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West of England
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USER PARTICIPATION IN THE DESIGN AND DEVELOPMENT OF WEB 2.0 TECHNOLOGIES FOR PEOPLE WITH LEARNING DIFFICULTIES

by

SOTIRIS FANOU

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Faculty of Health and Applied Sciences, University of the West of England, Bristol

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Abstract

In the twenty-first century People with Learning Difficulties (PWLD) still face oppression, discrimination and exclusion from the mainstream of social life. Over recent decades the policy of the United Kingdom's (UK) government and activist organisations regarding people with learning difficulties has been on enabling inclusion, ensuring rights, providing choice and developing advocacy and independence. People with learning difficulties have been moved out of institutions with the intention to be included and respected as equal members of society. During the same decades that the government and activist organisations have been striving for the inclusion and equality of people with learning difficulties, the use of Information Technology (IT) has reached pervasive levels, to the degree that it is almost impossible for individuals to socially function successfully, unless they have access to it. Unfortunately, most IT is not designed to be usable and accessible to people with learning difficulties and this is a major barrier for their social inclusion.

Participatory Design (PD) methodologies which emphasise end-user involvement in the software development process are widely considered the key to system usability and accessibility. However, most researchers and software developers believe that people with learning difficulties are not capable of participating in the process of development as a result of their disabilities. Others, report that they do not know how to work with this specific group of disabled end-users. This discriminatory behaviour is a major reason why IT remains inaccessible to people with learning difficulties. The study described in this thesis combined Evolutionary Prototyping, a software development methodology and Participatory Action Research (PAR), a social science methodology, in order to involve a cohort of four Health Trainers with learning difficulties in the development of a Web 2.0 based system. The aims of the study were to explore how people with learning difficulties could be involved in the development of a software system and if they could use a system developed with their participation. A further aim was to explore how software developers can approach the field of Learning

Disability, the issues they will face and how those issues can be overcome. Qualitative data was gathered during fourteen Participatory Action Research meetings, in which the Health Trainers were involved in research, software development and system use. The data was analysed using Thematic Content Analysis facilitated by the use of the NVivo software package. The findings were validated by the participating Health Trainers.

The findings suggest that during software development participation, the Health Trainers faced a number of challenges. However, the Health Trainers indicated the type of support they needed from the researcher in order to overcome them. The support required was easy to provide and the Health Trainers managed to engage in the software development process. The study conducted a system use evaluation to explore if the developed system was usable and accessible to the Health Trainers. The Health Trainers managed to complete all the system tasks posed to them during the evaluation. This suggests that the developed system was usable and accessible to the Health Trainers. Further evidence suggests that a number of factors affected the participation of the Health Trainers during development and during the use of the system. Finally, the study explored how the developed system was used over the long run, in a period of eighteen months. The findings suggest that system use over time was affected by factors other than the system's accessibility and usability.

Concluding, the findings suggest that with easy to provide support, the Health Trainers with learning difficulties could be involved in software development and they could use a system developed with their participation. It is hoped that the findings be used by policy makers and advocacy groups, to make a case towards convincing researchers and software developers to involve more people with learning difficulties in software development, thus making systems accessible to this community of end-users.

Acknowledgements

Author's Declaration

I hereby declare that this entire thesis is the work of the author and works quoted have been referenced. This thesis has not been submitted to any other awarding body.

Signed:

Date:

Dedication

I dedicate this work to my wife Maryana, for believing in me, and for her patience and support during this adventure. I also dedicate it to my children Stefanie and Marios as they had to live with less attention from daddy.

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Chapter One: Introduction to the Thesis

1.1 Introduction

This thesis documents research conducted into exploring how people with mild learning disabilities can be involved in the software development process. This introductory chapter sets the research context, demonstrates its relevance and describes its aims and objectives. It closes by describing the content of the rest of the chapters of the present work.

1.2 Language Used in this Thesis

Over recent decades there has been increasing interest in the role of language and its influence on attitudes towards contested social issues, such as discrimination towards minority groups (Barnes, Mercer 2006). In most cases, there has been a positive social response towards the use of none discriminatory language, although the same sensitivity has been slow to extend to people with disabilities. The debate over language and definitions has been central to the Disabled People's Movement's critique of academic approaches in the social sciences (Barnes, Mercer 2006). Therefore the researcher of this thesis tries to employ language that is not stigmatising or discriminatory.

Rather than using 'learning disabilities,' **'learning difficulties'** is the term that will be employed in the rest of the thesis as it is believed to be the least stigmatising when compared with all the other terms (the various terms used for learning difficulties found during the literature search are listed in Section 2.2.1). The adoption of this term also reflects the expressed wishes of the Health Trainers with learning difficulties who took part in the current study. Adopting the term preferred by the Health Trainers supports the philosophical position and the participatory approach used in the research. However, readers should note that many referenced works employ different terms and when this is the case the direct quote is included as such.

Many scientists, especially those educated in technology rather than the social sciences, such as the researcher of the current study, have not learnt the sensitivities of language use, as they do not typically write about people. This is obvious in the literature reviewed for the study in which many authors with a background in technology often use stigmatising language. Here the researcher made a serious effort to avoid stigmatising terms both during the writing of the present work and during interaction with the Health Trainers. However in certain circumstances avoiding stigmatising language was difficult. The researcher found the use of non stigmatising language particularly challenging when he tried to describe and evaluate the findings of the study with the Health Trainers. Writing about the challenges that the Health Trainers faced during their involvement in software development (Section 5.2.2) was another circumstance where the use of non stigmatising language was more challenging compared to writing other thesis sections.

The research described in this thesis was interdisciplinary. The study explored whether and how people with learning difficulties could be involved in software development using a social science methodology. A software system was developed for the needs of the study. The author of the present work acted both as a *researcher* and as a software *developer*. Therefore throughout this thesis the author refers to himself using two different terms: '*the researcher'* and *'the developer.'*

The software system developed for the needs of the study is sometimes referred to as *the system*, *the wiki, the site* or *the website*. This situation arises as the developed system was a Web based wiki type software system typically used to create websites (wikis are described in Section 4.3). The wiki system developed during the present inquiry was used to create a website for the occupational needs of the people with learning difficulties who participated in the study.

Throughout the thesis *Italics* are used to emphasise and draw attention to specific important phrases, while square brackets [ ] are used for the researcher's remarks and clarifications. All Health Trainers' names used within this thesis, including

the names of participants in other studies referred in the literature review are pseudonyms. This was stated as such in the literature that describes the other studies. Finally, in order to make the writing and the explanation of the research easier, the following terms with specific meanings are used throughout the thesis:

Participatory Research Team – refers to the Health Trainers and the researcher of the present inquiry as we worked together in most aspects of the research.

Software development – refers to all three phases of software development, *analysis*, *design/implementation* and *use evaluation* or *usability testing* as described in Chapter Four. *The software development part of the current study* refers to the phases in the study which directly related to the development of the system built to meet the Health Trainers' needs. It includes all three previously mentioned phases of analysis, design/implementation and system use evaluation.

Research part of the study – as the adopted methodology was Participatory Action Research (described in Section 3.4) most decisions regarding the research were taken with the Health Trainers. Therefore the Health Trainers were involved in both the software development and the research processes of the study. During the software development part the Health Trainers offered input to make the developed system accessible. During the research part the Health Trainers were involved in the research process. For example, the Participatory Research Team decided the procedure to be followed for the findings evaluation. This example belongs to *the research part of the study* as it does not relate to software development. Therefore the research part of the study refers to the processes which did not directly relate to software development.

1.3 The Research in Context

In the twenty-first century disabled people still face oppression, discrimination and exclusion from the mainstream of social life (Barnes, Mercer 2005). Individuals with different disabilities, including people with learning difficulties, face social and environmental barriers when trying to perform many of the everyday activities that the rest of society take for granted (Bynoe, Oliver et al.

1991, Barton 1996, Barnes 1991, Barnes, Mercer et al. 1999, Oliver 1996). Despite the fact that many activists, writers, researchers, and academics have done much to promote the issue of discrimination against the disabled, they still remain one of the most oppressed minorities in both Europe and the United States of America (USA) (Barnes, Mercer 2005). In the last two decades disability issues have become a major issue for political debate and many countries including the United Kingdom (UK) have introduced legislation to reduce discrimination (Bynoe, Oliver et al. 1991). Despite the introduction of legislation such as the Disability Discrimination Act (DDA) of 1995, progress has been limited (Barnes, Mercer 2005). One major reason behind the limited progress is the fact that discrimination is based on stereotypical beliefs which we learn as children and which remain within us for the rest of our lives (Oliver 1991, Oliver 1990).

For most of the twentieth century disability was viewed as a personal tragedy or misfortune. People with disabilities were 'victims' who 'suffered' from 'mental illness,' 'mental handicap,' blindness or deafness and other conditions that affected their physical or mental state. Many were segregated and institutionalised and generally considered a 'burden' on society (Oliver 1996, Oliver 1990, Barnes, Mercer 2003).

During the 1960s there was an outcry and demand for change led by several organisations and social movements such as the Normalisation Movement, the Independent Living Movement (ILM) and the Civil Rights movement (Barnes, Mercer 2006, Emerson 2001). The Normalisation Movement arose in Scandinavia and the USA in response to increasing recognition of the negative impact that institutionalisation had on the lives of people with learning difficulties. The followers of normalisation demanded change so that support services would provide an existence for people with learning difficulties that was as close to normal living conditions as possible. They also supported the utilisation of culturally normal means to establish and maintain behaviour that is as culturally normative as possible (Flynn, Nitsch 1980, Culham, Nind 2003).

