy skills he can read large print text, write in sentences and with a certain level of support/assistance can produce creative writing pieces.

He also has an ocular visual impairment, which is managed by wearing corrective lenses for both general purpose and reading activities. It is felt that visual impairment does not have a significant impact on function if he is able to access his corrective lenses.

#### **Additional considerations**

- Connor's ASD diagnosis relates to a relative lack of flexibility in thinking skills and self-directed behaviours. Consequently, there are times when he can find it challenging to

maintain his attention, particularly if it is an activity that he has little interest in or is not motivated to engage with.

- Connor has a good knowledge of ICT and is passionate about ICT activities. Whilst his practical skills are considered very good, there have been previous concerns when he has engaged in social media platforms. This centres around appropriate behaviour with regards to social boundaries. It appears he is still developing knowledge and skills in this area.
- Connor lives with his cousin who is also his legal guardian. His guardians encourage him to be an independent young person. Consequently, Connor commutes by cycling several miles on public roads independently without supervision.
- Connor has engaged in several work experience opportunities alongside attending full time education.

Participant Profile			
Personal Details			
Name:		Date of birth:	
Ethnic background:	WHITE BRITISH	First language spoken:	English
Background			
<p>1. How would you describe the participant in terms of his or her strengths and support needs?</p> <p>Strengths: Keyworker, knowledge of young person. Level of enthusiasm.</p> <p>Support: eye gaze, photos, pictures, needs a wheelchair, legsplints, armsplints, gastro feed</p>			
<p>2. What other factors or difficulties need to be taken into consideration when supporting this participant on a daily basis?</p>			
a) Hearing problems	<input type="checkbox"/>	e) Challenging behaviour	<input type="checkbox"/>
b) Visual impairment	<input type="checkbox"/>	f) Other - please state:	<input type="checkbox"/>
c) Physical/motor difficulties	<input checked="" type="checkbox"/>		
d) Attention problems	<input checked="" type="checkbox"/>		
Communication Skills			
<p>3. What are the ways that the participant likes to communicate?</p> <p>* Facial expressions * vocal sounds, laughter * Eye contact/eye gaze            * Eye gaze technology (occasionally) * Body language * simple hand movement * Photographs, symbols etc.</p>			
<p>4. Tick the box representing the 'best fit' to the individual's communication skills</p>			
a) Communication is mainly through body language, facial expression, gesture and vocal behaviour.	<input type="checkbox"/>		
b) Communication is mainly through body language, facial expression, gesture and vocal behaviour as well as pointing at objects and using objects of reference.	<input checked="" type="checkbox"/>		
c) Communication is mainly through single words, either by use of speech, key word signing, or pointing at pictures/symbols	<input type="checkbox"/>		
d) Communication is through word combinations either by use of speech, key word signing, or pointing at pictures/symbols	<input type="checkbox"/>		
<p>3. Which description represents the 'best fit' to the individual's literacy skills?</p>			
a) No known or observed ability to read or write	<input checked="" type="checkbox"/>		
b) Some social sight reading, uses pictorial support, can write own name & copy write	<input type="checkbox"/>		



c) Can read large print text, newspaper headlines & write in sentences	<input type="checkbox"/>
d) Can read text in books & newspapers; can write letters, e-mails, etc.	<input type="checkbox"/>
<b>5. What are the different ways it helps you to communicate with the participant?</b>	
a) Facial expression <input checked="" type="checkbox"/>	i) Communication book or board <input type="checkbox"/>
b) Signs & gesture <input checked="" type="checkbox"/>	j) Electronic/computer aided communication <input checked="" type="checkbox"/>
c) Objects of reference <input checked="" type="checkbox"/>	k) Other (please state) <input checked="" type="checkbox"/>
d) Graphic symbols <input checked="" type="checkbox"/>	Eye gaze technology.
e) Photographs & pictures <input checked="" type="checkbox"/>	
f) Having a supporter (e.g. staff/parent) present <input checked="" type="checkbox"/>	
g) Having a supporter (e.g. staff/parent) present <input type="checkbox"/>	
h) Short, simple sentences <input checked="" type="checkbox"/>	
<b>Motor skills</b>	
<b>6. What functional motor abilities does the participant have?</b>	
a) Uses a wheelchair for mobility	<input checked="" type="checkbox"/>
b) Able to walk with some support	<input type="checkbox"/>
c) Able to walk independently	<input type="checkbox"/>
d) Able to use arms/hands to grasp something	<input type="checkbox"/> ? - with support
e) Able to pick up items and move them	<input type="checkbox"/>
f) Able to perform fine motor tasks	<input type="checkbox"/>

Form completed by (print name)	
Relation to service user (e.g. key worker)	Transition Worker
Date	22nd July <input type="text"/>



**SCHOOL OF PSYCHOLOGY**

Dean: Professor Mark N. O. Davies, PhD, CPsychol, CBiol.