In the USA the ILM emerged as an effort by groups of disabled people to improve their own lives and the actions of rehabilitation professionals. It was inspired by contemporary social movements such as the Civil Rights, Consumerism and Self-Help, opposed medicalisation and institutionalisation while supporting self-care. Ed Roberts and other disabled students at the University of California in Berkeley attracted national interest with campaigns for self managed accommodation with the aim of making themselves 'independently dependent.' Subsequently the 'Rolling Quads,' a group of disabled students formed by Roberts, were allowed to access California's Aid to the Totally Disabled programme to recruit, train and fire their own care attendants. A marked increase in the number of off-campus users triggered the establishment of the first Centre for Independent Living (CIL) at Berkeley in 1972. Its goal was to facilitate the integration of disabled people into the community by providing a broad system of support services. These initiatives in the USA attracted considerable interest from disabled activists from Britain and the whole of Europe during the 1980s (Barnes, Mercer 2006).

Early disability activism in Britain centred on small groups of disabled people living in residential institutions. These groups promoted debate about disability and appropriate collective action. Their approaches to independent living stressed self-determination, choice, for example where and how to live, and control over support services like who assists, how and when. They also supported the removal of disabling barriers in mainstream society (Barnes, Mercer 2006, Oliver, Barnes 1998).

The term 'independent living' refers to disabled people having the same choice, control and freedom as any other citizen and as members of the community. This does not necessarily mean that disabled people will be doing everything for themselves, but it does mean that any practical assistance required should be under the control of disabled individuals. Independence is formed by having assistance when and how one requires it (Barnes, Mercer 2006, Oliver 1996).

In the USA the Civil Rights movement supported the direct empowerment of people with learning difficulties. This movement argued that society should help

people with learning difficulties to gain control over their lives by including them in decision-making, enfranchising them with full citizenship rights, maximising their autonomy and self-determination, and ensuring that they enjoyed similar standards of living and well-being as those without disabilities. These ideas reflected both the liberal ideals of the 1960s and the social model of disability (please see Section 2.4). For the first time social barriers where considered to be a disabling factor to people with disabilities (Oliver 1996, McConkey, McCormack 1983).

Since the publication of the previous Labour government's White Paper for England, *Valuing People* in 2001, the policy and service focus in the UK regarding people with learning difficulties has been on enabling inclusion, ensuring rights, providing choice and developing advocacy and independence. The previous government was venturing to build a country in which, by 2025, disabled individuals are included and respected as equal members of society (DH 2001, Blair 2006). Over recent decades people with learning difficulties have been moved out of institutions with the expectation to participate as full and equal members of society (Barnes, Mercer 2006).

During the same decades that governments and social movements have been striving for inclusion and the equality of people with disabilities, the use of Information Technology has increased to a pervasive level. In the developed world at least, it has become almost impossible for individuals to successfully function unless they have access to and can use Information Technology. Computers and the Internet have the ability to positively change the lives of those with disabilities through enhancing personal development, educational and social skills and by offering employment opportunities. Information Technology can also be used for a range of other purposes including leisure, communication and social interaction. Unfortunately most Information Technology systems are not designed to be usable and accessible to people with learning difficulties and the promise of social inclusion, reinforced by Information Technology, has not been realised (McKenzie 2007, Gibson 2007, Wattenberg 2004).

A major reason for the inaccessibility of Information Technology to people with learning difficulties is the fact that they are seldom involved in the software development process. Involvement would allow them to offer their input to ensure that systems are designed in ways that they are accessible to them. User-centred and Participatory Design methodologies are considered by the software engineering community to be the key for the development of usable products. Through engaging users in the development process the designers can better understand the users' needs (Mao, Vredenburg et al. 2005, Lopresti, Mihailidis et al. 2004).

According to Henry (2011) accessibility can be approached through usability. The International Organisation for Standardisation (ISO) defines usability as the "extent to which a product can be used by specified users to achieve specified goals with effectiveness, efficiency and satisfaction in a specified context of use" (International Organization for Standardization (ISO) 1998) Accessibility focuses on including people with disabilities as the specified users and a range of situations as the specified context of use. Usability means designing a system which is effective, efficient, and satisfying, while accessibility makes sure that the system is effective, efficient and satisfying in more situations and for more people, especially people with disabilities (Henry 2011a).

Yet the opinion of people with learning difficulties on the accessibility of software systems is almost never sought. The software industry or the market research agencies it employs to run focus groups and gather usability data on their behalf, believe that people with learning difficulties are not capable of involvement in the development process. They state that they may not be able to articulate what they want or need. Some developers and researchers also state that they are uncertain about how to work with people with learning difficulties (McKenzie 2007, Grammenos, Savidis et al. 2009, Sullivan, McGrenere 2003, LoPresti, Bodine et al. 2008). McKenzie (2007) asserted that, people with learning difficulties are still viewed as part of a stigmatised group and this affects others' expectations of their abilities and their self-efficacy.

Research on the Information Technology accessibility needs of people with learning difficulties is also limited. Lewis (2007) observed that people with learning difficulties are rarely included in Information Technology usability studies and that this has a dual impact. It reduces the extent to which the needs of people with learning difficulties are reflected in research and development, and it limits the understanding that the research and development community has of people with learning difficulties. A small number of studies have involved people with learning difficulties in software design and development as presented in Section 2.9 (Grammenos, Savidis et al. 2009, Dickinson, Gregor et al. 2003, Newell, Gregor 2000, Dawe 2007a, Aspinall 2008, Harrison, Stockton et al. 2008a). The emphasis of these studies was on the technology though, and there is a lack of research that concentrates on the engagement itself, to explore the question of how people with learning difficulties can be involved in the software development process. An answer to this type of question could be an instrument in the hands of advocacy organizations and policy makers which could be used to support the involvement of people with learning difficulties in software development. It could also make a case towards convincing the industry and research communities to work more towards the inclusion of people with learning difficulties in the software development process thus making systems more accessible to them.

1.4 Relevance of the Research

Section 2.9 presents a number of research studies which involved people with learning difficulties in software development but whose emphasis was mostly on technology, how to elicit principles of design, and how to produce specialised software systems for targeted groups of users with learning difficulties. The examined studies assume that people with learning difficulties can be involved in the development of software and never ask questions such as what type of challenges people with learning difficulties face during involvement or how easy or difficult it is to involve them. These questions are posed by many other researchers and software developers (Sullivan, McGrenere 2003, LoPresti, Bodine et al. 2008). Therefore there is lack of research which concentrates on the

participation itself in order to establish how people with learning difficulties can be involved in the software development process.

If the aim is to include people with learning difficulties as equal members of society then most Information Technology and not just a few specialised systems, must become accessible to them. Therefore the software industry and a bigger fraction of the research community must be convinced to engage people with learning difficulties on a greater scale. Involvement will facilitate the understanding of their needs and thus produce more accessible systems. Furthermore, advocacy groups and policy makers must be convinced to further promote this issue. It is therefore important to understand how people with learning difficulties can be engaged in the software development process. The literature contends that one of the reasons for which developers and researchers do not involve people with learning difficulties is because of uncertainty of how to work with them (LoPresti, Bodine et al. 2008, Lewis 2005). Therefore if they could be shown how to do it then it would alleviate that uncertainty and this would make a case towards convincing them to engage this community of users in their projects.

1.5 Research Aims and Objectives

This research explored the factors and challenges that the Health Trainers with learning difficulties faced during software development involvement. The study also explored the issues and challenges which the software developer faced by involving this specific group of Health Trainers in software development. The study presents the approach taken by the developer to overcome such challenges.

The participants were a cohort of individuals with learning difficulties who were working as Health Trainers in the National Health Service (NHS). The Health Trainers' role is to advise members of the learning difficulty community on health related issues (explained further in Section 3.5). The study concentrated on answering three research questions:

1. How can Health Trainers with learning difficulties be involved in the development of software in order to create a system customised to their needs and for their own use?

2. Can Health Trainers with learning difficulties use a Web 2.0 based, e-learning system to help them in their health trainer duties?

3. How do Health Trainers with learning difficulties engage with such a system over time?

Regarding research question one, it was hoped that exploring how people with learning difficulties engage in the software development process, would make a contribution towards convincing the research and software development communities to involve this group of end-users to a greater extent, and encourage activist organisations to promote this goal further. It would also demonstrate and explore how software developers can approach the field of learning difficulties, the issues they will face, and how these issues can be overcome. Research question two aimed to explore the factors and any challenges that the Health Trainers faced while using the system developed with their involvement. Research question three aimed to explore how the Health Trainers used the system over a long period of time. Exploring how the system was used over a longer period would show how useful the system was to the Health Trainers and their clients. It could also reveal factors that may affect the use of similar systems over a longer period of time. The study also wanted to produce a software system customised to the Health Trainers' needs so that it could be used to enhance the service they offered.

1.6 The Structure of the Thesis

This thesis consists of a further six chapters with corresponding appendices where appropriate. Chapter Two critically reviews the pertinent research literature, and sets the study in its theoretical context. The chapter presents a number of studies, which involved people with learning difficulties in software development.

However, all the presented studies had mostly technological objectives. The chapter shows that there is a lack of research that takes participatory design as its focus and concentrates on the participation itself to address the question of how people with learning difficulties can be involved in the development process and how software developers can approach this field. An answer to this type of question would probably mobilise disability advocacy groups to work harder towards convincing the industry and research communities to involve people with learning difficulties thus making software more accessible.

Chapter Three describes and explains the methodological approach followed for conducting the present inquiry. The chapter starts by identifying an appropriate research and philosophical approach and explains the interpretive/constructivist research position assumed and the methodology of Participatory Action Research adopted. Participatory Action Research is first put into context by presenting a short history. Different elements of the methodology are considered, definition, basic principles, criticism, justification for choosing it and the difference between how it was intended to be applied and how it was applied in practice. Sampling and ethical issues along with the Health Trainers' characteristics are also discussed. The chapter also considers data collection methods used with Participatory Action Research and describes the Participatory Action Research Meeting, the method chosen for the present study. The final section describes Burnard's framework, the chosen data analysis method and how it was applied (Burnard, Gill et al. 2008, Burnard 1991, Burnard 1994).