**School of Psychology  
Professional Doctorate Programmes**

To Whom It May Concern:

This is to confirm that the Professional Doctorate candidate named in the attached ethics approval is conducting research as part of the requirements of the Professional Doctorate programme on which he/she is enrolled.

The Research Ethics Committee of the School of Psychology, University of East London, has approved this candidate's research ethics application and he/she is therefore covered by the University's indemnity insurance policy while conducting the research. This policy should normally cover for any untoward event. The University does not offer 'no fault' cover, so in the event of an untoward occurrence leading to a claim against the institution, the claimant would be obliged to bring an action against the University and seek compensation through the courts.

As the candidate is a student of the University of East London, the University will act as the sponsor of his/her research. UEL will also fund expenses arising from the research, such as photocopying and postage.

Yours faithfully,

A handwritten signature in blue ink, which appears to read 'Mark Finn', is written over a faint, circular official stamp.

Dr. Mark Finn

Chair of the School of Psychology Ethics Sub-Committee

## INVITATION LETTER

UNIVERSITY OF EAST LONDON  
School of Psychology  
Stratford Campus  
Water Lane  
London E15 4LZ  
SUPERVISOR: DR MARK FOX

ESSEX EDUCATIONAL PSYCHOLOGY SERVICE  
Richard Westerman  
Email: [richard.westerman@essex.gov.uk](mailto:richard.westerman@essex.gov.uk)  
Tel: +44 3330 138 576  
Supervisor: Paul Hammond  
Daniel Tunbridge

TO.....

Hello. My name is Richard Westerman. I am training to be an Educational Psychologist

I am trying to find out more about how young people with Cerebral Palsy speak out and express their thoughts, beliefs, values, interests, desires, needs, and rights



I would like to ask you to talk about your experiences and this will be broken into 3 activities



We will start by having a discussion that will introduce the wiki page technology and what you might wish to include on it.



You will create your individual wiki-page (with as much assistance as you require). This will take place over 6 sessions



After completing your wiki page we can talk about it and you can ask any questions that you might have.

You can decide to stop at any time. If there is something that you do not wish to discuss that is fine



I will record everything we do so that I can remember it later on



Everything said in our meeting will be kept confidential, unless you or someone else is at risk. I will not use your real name when I report the findings



How would you like me to tell me about our research? Maybe you would like it by letter, email, telephone conversation, or a different way? You can think about this now and tell me later

If you would like to take part in my research, please let your parents/caregiver know and contact me at the details at the top of this page. Please do get in touch if you have any questions or require more information.



## Appendix I

### Consent Form

This is the consent form that you need to fill in if you want to take part in the research project

PLEASE READ THE STATEMENTS CAREFULLY IN THE TABLE BELOW AND  
EITHER 'YES' OR 'NO'.

UNDERNEATH THE TABLE THERE IS SPACE FOR YOU TO SIGN YOUR NAME, PRINT YOUR  
FULL NAME AND WRITE THE DATE.

	YES 	NO 
<b>RICHARD HAS EXPLAINED HIS PROJECT TO ME AND I UNDERSTAND WHAT WILL HAPPEN IF I DECIDE TO TAKE PART.</b>		
<b>I KNOW I CAN ASK..... TO CONTACT RICHARD AT ANYTIME IF I WANT TO ASK HIM A QUESTION ABOUT THE RESEARCH PROJECT.</b>		
<b>I UNDERSTAND THAT IT IS MY CHOICE WHETHER OR NOT TO TAKE PART. I KNOW THAT IT IS OK IF I DECIDE THAT I DO NOT WANT TO TAKE PART.</b>		
<b>I UNDERSTAND THAT ALL THE SESSIONS WITH RICHARD WILL BE RECORDED.</b>		
<b>I UNDERSTAND THAT IT IS MY CHOICE TO CREATE A WIKI-PAGE. I AM ALSO AWARE THAT IF I AM WITHIN MY RIGHTS IF I DECIDE THAT I DO NOT WANT TO BE INVOLVED IN THE PROJECT BEFORE, DURING OR AFTER THE PROCESS.</b>		
<b>I UNDERSTAND THAT ESSEX EDUCATIONAL PSYCHOLOGY SERVICE WILL RECEIVE A COPY OF THE RESEARCH, BUT THAT NOBODY WILL BE ABLE TO IDENTIFY ME IN THE RESEARCH BECAUSE I WILL BE GIVEN A DIFFERENT NAME.</b>		
<b>I UNDERSTAND THAT RICHARD WILL NOT SHARE WHAT I TELL HIM WITH ANYONE ELSE, UNLESS HE IS WORRIED THAT I OR SOMEONE ELSE IS IN DANGER.</b>		
<b>I HAVE READ THE PARTICIPANT INFORMATION SHEET, HAVE BEEN ABLE TO ASK RICHARD ANY QUESTIONS THAT I HAVE ABOUT HIS RESEARCH AND I WOULD LIKE TO TAKE PART IN HIS PROJECT.</b>		