In order to explore the participation of people with learning difficulties the present study developed a software system with the involvement of the Health Trainers. Chapter Four presents the process of developing this system. It starts with a description of Web 2.0, the type of technology used. The principles of Evolutionary Prototyping, the software development methodology adopted, are discussed next, along with justifications for choosing it. The chapter continues by describing the procedure followed during system requirements and data gathering. It then discusses the system requirements asked by the Health Trainers. Later it describes how an open source system was chosen to be used as an initial prototype

which was adapted in a number of iterations in order to meet the needs and requirements of the Health Trainers. Details of the system architecture, class and database structures are also presented in detail. The research performed a system usability and accessibility evaluation by observing the Health Trainers while using the system. The procedure used for the evaluation is described and the conclusions explained. The chapter ends by explaining a number of system limitations which were the result of limitation in resources.

Chapter Five presents the qualitative findings which arose by analyzing the data gathered during fourteen Participatory Action Research Meetings. The chapter lists the three research questions of the study along with their relevant identified categories and themes and discusses each theme individually. Important data are presented for each theme in order to demonstrate and support it. The final section of the chapter presents a summary of the conclusions reached.

Chapter Six includes a discussion of the findings presented in the previous chapter. The chapter starts with an overview of the key literature on the explored issue. It continues with a discussion of the findings outlined in Chapter Five. Each research question is presented along with the relevant categories and themes identified during the analysis. Each theme is then discussed in relation to answering the research questions and in relation to the existing body of literature. The discussion reveals findings which support the unique contribution the study makes to the current scientific body of knowledge. Next, this unique contribution is discussed, taking cognisance of the limitations of the study. The chapter closes with suggestions for further research.

Chapter Seven presents a summary of the findings and their technical and social implications. It reiterates the objectives of the study and how the research questions were answered. The chapter recommends social applications of the findings, which could support attitudinal change towards people with learning difficulties so that they obtain the equitable and accessible lifestyle they desire. Finally the chapter discusses the implications of the findings and recommendations for future researchers and software developers.

Chapter Two: Critical Review of the Literature

2.1 Introduction

This chapter will explore the pertinent literature in order to set the present study in its proper context. The chapter provides a critical appraisal of the contributions of others, and identify limitations in the current evidence base. The process used to choose appropriate material and conduct a thorough literature review is described in Appendix 1. Before describing relevant existing studies a few sections are dedicated to the incidence of learning difficulty in the United Kingdom (UK), the social model of disability and the issues that people with learning difficulties face today, including issues accessing technology. This is necessary in order to reveal the position of the current study within a broader social context. Another section is dedicated to describe the various terms used for learning difficulty, which were encountered during the literature search. This is necessary as many of these terms appear in the thesis when directly quoting other researchers. The chapter also describes user participation, the different participation approaches and the range of involvements which individuals and groups may have in organizations, institutions and decisions affecting them and others.

2.2 Defining Learning Difficulties

This section describes the different terms and definitions used for learning difficulties. As revealed by the literature search conducted for the needs of the study, there is no one common and internationally accepted term for learning difficulties and instead a number of terms are used. Additionally, there is no uniform or internationally accepted definition which clearly outlines the meaning of the term. All the various terms are defined slightly different but their meanings are very similar and overlapping (Emerson 2001, AAIDD 2010b, WHO 2006b). The present study employs the definition used by the UK Department of Health (DH 2001, p14 – 15). However, due to the variety of terms used one must be cautious when searching and reviewing the related literature. Unfortunately, this

multitude of terms and definitions makes it more difficult to identify relevant literature.

2.2.1 Terms Used for Learning Difficulties

The literature search conducted for the needs of the current study showed that a range of terms are used in different geographical locations and by different organizations to describe learning difficulties. During the search each found term was marked down and its definition examined. Using this method the researcher compiled the list shown in Table 2.1. The correctness of the list was confirmed by personal communication with the learning difficulties advisory group assigned to the study.

Table 2.1 - The various terms used to describe Learning Difficulty roughly categorised by geographical area.

Geographical area in which the term is used	The term used
UK	Learning disabilities Learning difficulties
United States of America (USA)	Developmental disabilities Intellectual disabilities Mental retardation Cognitive disabilities
Common terms used internationally (other than the UK and the USA)	Intellectual disability Cognitive disability Cognitive disorder Cognitive dysfunction Cognitive impairment
Older stigmatising terms used internationally (including the UK)	Mental handicap Mental retardation Mental sub-normality Mental deficiency

The categorisation of the terms in Table 2.1 is not strictly adhered to by all authors or institutions in a geographical area. A different term from the most common maybe used even within the same geographical area. For example, an author in the UK is not obliged to use learning disabilities or learning difficulties and may use a different term such as 'cognitive disabilities.' Even though this

thesis is using a specific term as described in Section 1.2 many of the terms presented in Table 2.1 may appear throughout the thesis while directly quoting an author, therefore all terms found in the literature are listed.

In the UK, the location of the current study, the term 'learning disabilities' was used officially for the first time in 1991 by Stephen Dorrell then Minister of Health in a speech to Mencap. The term 'learning disabilities' is now used by most services, professionals and carers (Emerson 2001). People First a self-advocacy movement, and some professionals, prefer the term 'learning difficulties' which sounds even less stigmatizing or intimidating. 'Learning disabilities' replaced some previously perceived negative terms such as 'mental retardation,' 'mental handicap,' 'mental sub-normality' and 'mental deficiency.' These terms are now considered obsolete in the UK (Emerson 2001). Unfortunately, negative terms such as 'mental retardation' are still used by important organizations such as the World Health Organization (WHO) (WHO 2006a) and in the USA; however, this is changing. For example, in June 2006 the American Association on Mental Retardation (AAMR) changed its name to American Association on Intellectual and Developmental Disabilities (AAIDD) (AAIDD 2010a).

Another common term used internationally for learning difficulties is 'intellectual disabilities.' All the aforementioned terms refer to similar types of impairments but each carries different connotations. That is why some are preferred over others by different organizations and in different parts of the world (Emerson 2001).

2.2.2 Definition of Learning Difficulty

There is not a single and internationally accepted definition for learning difficulties. Instead, each of the terms observed in the previous section are defined slightly differently though similarly. (There is one exception as in the USA the term 'learning disabilities' is used to describe a neurological disorder that affects the understanding of spoken or written language as explained at the end of this

section). In the UK the Department of Health suggests the following definition for 'learning disability' (DH 2001, p14):

'Learning disability' includes the presence of:

- A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;

- A reduced ability to cope independently (impaired social functioning);

- which started before adulthood, with a lasting effect on development.

The Department of Health also observes the following (DH 2001, pp14 – 15):

"This definition encompasses people with a broad range of disabilities; the presence of a low Intelligence Quotient (IQ), such as below 70, is not, of itself, a sufficient reason for deciding whether an individual should be provided with additional health and social care support. An assessment of social functioning and communication skills should also be taken into account when determining need. Many people with learning disabilities also have physical and/or sensory impairments. The definition covers adults with autism who also have learning disabilities, but not those with a higher level autistic spectrum disorder who may be of average or even above average intelligence; such as some people with Asperger's Syndrome"

The World Health Organisation (WHO) uses the negative term 'mental retardation' on its website with the following definition (WHO 2006b) [online]:

"A condition of arrested or incomplete development of the mind, which is especially characterised by impairment of skills manifested during the developmental period, skills which contribute to the overall level of intelligence, i.e. cognitive, language, motor, and social abilities. Retardation can occur with or without any other mental or physical condition"

Skills which contribute to the overall level of intelligence are defined as an IQ score more than two standard deviations below the mean of the general population. This means an IQ below 70 on recognised IQ tests such as the UK editions of the Wechsler Adult Intelligence Scale 3rd edition or the Wechsler Intelligence Scale for Children 3rd edition (Emerson 2001).

In the USA the American Association on Intellectual and Developmental Disabilities (formerly American Association on Mental Retardation) defines 'intellectual disability' as (AAIDD 2010b) [online]:

> "Intellectual disability is a disability characterised by significant limitations both in intellectual functioning and in adaptive behaviour, which covers many everyday social and practical skills. This disability originates before the age of 18.
>
> Intellectual functioning, also called intelligence, refers to general mental capacity, such as learning, reasoning, problem solving, and so on.
>
> One criterion to measure intellectual functioning is an IQ test. Generally, an Intelligence Quotient test score of around 70 or as high as 75 indicates a limitation in intellectual functioning."

All the above examples and indeed all definitions for learning difficulties encountered during this literature review have the following common characteristics (Emerson 2001, DH 2001, AAIDD 2010b, WHO 2006b):

- A learning difficulty affects Intelligence Quotient scores, in effect lowering them below average
- Learning difficulties impair the social functioning or the communication skills of an individual
- Learning difficulties are not necessarily accompanied by another physical or sensory impairment, but quite often this is the case

- The impairment must have started before adulthood

In the USA where the terms 'developmental disabilities,' 'intellectual disabilities' and 'mental retardation' are used most commonly, the term 'learning disabilities' means something different (LDA 2011). The Learning Disabilities Association of America (LDA) defines 'learning disabilities' in the following way, "A learning disability is a neurological disorder that affects one or more of the basic psychological processes involved in understanding or in using spoken or written language" and "Generally speaking, people with learning disabilities are of *average or above average intelligence*" (LDA 2011) [online].

Unfortunately, this multitude of terms and definitions, but also the fact that people with learning difficulties typically have other disabilities, make it more difficult to identify relevant literature. The literature material chosen for the current study was deemed to be appropriate by examining the definition given. If a definition was not present, then logic and common sense were used in order to determine which literature was relevant to the study.

2.2.3 Learning Difficulties Severity Continuum

Quite often learning difficulty is categorised into severity groups like for example mild or severe. There are several classification systems, each placing learning difficulty severity on a continuum. The continuum ranges from mild to more severe/profound learning difficulties and is sub-divided differently according to each classification system (Emerson 2001). The Department of Health uses a continuum sub-divided to three severity groups, 'mild,' 'moderate' and 'severe.' According to the Department of Health, "People with severe learning disabilities are those who need significant help with daily living. People with mild/moderate learning disabilities will usually be able to live independently with support" (DH 2001, 15).

Learning Difficulties Severity Continuum
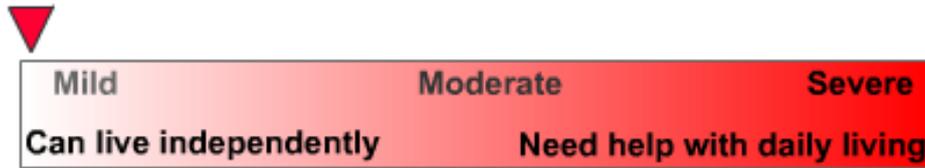
Figure 2.1 - Learning difficulties severity continuum as defined by the Department of Health (DH, 2001).

WHO uses a severity continuum sub-divided into four severity groups as follows: mild (IQ 50-69), moderate (IQ 35-49), severe (IQ 20-34), and profound (IQ below 20) (WHO 2006b) [online]. Furthermore for the mild category it states "Mild mental retardation: Approximate Intelligence Quotient range of 50 to 69 (in adults, mental age from 9 to under 12 years). Many adults will be able to work and maintain good social relationships and contribute to society" (WHO 2006b) [online].

However, labeling people with learning difficulties into severity groups of mild or more severe disabilities using IQ levels is a social construct, which promotes stigmatization and could encourage discrimination. The current study adopts the position and tenets of the social model of disability (described in Section 2.4) and opposes such labeling. The social model of disability supports that it is the social and environmental barriers build on top of the medical condition, which socially excludes people with disabilities. Therefore, labeling people with learning difficulties into severity groups can be seen as a socially constructed barrier.

According to Dajani (2001), the linguistic scholar Benjamin Lee Whorf, contended that language tends to structure thinking and acting. The meaning of a word or of an expression affects the actions of its hearers. A name can determine the nature of the response given to it by virtue of the associations which it invokes (Dajani 2001). "The very act and fact of changing the designation will cause the individual to be re-designated, to be reconsidered, not only in terms of his past

and his present, but hopefully in terms of his future. Designation has an important bearing on destiny" (Rose 2009, p. 382).

Labels play an important role in defining groups and their members. Labels or names that define groups help to determine how both outsiders and also group members respond to the group. This is also true for disability groups such as people with learning difficulties. The language used by society regarding disability demonstrates that people with disabilities are frequently perceived exclusively in terms of their disabilities. "The community of disabled people is rarely contrasted or balanced with able bodied people. They are limited to a 'handicapped role' in which they are seen as recipients of medical treatment. This role includes ascribed traits of dependency, helplessness, abnormality of appearance and mode of functioning, pervasive incapacitation and ultimately sub-humanness" (Dajani 2001, p. 197).

A disturbing aspect of language use toward disability affecting social attitudes, concerns the use of adjectives as nouns. Many people refer to disabled individuals as the blind, the deaf, the handicapped, the disabled, the mentally retarded and the developmentally disabled. This specific use of language evidently avoids the humanizing people, person, individual and the like. The practice sets disabled people apart from people without disabilities. All of these adjectives which are used as nouns contribute to the process of stigmatisation by reinforcing the tendency to view persons with disabilities only in terms of their disabilities (Dajani 2001).

In recent decades a more appropriate language is being formulated by the people with disabilities themselves. This reflects an effort to escape the 'handicapped role' and create an alternative, self defined social identity. In order to avoid the prejudicial labeling a number of euphemisms are used such as: special, special needs, atypical, exceptional, and persons with exceptionalities. Yet even these terms continue to emphasize the perception of dissimilarity between people with and without disabilities and continue to put people with disabilities in a separate category (Atherton, Crickmore 2011).

Some people support that any term is stigmatizing and discriminatory and that none should be used. This, however, would make it very difficult and even impossible to offer services and support to people with learning difficulties including support for using Information Technology (IT) (Emerson 2001). Therefore, most experts including the participating Health Trainers who are people with learning difficulties, believe that some terms such as 'learning disabilities' or 'learning difficulties' which are less intimidating, should remain.

2.3 Incidence of Learning Difficulties in the UK

The numbers of people with learning difficulties in the UK are considerable and excluding them from the use of IT would indeed be socially unacceptable. This is one reason which makes the current study important. According to the Department of Health's white paper *Valuing People* in England alone there are about 1.2 million people with mild or moderate learning difficulties and about 210,000 people with severe learning difficulties, that is a total of about 2% of the general population (DH 2001). For the UK as a whole the figure for people with a learning difficulty is generally rounded up to 1.5 million (Mencap 2011).

A report titled *People with Learning Disabilities in England* published in 2008 by the Centre for Disability Research (CeDR) of Lancaster University provides the following data. It is estimated that 985,000 people in England have a learning disability (2% of the general population). This figure includes 828,000 adults (aged 18 or more). For children, information suggests that (as of January 2006), 210,510 (2.6%) pupils were identified as having a primary special educational need (SEN) associated with learning disabilities (Emerson, Hatton 2008).
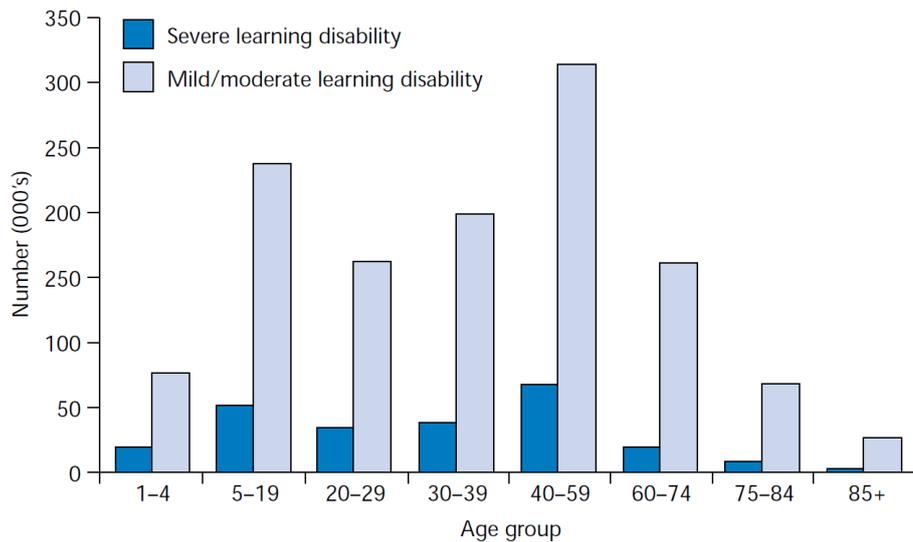
Figure 2.2 – Number of people with learning difficulties depicted by age group (Source: *Valuing People: A New Strategy for Learning Disability for the 21st Century,* **DH 2001, 15)**

The prevalence of severe learning difficulties is uniformly distributed across the whole country and across socio-economic groups. Mild/moderate learning difficulties however do relate to socio-economic classes and rates are higher in deprived and urban areas (DH 2001).

The *Valuing people* report also observed that the number of people with severe learning difficulties was expected to increase by around 1% per year for the following 15 years (the report was published in 2001) as a result of (DH 2001, 16):

- Increased life expectancy, especially among people with Down's syndrome
- A growing number of children and young people with complex and multiple disabilities who now survive into adulthood
- A rise in the reported numbers of school age children with autistic spectrum disorders, some of whom will have learning difficulties
- Greater prevalence among some minority ethnic populations of South Asian origin

2.4 The Social Model of Disability

During the last decades of the twentieth century several disability activists, writers and academics campaigned in support of the social model of disability rather than the medical one. They argued that even though an individual's medical condition is important it is also important to recognise that barriers imposed by society also disable a person. The medical model used until then had focused on the impairment itself while the social model offered a new paradigm for understanding disability, where the person was disabled by society(Barnes 1991, Oliver 1996, Oliver 1990).

In developing what became known as a social or political approach to disability, disabled people in Britain argued that it is society that disables people with impairments, and therefore any significant solution should be directed at socio-political change rather than individual adjustment and rehabilitation (Barnes, Mercer 2006).

Barnes, Mercer et al. (2006) observed that in the forefront of those calling for an alternative model of disability was the Union of the Physically Impaired Against Segregation (UPIAS), an organization controlled and run by disabled people. In 1976 UPIAS released its manifesto, *Fundamental Principles of Disability,* which clearly placed the responsibility for disability on society's failures stating:

> "In our view it is society which disables physically impaired people.
> Disability is something imposed on top of our impairments by the
> way we are unnecessarily isolated and excluded from full
> participation in society. Disabled people are therefore an oppressed
> group in society (UPIAS, 1976, p. 14)"

While impairment is regarded as an individual characteristic, disability is described as the result of an oppressive relationship between people with impairments and society. Once defined as disabled, the individuals are stigmatised and social expectations about their behaviour, or what they are capable of doing, influence them, independent of their impairment. This reformulation of disability

prompted Mike Oliver to coin the phrase the 'social model of disability' (Barnes, Mercer 2006).