SIGNATURE.....

NAME (IN CAPITALS).....

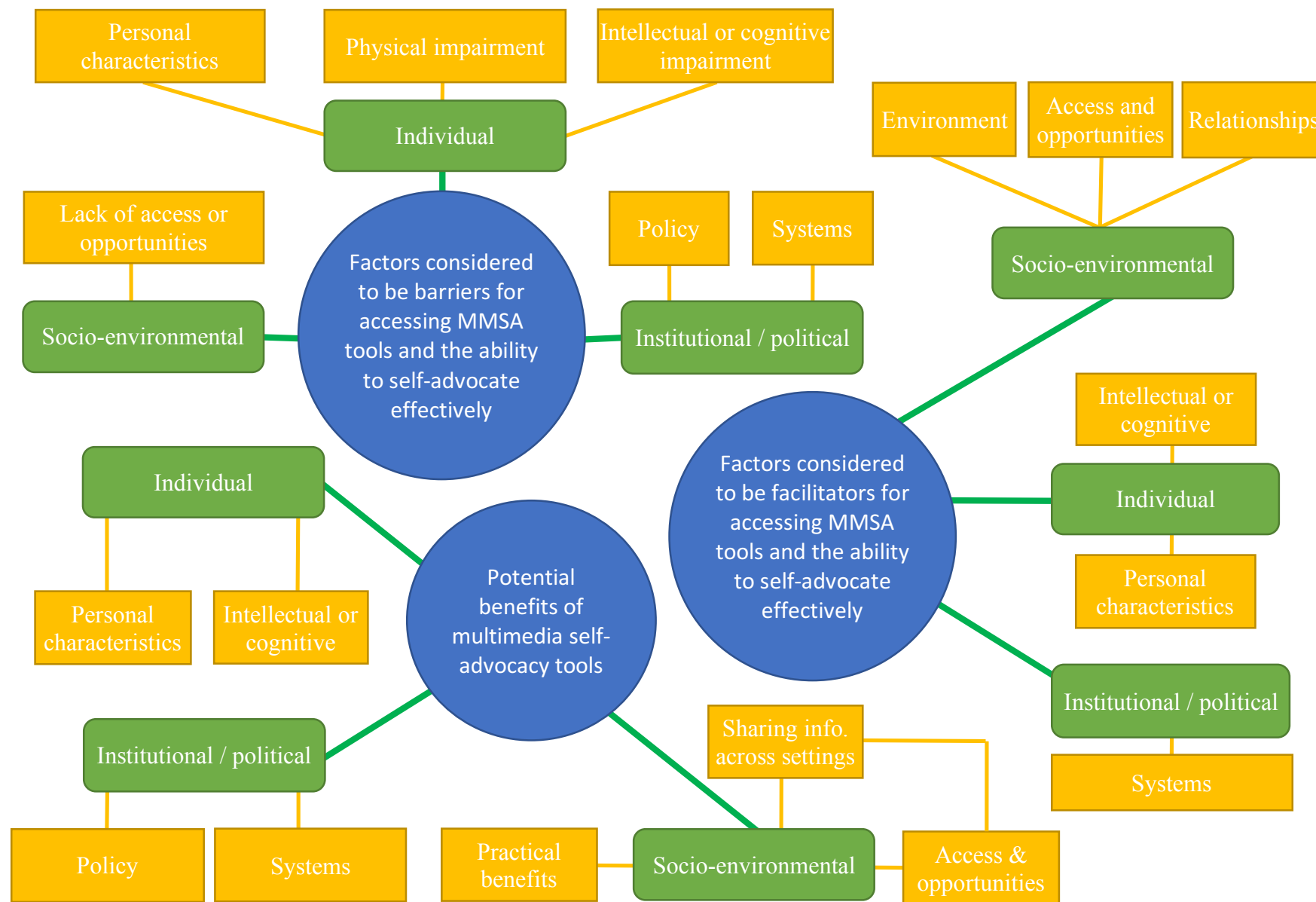
DATE.....