The social model equates disability with disabling barriers and attitudes instead of concentrating on the link between the underlying medical condition and functional limitations, and redirects attention to things like defects in the design of the built environment or the inaccessibility of technology that restrict social inclusion. Thus, measures of disability should focus mainly on the physical, social and economic disabling barriers experienced by disabled people and the impact of anti-discrimination policies. This politicisation of disability revolved around citizenship and rights. The construction of a social model of disability together with the formation of advocacy organisations of disabled people provided a base for political resistance. The emphasis shifted from charity to rights and from social exclusion to inclusion with the replacement of a culture of dependence and pity to one based on acceptance as equal citizens (Barnes, Mercer 2006).

A newer evolution of the social model of disability suggests that everyone should be seen as somehow impaired and not just disabled people, and that people with disabilities are just individuals with special needs (Barnes, Mercer 2006, Shakespeare, Watson 2001). This model maintains that all of us are impaired at some point in our lives. Whether through a broken limb, an illness, an accident, a permanent injury, depression or old age, at some time in our lives we will all have some kind of impairment even if it is only for a short period of time (Shakespeare, Watson 2001). According to this paradigm the removal of barriers for people with disabilities is beneficial to everyone. This applies to IT as well. Any accessibility features integrated into software systems should be helpful not only to people with disabilities but eventually for everyone. If a software system is designed to be accessible to people with learning difficulties, the same system can also be accessible to individuals who, although they do not have a permanent disability, may suffer from a temporary impairment of short term memory for example, as a result of serious depression or even tiredness.

> "Short term changes in cognitive ability occur with everyone. These
> can be caused by fatique, noise levels, blood sugar fluctuations,

lapses in concentration, stress or a combination of such factors; they
can produce significant changes over minutes, hours, or days"
(Newell, Carmichael et al. 2002).

The current study adopts the views of the social model of disability which
maintain that society disables an individual by imposing social and environmental
barriers. Software developers and the software industry impose social barriers to
people with learning difficulties as a result of the fact that this community of users
are not involved in software development (Lewis 2005, Gregor, Dickinson 2007,
Czaja, Lee 2007, Keates, Adams et al. 2007). This non-involvement results in
inaccessible software systems thus resulting in an environmental barrier. The
current study aspires to make a case towards advocacy groups, to work in the
direction of influencing researchers and the software industry to involve more
people with learning difficulties in software development processes. This would in
turn contribute towards creating more accessible software systems and towards
removing an environmental barrier for people with learning difficulties.

2.5 Issues Faced by People with Learning Difficulties

Today, people with learning difficulties remain amongst the most vulnerable and
socially excluded in our society. Most of them live at home throughout their lives
with their parents or other carers (DH 2001). Consequently, they are denied the
same opportunities as others to gain independence and make choices about their
lives. Fifty-eight thousand people with a learning difficulty are supported by day
care services (Mencap 2011). Less than a third of them can choose who to live
with, and less than half where to live. Twenty-nine thousand adults with a learning
difficulty live with parents aged seventy or over, many of whom are too old to be
caregivers. About half of the families with a disabled child live in poverty
(Mencap 2011). Generally, people with learning difficulties have little choice or
control over many aspects of their lives and they face challenges and prejudice
every day. Most of them are treated as 'different.' Children with a learning
difficulty are quite often socially excluded and 80% of them are bullied at some
stage in their lives (Mencap 2011).

People with learning difficulties experience extreme health inequalities and are more likely to experience major illnesses and die prematurely. They are fifty-eight times more likely to die before the age of 50 compared to the general population. Furthermore, they are four times more likely to die of preventable causes (Mencap 2011). They are less likely to receive health assessments and essential treatments and face real obstacles in accessing services. Seventy-five percent of general practitioners (GPs) have received no training in the treatment of people with learning difficulties (Mencap 2011, Disability Rights Commission 2006). Most of them are unemployed, less than 20% work as compared with 50% of generally disabled people, but at least 65% of them want to work (Mencap 2011). Of the latter most only work part time and are low paid. Only 1 in 3 people take part in some sort of education or training program (Mencap 2011).

2.6 The New Vision

The social model of disability which evolved in the 1960s and 1970s described disability in terms of social oppression and barriers imposed by society. As a result of this model, inclusion, empowerment and the removal of barriers became the new vision of interested organizations and policy makers (Oliver, Barnes 1998). The *Valuing People* white paper represented the UK's previous Labour government policy on the issue and it incorporated the tenets of the social model. It was the first such paper in more than thirty years (DH 2001, 14), the previous one was published in 1971 and had the stigmatizing title *Better Services for the Mentally Handicapped* (Department of Health and Social Security 2009).

2.6.1 Valuing People

The *Valuing People* white paper presented an ambitious and challenging program of action for improving services. It took a life-long approach beginning with services for children with learning difficulties and their families and then moved on to provide new opportunities to adults for a purposeful life. Its proposals intended to improve social services, health services, education, employment, housing and support for people with learning difficulties and their families or carers (DH 2001).

It was based on four key principles (DH 2001, pp. 23-24):

- **Legal and Civil Rights:** Eradicate discrimination; people with learning difficulties have the right to education, to vote, to marry and have a family, and to express their opinions.

- **Independence:** Non-dependence from public services. Independence in this context does not mean doing everything without any type of support.

- **Choice:** people with learning difficulty like everyone else should be able to make choices. They want to have a say in where they live, what work they should do and who looks after them. At the moment for too many of them these are unattainable goals.

- **Inclusion:** Enabling people with learning difficulties to be part of the mainstream, something most of us take for granted. Make use of mainstream services and be fully included in the local community and in society.

2.6.2 Web Accessibility Initiative

The Web Accessibility Initiative (WAI) (W3C 2011) is part of this new vision of inclusion. Its purpose is to try to make the Web universally accessible to everyone and its major emphasis is on the inclusion of people with disabilities. A number of other similar initiatives and regulations that aim toward providing universal access to the Internet also exist but the WAI is the most famous. The WAI is a global de facto accessibility standard as it is the most comprehensive compared to other initiatives and because it comes from an important international body, the World Wide Web Consortium (W3C).

The W3C was founded in 1994 and its purpose is to advance the Web mostly by developing standards and protocols which assure interoperability. The WAI

developed a number of guidelines which, when implemented, should make websites more accessible to people with disabilities including people with learning difficulties. Most national laws and regulations on Web accessibility recommend adherence to the WAI guidelines. For example, the European Union (EU) action plan on accessibility states "The eEurope Action Plan 2002 proposes adoption of the Guidelines [WAI guidelines] as an initial step towards making European public websites and their content accessible to people with disabilities. By adopting the Guidelines, the Member States and European institutions will give the target of Web accessibility broad recognition and support, through the use of the global de facto Web accessibility standard which the work of the WAI represents" (COM 2001).

The WAI guidelines are divided into three categories:

Web Content Accessibility Guidelines (WCAG 1.0)
The WCAG is a set of guidelines on making content accessible for disabled users (W3C 1999).

Authoring Tool Accessibility Guidelines (ATAG 1.0)
The ATAG is a set of guidelines for authoring tool developers (i.e. HTML editors) in both creating a tool which is accessible to disabled end-users but also a tool which creates accessible Web pages (W3C 2000).

User Agent Accessibility Guidelines (UAAG 1.0)
The UAAG is a set of guidelines for user agent developers (i.e. Web browsers) whose purpose is to make the content they handle more accessible to disabled users (W3C 2002).

In the UK the 2010 Equality Act anti-discrimination legislation protects individuals with disabilities and their rights to access Web information (The National Archives 2011). The Equality Act which replaced the Disability Discrimination Act of 1995 sets further obligations on website owners and hosts in order to ensure that sites are accessible and compliant to Web accessibility

standards. Under the Disability Discrimination Act of 1995 website owners were obliged to make reasonable adjustments in order to resolve access issues and thus make a site accessible to people with disabilities. This requirement remains but the new Equality Act also requires that a person with disabilities must not be put at a 'substantial disadvantage,' compared to a non-disabled user. Thus, the new law is stricter on website owners and hosts. Furthermore, the 2010 Equality Act recommends the involvement of people with disabilities in the development process (Dalziel 2010).

2.6.3 Web Accessibility Initiative and people with learning difficulties

The WAI has been successful in bringing the issue of accessibility to the attention of the wider Web community, but the model of Web accessibility developed by the WAI has been criticized in many occasions for its limited scope (Kelly, Sloan et al. 2005). In relation to the current study the greatest weakness of the WAI is the fact that there are very few guidelines for making content accessible, specifically to people with learning difficulties (Gregor, Dickinson 2007). Out of 14 specific guidelines for Web page authors only two guidelines (numbers 13 and 14) explicitly address the need to consider the cognitive processes involved in accessing, navigating, and understanding the content of Web pages (Keates, Adams et al. 2007).

The newer WCAG 2.0 were released in December 2008 to solve some of the issues of WCAG 1.0. Its core principles (POUR: perceivable, operable, understandable, robust) and related success criteria aim to be applicable to the widest possible range of present and future technologies used to deliver content on the Web (Kelly, Nevile et al. 2009). Yet, even these guidelines fail to adequately address the needs of people with learning difficulties. As is stated on the W3C website, "Note that even content that conforms at the highest level (AAA) will not be accessible to individuals with all types, degrees, or combinations of disability particularly in the cognitive language and learning areas" (W3C 2008).

This comparative lack of priority on addressing the needs of people with learning difficulties in the WAI guidelines is unfortunately representative of accessibility research in general. Concerning Web accessibility, the majority of research is focused largely on sensory impairments such as blindness and deafness and on motor impairments. Learning difficulties are rarely included when considering the accessibility of an IT system and people with learning difficulties are excluded from the use of IT in general and not just the World Wide Web (Keates, Adams et al. 2007).