## Appendix J

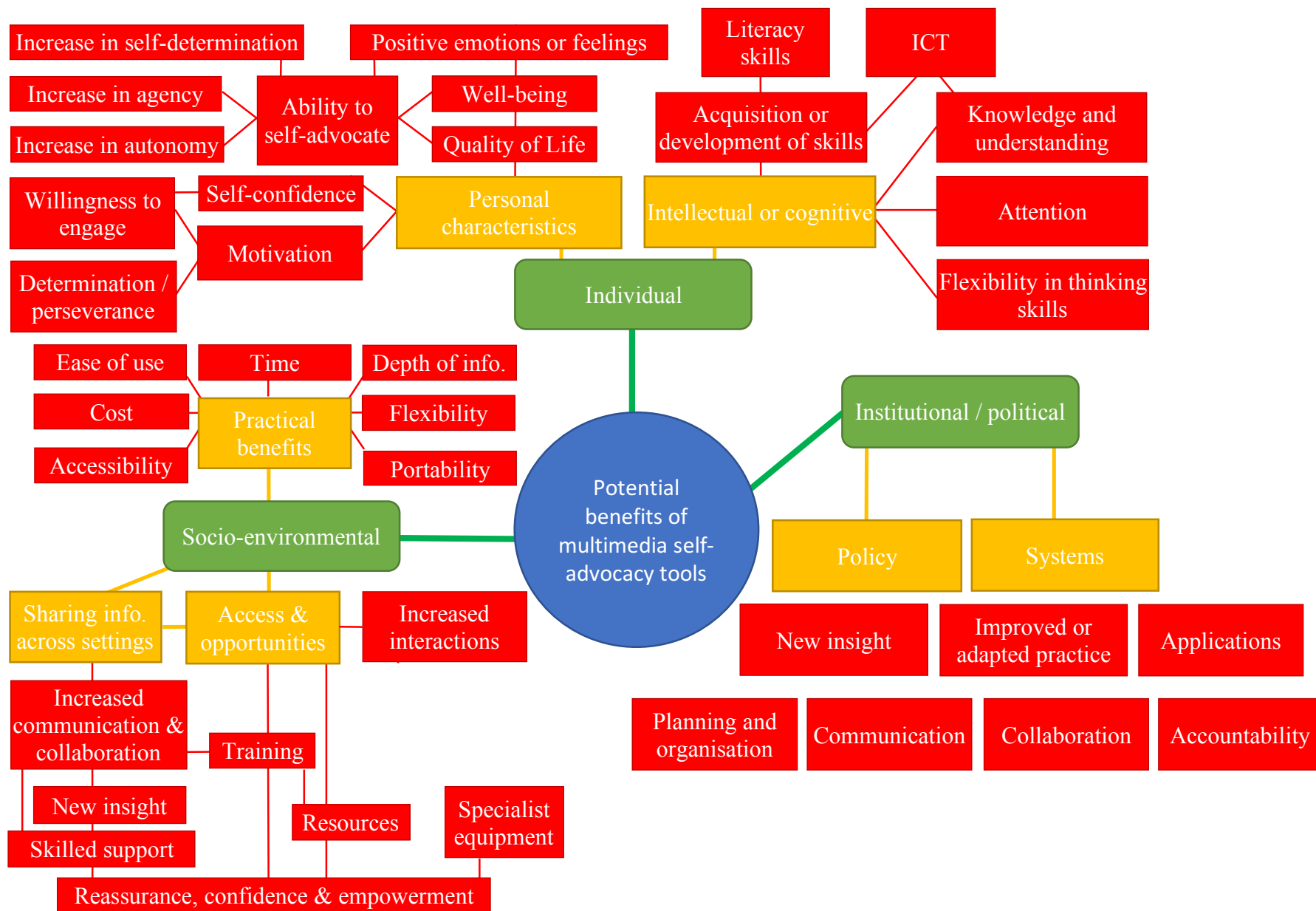
Pauline Codebook		
Code	Theme	Subtheme
Ability to share information with others	Benefits	Social
Access to resources	Facilitator	Socio-environmental
Access to skilled support	Facilitator	Socio-environmental
Access to specialist equipment	Facilitator	Socio-environmental
Adaptations/changes to professional practice	Facilitator	Socio-environmental
Applications of wiki-page	Benefits	Socio-environmental
Checking decisions/collaborating with individual	Facilitator	Socio-environmental
Collaboration between professionals	Facilitator	Socio-environmental
Control	Benefits	Individual
Difficulties maintaining attention	Barrier	Individual
Difficulties using specialist equipment/impractical	Barrier	Socio-environmental
Difficulties with speech, language and communication	Barrier	Individual
Disengagement	Barrier	Individual
Ease of use	Benefits	Socio-environmental
Encourages multi-disciplinary working	Benefits	Socio-environmental
Enlarged multimedia	Facilitator	Socio-environmental
Environmental factors	Barrier/facilitator	Socio-environmental
Familiarity/knowledge of individual needs	Facilitator	Socio-environmental
Fatigue	Barrier	Individual
Increase in positive emotional states	Benefits	Individual
Increased agency	Benefits	Individual
Increased autonomy	Benefits	Individual
Increased collaboration between professionals	Benefits	Socio-environmental
Increased communication between parents and professionals	Benefits	Socio-environmental
Increased communication using AAC	Facilitator	Socio-environmental
Increased motivation	Benefits	Individual
	Benefits	Individual