2.7 People with Learning Difficulties and Information Technology Use

In the last decade there has been a great deal of research looking at the reasons a number of social groups do not have equal access to IT. This has been called the 'digital divide.' Unfortunately people with learning difficulties are part of this digital divide and the promise of social inclusion, reinforced by IT, has not become the reality (McKenzie 2007, Gibson 2007, Wattenberg 2004).

The digital divide initially only considered financial reasons and was seen as a split between those groups in society which could financially afford IT and Internet connectivity and those who could not. Today this type of definition is seen as too narrow and the 'divide' now includes a number of different factors which affect access to IT. There is no single factor that determines whether a digital divide exists (Warschauer 2002). "Barriers go beyond the simple provision of computers and the availability of a supporting infrastructure to include factors such as cognitive ability, motivation, social identity and power" (McKenzie 2007).

Despite all the initiatives to include people with learning difficulties in IT use, they are still largely excluded compared to many other forms of disabilities and to the non-disabled population (Gregor, Dickinson 2007) Both, people with learning difficulties, and by extension, people who have similar impairments, but fall under different terminologies, face serious barriers when trying to access IT systems or the Web (Czaja, Lee 2007, Keates, Adams et al. 2007). For example older people

and people with Traumatic Brain Injury (TBI) have problems accessing IT similar to those that people with learning difficulties have. As people get older, specific cognitive areas decrease their functioning levels (e.g. short-term memory, increased distractibility, reaction times, openness to learning, problem solving, reasoning) producing impairments similar to learning difficulties(Czaja, Lee 2007). People with Traumatic Brain Injuries suffer from similar symptoms also. If the numbers of these two groups were added to people with learning difficulties then the figures would be much higher. Excluding such a considerable number of citizens from the benefits that IT offers would be unacceptable. Developing technology that is accessible to people with learning difficulties would therefore benefit these other groups of people as well.

2.7.1 Impact of Learning Difficulty on Information Technology Use

This section attempts to explain how learning difficulties affect IT use. Many scientists use a medical model in order to explain why people with learning difficulties face challenges in using IT and it is important to be presented here. However, the current study adopts the position that it is the social and environmental barriers build on top of the medical condition, that exclude people with learning difficulties from IT. This position coincides with the tenets of the social model of disability. Therefore, the medical model is presented only for explanation. The study supports that in order to make IT accessible to people with learning difficulties then the social barriers must be removed.
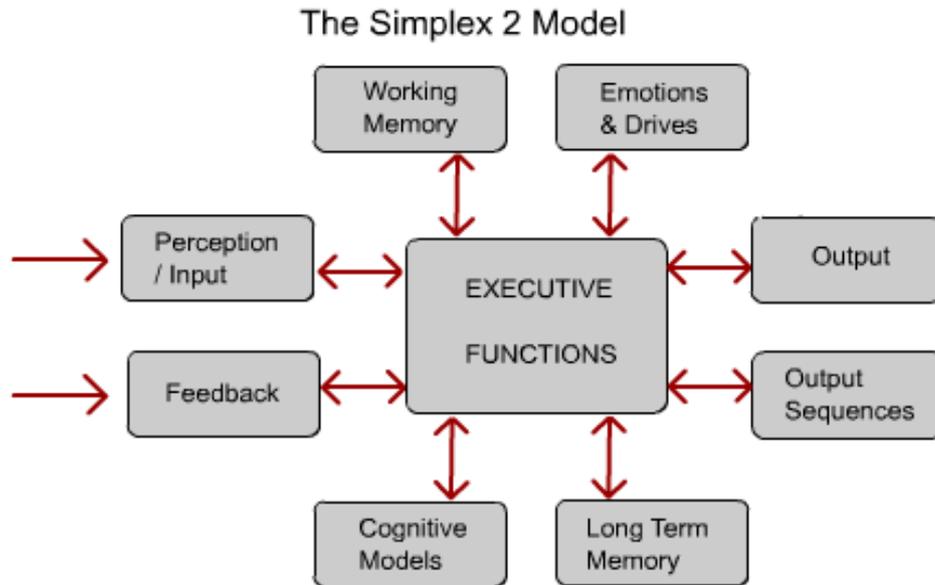
The Simplex 2 Model

Figure 2.3 – The Simplex 2 Model (Source: Adapted from Adams, 2005).

Individuals with learning difficulties share a number of cognitive difficulties which make accessing IT systems challenging. A number of specialised areas in the brain can potentially play a role in a user's interaction with an IT system. One model used as a framework for researchers in universal accessibility and for accessible systems design is Adams' Simplex 2 model, Figure 2.3. As shown in the figure, the model depicts cognition as consisting of a number of different processes linking different specialised areas within the brain. All of these processes are coordinated by a central area called the 'executive functions' area. The model asserts that these processes and specialised areas in the brain are necessary for intelligent human behaviour. Each of these specialised areas can potentially play a role in a user's interaction with an IT system. This sheds some light into the level of complexity involved in interacting with such a system.

People with learning difficulties can have any one or any combination of these specialised areas affected and in various degrees. This creates a great variety of intellectual disability combinations. This great variety indicates the potential level of complexity required for providing support for users with such difficulties in an IT system.

Despite the variety in combinations though, most people with learning difficulties also share a number of specific intellectual difficulties. Examples of these shared difficulties include generalising information, learning and retaining new information, understanding complex subjects and difficulty with language skills (McKenzie 2007). These shared difficulties make IT systems challenging to use. For example, a central technological barrier is the tremendous complexity of most software applications (Keates, Adams et al. 2007). Another is the language and assumptions associated with the use of Graphical User Interfaces (GUI). This language is a combination of technology terminology with metaphors from the real world which are misleading when used for a computer interface.

> "We are to think about the television display as if it was like a *desktop*; that on this desktop there are *windows* (!) which we can look through to see the *application* which is *running*; that in this case this is a *Web browser* which can be controlled by using *menus* and a *mouse*;" (Gregor, Dickinson 2007).

This combination of technical jargon, such as that an application is 'running' and the misleading references to everyday objects such as 'windows,' is confusing to people with learning difficulties and makes it challenging for them to use IT.

2.7.2 Information Technology Access Barriers

A number of social factors, such as unemployment, low income and unfamiliarity with technology have also been identified as affecting IT use by people with learning difficulties (McKenzie 2007). The most common theme in the literature though revolves around the fact that IT is not designed to be accessible. Existing software systems lack the necessary accessibility features for people with learning difficulties. Today's IT is simply not designed to be accessible to this community of users (Lewis 2005, Gregor, Dickinson 2007, Czaja, Lee 2007, Keates, Adams et al. 2007). This is caused mainly due to the wrong stereotypical beliefs that researchers and people involved in the software industry have for this community of users. The software industry or the market research agencies it employs to run focus groups and gather data on their behalf, discriminate against the involvement of people with learning difficulties in the development process, for reasons such

as uncertainty of how to work with them or stereotypical ideas like they may not be able to articulate what they need (McKenzie 2007, Sullivan, McGrenere 2003, LoPresti, Bodine et al. 2008, Lewis 2005). As a result most commonly used commercial software systems remain inaccessible.

Information Technology is typically developed for mainstream users and there are only a limited number of available systems developed to specifically meet the needs of people with learning difficulties (Lewis 2007). The limitation is also exacerbated by economic factors such as a limited market for this kind of product (Wehmeyer 1998, Braddock, Rizzolo et al. 2004). The development of suitable systems has also been held back by the heterogeneity of the population of people with learning difficulties and the lack of design models that account for the individual differences found among them (Lewis 2005). McKenzie (2007) also stated barriers to use such as lack of funds, lack of training and lack of information about the potential benefits.

The IBM Human Ability and Accessibility Centre and T.J. Watson Research Centre in the USA, hosted a symposium on *cognitive and learning difficulties and how they affect access to Information Technology systems* in October 2005. The central premise of the symposium was the recognition that learning difficulties have a profound impact on a person's ability to interact with IT systems, and that little support is currently being offered by those systems (Keates 2005). The symposium also tried to investigate the latest research relating to people with learning difficulties and access to IT. Some major conclusions were that,

> "Users with cognitive or learning difficulties are currently
> underserved by existing applications and also by existing research.
> This is not to say that there is no research being performed, nor that
> there is no support for users with cognitive and learning difficulties
> among existing applications" but "It is fair to say that there is a
> large body of people that are not being supported as they should be"
> (Keates, Adams et al. 2007, p. 338).

2.7.3 Making Information Technology Accessible

Designers can better understand usability needs by involving the final users in the design and development process (Lopresti, Mihailidis et al. 2004). More intuitive and user-centred designed interfaces are necessary in order to increase the accessibility and empower people with learning difficulties to use common IT systems (Braddock, Rizzolo et al. 2004). In Participatory Design methodologies, system development is guided by frequent interactions and the active involvement of the final users in the whole analysis, design and implementation process in order to improve the understanding of user and task requirements. Development typically happens in an iterative process between design and evaluation where users review prototypes and suggest needs and possible features. Participatory Design and User-Centred Design (UCD) methodologies are considered by computer scientists and software engineers as the most dependable methods to ensure product usability. (Mao, Vredenburg et al. 2005, Lopresti, Mihailidis et al. 2004, Smith 1997).

> "Much has been written in the research literature about User-Centred Design. As further proof of internationally endorsed best practice, User-Centred Design processes are also defined in ISO documents, including ISO 13407 and the associated technical report, ISO TR 18529" (Mao, Vredenburg et al. 2005).