Increased persistence		
Increased self-confidence in ability	Benefits	Individual
Independent use/access	Benefits	Individual
Investment in ICT equipment	Facilitator	Socio-environmental
Lack of access to skilled support	Barrier	Socio-environmental
Lack of previous knowledge and understanding of individual	Barrier	Socio-environmental
Motor skills impairment	Barrier	Individual
Negative emotional state	Barrier	Individual
New insight	Benefits	Social
New ways of working	Benefits	Socio-environmental
Ownership	Benefits	Individual
Physical impairment	Barrier	Individual
Positive emotional state	Facilitator	Individual
Practicalities of wiki-page	Benefits	Socio-environmental
Previous knowledge and understanding of individual	Facilitator	Social
Problems with alternative communication devices	Barrier	Socio-environmental
Promoting opportunities for self-advocacy	Benefits	Individual
Rapport	Facilitator	Social
Reassurance for carer	Benefits	Socio-environmental
Requires lots of additional support	Barrier	Socio-environmental
Responds well to adult support (1:1)	Facilitator	Socio-environmental
Self-advocacy	Benefits	Individual
Self-determination	Benefits	Individual
Time of day/length of sessions	Barrier/facilitator	Socio-environmental
Understanding of communication needs	Barrier/facilitator	Social
Visual support	Facilitator	Socio-environmental

## Appendix K



## Appendix L







# Appendix N



## *Appendix O*

Dear (name),

Thank you for participating in my research and allowing me to help you create your wiki-page. I really appreciate that you gave up so much time to come and work with me on your wiki for six sessions. You impressed me with how quickly you picked it up and you showed me so many of your wonderful skills. Thank you for sharing so many details about your life with me, they were so important to this research and will help me to do my job better in the future. They were extremely interesting but also informative and very useful. It really was great to meet you and work together as a team for the last two terms.

I hope you enjoyed being able to make choices and that you get the chance to do this as much as possible in the future. Hopefully, this wiki-page, which is yours to keep, will help you with this.

Here is a reminder of some of the things we did, outlining some of your achievements:

- You were able to add photos, videos and songs to your wiki-page.
- You were able to decide which of these you preferred and choose your favourite things to add.
- You tried lots of different computer equipment and it seemed that your favourite was the iPad.
- You seemed to work well with Lola and I thought you made a great team.
- I particularly enjoyed it when you decided the activities for the sessions.
- You were able to involve your parents in the research and it was really nice for me to learn about your family.
- You were happy to try new things and I thought that you were really determined to get things right.

I really have greatly valued your participation in this research study.

Good luck with your exciting journey next year. I am sure you will make many new friends at adult college.

Again, thank you so very much for your time and effort. You made this research possible – after all, it is all about you and I hope the research reflects this. If you need help with your wiki Gosia will gladly support you with any questions you have.

Kind regards,  
Richard