Involving people with learning difficulties in the development of software systems is necessary in order for these systems to become accessible. Yet few designers include end-users in the design process and in the case of people with learning difficulties they are seldom involved at all (Lewis 2005, Dong, Clarkson et al. 2005). Designers typically begin with the assumption that potential end-users have the same expectations and experiences as their own, while others use their colleagues or other non-disabled representatives as models. Those few who would like to involve users consider appropriate end-users difficult to identify and recruit and usually commission market research agencies to run focus groups and gather data on their behalf. Unfortunately, few designers acknowledge the need for user involvement, or the wide range of end-users who may be using their product, like people with disabilities (Dong, Clarkson et al. 2005, Säde 2001). Dong, Clarkson

et al. observed that "... designers tend to be critical of focus groups, " that "... focus groups are prone to 'sheep mentality,'" "... the results can be biased by dominating participants" and "... they are 'cost and time consuming' and 'complex'" (Dong, Clarkson et al. 2005, p. 63). Also, designers consider that "... identifying users, interviewing them and interpreting the findings all need specialism" (Dong, Clarkson et al. 2005, p. 50).

If designers are hesitant to involve non-disabled final users in the process, they are even more so with learning difficulty participants. Unfortunately, people with learning difficulties are rarely included when designing IT systems and no effort is made to make these systems accessible to them (Sullivan, McGrenere 2003, LoPresti, Bodine et al. 2008, Keates, Adams et al. 2007, Friedman, Bryen 2007b, Fanou 2008). With the exception of a few studies which did involve people with learning difficulties in software development (described in Section 2.9), this community of users is still largely discriminated against by the wider research and software communities. Regrettably, people with learning difficulties are still being viewed as part of a stigmatised group and this affects the researcher's and developer's expectations of their abilities. Until recently this group of people were segregated and considered incapable to contribute to society. Sadly, this is still true regarding their contribution to software design (McKenzie 2007).

Information Technology must become accessible to people with learning difficulties if they are to participate as equal members in society. It is therefore imperative to find ways to involve these individuals and their input in the software development process on a wider scale and not just in a few studies. In order to eradicate the type of discrimination that people with learning difficulties face from the research and software communities it is necessary to study how people with learning difficulties can participate in software design and development. As Sullivan (2003) put it:

> "What communities must be involved to design cognitive technologies that are useful and usable? What can we learn about ethnographic study and Participatory Design to overcome the following multi-tiered 'proxy' problems:

1. End users may not be able to articulate what they want or need.

2. Communities who may be able to articulate what should be designed (i.e. caregivers, family members) are not necessarily the same communities who create the technologies.

3. Communities who know how to develop, select, or customize information systems (i.e. technology developers) are often not in a position to offer this service" (pp. 148 - 149).

2.8 User Participation

Participation is contentious and without clear or agreed definition. There is no consensus about terminology, with different terms used sometimes synonymously, sometimes to convey different meanings, including 'citizen participation,' 'self-advocacy' and 'consumer involvement' (Vroom, Jago 1988, Beresford, Croft 1993). The term participation itself is used both as an umbrella term and to denote a degree of involvement (Taylor 1996).

User participation refers to a range of involvements which individuals and groups may have in organizations, institutions and decisions affecting them and others. These extend from having control of the whole process to just being an information source. Participation is essentially judged by the extent to which people can exert influence and bring about change (Beresford, Croft 1993, Brodie, Cowling et al. 2009). This conceptualisation of participation implies that in software design an individual participates when the individual exerts influence to bring about change to the system under development. Moreover, the extent of the influence and the control over the process are inherent to participation.

In the fields of social work and social care, participation, generally means 'user involvement,' and emerged in the late twentieth century as a policy and practice required by legislation. Participation in social care is generally associated with

service users (Beresford, Croft et al. 1997). Outside social care it can also relate to the involvement of workers and other citizens, for the negotiation of their different rights and interests. The concept of public participation became a key concern of community development, and is central in a growing number of developments, including the emergence of new social movements and the rebirth of interest in citizenship, social exclusion, and participatory politics.

The emergence of the idea of user involvement is attributed to two political developments (Taylor 1996). The first is associated with a retreat from the welfare state while paying increasing emphasis on the market, which are linked with the philosophies of consumerism, including purchase of service, consumer choice and involvement. The second was the development of increasingly powerful and influential movements of disabled people and other recipients and users of social care. These movements formed their own democratically constituted local, national and international organizations. The result was two competing approaches to user involvement in social care. The one, from the state and service system, reflecting consumerist concerns such as improving the efficiency, effectiveness and economy of services and products. The other, from the disabled people's and service-users' movements devoted to the ideas of people speaking for themselves, securing and safeguarding their human and civil rights, choices and quality of life. The first consumerist approach starts with the service system while the second democratic approach, with people's lives. The one is managerial and instrumental in purpose, without any commitment to the redistribution of power, while the other liberational with a commitment to empowerment (Taylor 1996, Brodie, Cowling et al. 2009)

The two approaches are also associated with different participation strategies. The consumerist view is interested in service-user feedback and pays emphasis on consultation and data collection exercises focusing on the planning, management and market testing of specialist services or products in order to make them more economic, effective or efficient. Conversely, service users and their organizations support that such exercises have very limited effects in improving their lives and services, while making significant demands upon them. Their concern is with

bringing about direct change in people's lives through collective as well as individual action (Taylor 1996). The disabled people' movement bases its approach to participation on the social model of disability, using both parliamentary and direct action. It has given priority to civil rights and freedom of information legislation and the provision of adequate support for organizations controlled by disabled people themselves (Beresford, Croft 1993, Brodie, Cowling et al. 2009).

While participation is generally associated and affected by the social sphere, it is also affected by people's personal circumstances and responsibilities. Personal circumstances can limit the participation of many groups, like for example women. Two components are necessary in order for people to have a realistic opportunity of participating and the various groups to have equal access to involvement. These are access and support. Without support only the most advantaged, well-resourced and confident people or groups are likely to become involved, while without access, efforts to become involved are likely to be difficult and ineffective. Support includes increasing people's confidence, broadening their skills, offering practical support like child care and transport, and ensuring that minority groups and others facing discrimination can be involved on equal terms. Access includes equal access to the political structure at both central and local levels and to other organizations and institutions which affect people's lives (Beresford, Croft 1993, Taylor 1996, National Council for Voluntary Organisations (NCVO), Institute for Volunteering Research (IVR) et al. 2011).

While participation is generally presented positively it can also have another side. Participatory initiatives can serve to obstruct rather than increase people's involvement, they can be used to delay decisions and/or action and to legitimate predetermined decisions and agendas. This relates to a more general tension which is created when arrangements for participatory or direct democracy are made in a society based primarily on a system of representative democracy. (Beresford, Croft 1993, Taylor 1996)

The current study tried to use participation elements from both the consumerism and service-users approaches. The study tries to make a case towards convincing the research and software communities to include people with learning difficulties in their user panels more, thus stopping a discriminatory behaviour. It is also hoped that the results of the study will contribute towards encouraging activist organisations to promote this subject more. In order to achieve these goals, the study involved a specific group of Health Trainers with learning difficulties using Participatory Action Research. Thus the Health Trainers were taking action in order to promote the interests of their community and work towards stopping the research and practitioner communities from discriminating against them. Such actions relate to the disabled people's and service-users' movements which are devoted to the ideas of people speaking for themselves, securing and safeguarding their human and civil rights and their quality of life.

Conversely, in order to show how people with learning difficulties can be involved in the software development process, an accessible and usable software system was developed. To achieve this aim the Health Trainers provided input and consultation and the study collected system requirements in order to improve a software product and make it more effective, usable and accessible. These elements reflect the consumerist participation approach which is concerned with improving the efficiency, effectiveness and economy of services or products.

2.9 User Participation in Other Studies

A number of studies have involved people with learning difficulties in the software development process. A thorough review of the literature revealed a number of such studies. They are presented in the present section. All the presented studies primarily had technology oriented objectives. None of them examine the participation itself or try to explore how software developers can approach the field of learning difficulties, the issues they will face, and how they can be overcome. Therefore the studies presented in the section had different aims than the current study.

Dickinson, Gregor et al. (2003) described the design and development of two systems, SeeWord and Piloot, developed through involving final users from traditionally excluded groups. SeeWord was developed with the involvement and for the needs of people with dyslexia, while the Piloot system was developed with the involvement and for the needs of people with learning difficulties. Piloot enables the communication of people with learning difficulties with their carers and relatives. It is Internet based and works as a shared book in which a predefined group of users (for example a main user who could be living in sheltered housing, and his relatives or carers that live in another city) can compose messages using a combination of text, images, pictograms, webcam photographs and drawings. Dickinson, Gregor et al. (2003) compared the development processes of these two systems in order to distil methodological insights and wider implications of the similarities and differences for interface design for the diverse and untypical groups of users they involved in the study.

The term learning difficulties was not defined in the literature but as the research was conducted at the University of Dundee, Scotland, the researcher assumed that the definition for learning difficulties used is the UK one. The following website was cited, http://www.piloot.org as a place where the reader could get more information about the study. Unfortunately, this Web address is obsolete and at the time of this writing belongs to another organisation. Therefore, there is lack of in depth information about the Piloot study which involved people with learning difficulties.

Regarding the participants' degree of learning difficulty, Dickinson, Gregor et al. (2003) stated the following:

> "During the development of Piloot the users involved varied in terms of the severity of their impairments. Piloot is mainly aimed at users who have limited reading and writing skills, are educated at special schools, and are living semi-independently, for example in sheltered housing. Within this group of users with learning difficulties there is a wide variety in symptoms" (p. 62).

The literature therefore did not explain in detail the severity levels of learning difficulty and the exact symptoms which the involved users had. The present study concentrated on the participation of people with mild learning difficulties only.

Piloot was developed using a 'user sensitive iterative process' (Dickinson, Gregor et al. 2003). This process was explained as following multiple lines of interest simultaneously, and included learning about the users and their abilities, defining functional requirements for the application, developing interface elements through partial prototypes, and understanding the context of use of the application (Dickinson, Gregor et al. 2003). Regarding the process Dickinson, Gregor et al. (2003) also supported, "The experience and successes gained with the two applications highlights the usefulness of the concept of 'user sensitive inclusive design' proposed by Newell and Gregor (2000)" (p. 67).

User sensitive inclusive design was proposed as a methodology by Newell and Gregor (2000), who maintained that universal usability requires that designers consider all potential user groups of systems, including people with disabilities. Such user groups would have a very broad set of functionalities and characteristics and it would be difficult to be encompassed within the traditional User-Centre Design methodologies. Additionally there are ethical and other challenges in dealing with people with disabilities. Newell and Gregor (2000) extended the User-Centred Design methodology making it more appropriate for wider groups of users and proposed a new methodology called 'user sensitive inclusive design.' Therefore user sensitive inclusive design is a methodology which includes people with disabilities within User-Centred Design methodologies. Like User-Centred Design, the methodology proposed by Newell and Gregor (2000) emphasises the design of technology rather than the conduct of social science research.

Other than using a user sensitive iterative process for the development of Piloot, Dickinson, Gregor et al. (2003) did not mention any other methodology or research paradigm used to guide the research process. The methodology of the

Dickinson, Gregor et al. (2003) study therefore suggests that the emphasis was on technology. The current study combined two different methodologies, Evolutionary Prototyping a software development methodology described in Section 4.4.1 which guided the development of the software system and Participatory Action Research, described in Section 3.4 which was used for guiding the research process.

Within the disability field there is a growing awareness of the rights of disabled people and these have been expressed in the ideas of Participatory Action Research. For example, in Participatory Action Research individuals with disabilities are involved in setting the research agenda, developing research questions, participating in the research as researchers and consultants, testing research ideas, and evaluating the results of the research (Newell, Gregor 2000). This is appropriate within a sociological research agenda, but in User-Centred Design although the needs and wants of users are the focus, the user can not be in control of the research, as is sometimes suggested by the proponents of Participatory Action Research. According to Newell and Gregor (2000):

> "In product research and development, the role of potential users who are disabled should not include setting research agendas, developing research questions, the choice of evaluation methodologies, which need trained researchers. Users should be 'involved in' the process, but not have a dominant role in it" (p. 40).

This demonstrates further that the user sensitive inclusive design methodology proposed by Newell and Gregor (2000) and which was endorsed by Dickinson, Gregor et al. (2003, p. 67), emphasises product development rather than the conduct of social science research like this study did.

Dickinson, Gregor et al. (2003) also supported that their research had wider implications, specifically the similarities and differences for interface design for diverse and untypical groups of users:

> "We discuss parallels and differences in the design and development processes of these systems in an attempt to elicit general principles of inclusive interface design" and "…the

development processes followed have significance for the

development of more appropriate systems in general" (p. 61).

There was therefore a difference between the objectives of the current study and the Dickinson, Gregor et al. (2003) study. Dickinson, Gregor et al. (2003) used a more product design oriented methodology aiming to elicit general principles for the design of inclusive systems. The aim of the current study was to consider how people with learning difficulties could participate in the software development process and to explore how software developers can approach this field, the issues they will face, and how those can be overcome. Thus the emphasis of the current study was on the participation rather than the design of technology.

Harrison, Stockton et al. (2008) described the Portland Partnership project led by Portland College in Nottinghamshire, England, which also involved partners from Higher Education, as well as the private sector and the University of Teesside. The project used iterative processes for the development of a Virtual Learning Environment (VLE) based on the ISO 13407:1999 standard 'Human-centred design processes for interactive systems.' This standard from the International Organization for Standardization (replaced by ISO 9241-210:2010) describes User-Centred Design which is oriented towards the development of technology and provides recommendations for human-centred design principles and activities throughout the life cycle of computer-based systems. The methodology is intended for managing design processes, and is concerned with ways in which both hardware and software components of interactive systems can enhance human–system interaction (International Organization for Standardization (ISO) 2010). The standard was not designed for dealing with the ethical and other challenges of involving people with disabilities or for guiding social science research processes. Newell, Carmichael et al. (2002) supported the need to adapt design methodologies for participants with learning difficulties. Harrison, Stockton et al. (2008) did not mention any changes to the used methodology in order to adapt it to the needs of people with learning difficulties. Furthermore, the literature did not mention an ethical framework used for working with people with

disabilities or any other methodology or research paradigm used to guide the research process like the current study did.

According to Harrison, Stockton et al. (2008):

"The aim of this research project was, with the assistance and support of the learners and their tutors, to design and develop an adaptable and inclusive online learning environment specifically catering for the needs of young adults with SLD [Severe Learning Difficulties]" (p. 1023).

Therefore the goal of the research was the design of accessible technology. The study did not explore participation and the challenges software developers face while working in the field of learning difficulties, which was the aim of the current study. The Portland Partnership Project mostly concentrated on the technology product and what it does, without observing the participation of the users with learning difficulties. Moreover, the participants involved were people with severe learning difficulties and physical disabilities as compared to the Health Trainers of the current study who were individuals with *mild* learning difficulties (Harrison, Stockton et al. 2008b).

Regarding the users of the system the following were observed (Harrison, Stockton et al. 2008b) p. 1023):

The characteristics of a learner with profound and multiple disabilities vary greatly from one learner to another, but may include:

- limited or no sight e.g. lack of depth perception or reduced visual fields
- limited or no verbal communication e.g. dysarthria
- learning difficulties e.g. low levels of literacy and numeracy (The learner may be learning to recognise individual letters of the alphabet or count to five.)
- physical disabilities e.g. poor or no fine motor skills or quadriplegia

User-Centred Design tries to make users the focus of the design activity and considers them appropriate experts for their usability needs (Smith 1997). Therefore, when attempting to make a system accessible, people with disabilities are consulted for their input because they are seen as appropriate experts for their own needs. The VLE developed by the Portland Partnership Project was intended to be used by both tutors and people with disabilities (learners) therefore both groups of users should and were involved in development. Yet, the parts of the system interface which would be used by the learners with disabilities should be designed with their input and not what their tutors believed they needed. Harrison, Stockton et al. (2008) failed to explain in detail how the two groups of users were involved in the design and development of the system and for which parts of the system each group offered input. The only mention about the involvement of the two groups was the following:

> "At every stage, learners *and tutors* were involved in the development of the project's outputs" and "The data gathered from these interactions with the learners and tutors helped to form a catalogue of the specific functionality and entry requirements the VLE would need to encompass for it to be adaptable and accessible to the needs of these learners" (p. 1025).

This vague description of how the two groups of users were involved in system development is a shortcoming of the study. Harrison, Stockton et al. (2008) should have provided details on the contribution of each of the two groups of users and how they were involved.

The TATE (Through Assistive Technology to Employment) Project was launched in November 2004 and ended December of 2007. It was a trans-national research and development partnership of eighteen organizations funded by the European Social Fund (ESF) with a budget of £4.4 million. The partnership was led by the Home Farm Trust (HFT), a national charity providing services for people with learning difficulties. The project had undertaken research into ways that Electronic Assistive Technology (EAT) can support the independence of people with learning difficulties and enhance their employment prospects. It was based in the UK but had a trans-national dimension with development partners from

Hungary, Spain and Latvia. The following website was cited, www.tateproject.org.uk as a place where more information about TATE was available. Unfortunately, as was the case with the Piloot study presented earlier, the cited Web address is obsolete and unavailable and therefore there is lack of in depth information on some areas of the study (Aspinall 2008, Aspinall, Nichols 2008, Aspinall, Barnard 2007).

The literature mentioned a number of different assistive technologies which were developed with the involvement of people with learning difficulties and their carers as both hardware and software (Aspinall 2008). Initially the project focused on innovative technology devices. Aspinall (2007, 2008) stated that a 'person-centred approach' to technology was adopted but the approach was not explained in enough detail. What was mentioned about the approach was the following, "This development has been based on an approach to partnership with manufacturers, providers, purchasers (also as local policy-makers) highlighting that positive partnerships achieve positive results and benefits for all involved" (Aspinall, Barnard 2007, p. 55). The literature also mentioned that researchers worked closely with users at several trial sites to develop technology that would address some of the barriers to independence and employment (Aspinall 2008).

Some of the hardware devices developed were, a customized mobile phone, a disco shower, a prompter, a scheduler and an intelligent microwave oven. Other examples of the successful outcomes of TATE include innovative life skills software packages to be used at home or at work, and a revised nationally recognised and accredited qualification in Assistive Technology for care staff and for people with a disability (Aspinall, Nichols 2008, Aspinall 2007).

The accessible software programs were grouped under the title 'Out and About' series. The first is called 'Out and About 3: Gadgets at home' and introduces the use of everyday technology such as microwave ovens, cookers and washing machines through videos. The user can then choose from a series of activities based on the videos. The second life-skills software 'Out and About 4: Finance and money' follows the same format as 'Out and About 3' and it explores through

a variety of videos and activities the issues around personal budgeting and the impact of paid employment. Another software system called 'Out and About: Assistive Technology – Assessing needs' suggests assistive technology solutions which may reduce or remove the barriers to employment through a series of responses to a sequence of questions. Finally, the development partnership also produced a health and safety training resource pack called 'Safe at Work.' This is a system that delivers in an accessible format health and safety training to people who have limited literacy skills (Aspinall, Nichols 2008).

The term 'learning difficulty' was not defined in the literature (Aspinall 2008, Aspinall, Nichols 2008, Aspinall, Barnard 2007, Aspinall 2007) but while describing Jo one of the project participants, Aspinall and Nichols (2008) mentioned, "Jo is one of a team of 28 individuals with some form of cognitive disability, also known as intellectual disability, learning disability, learning difficulties or mental retardation, all of whom are taking part in TATE" (p. 237). The above terms mentioned by Aspinall and Nichols (2008) are commonly used for learning difficulties (as described in Section 2.2.1) and therefore the researcher considered that the TATE project involved people with learning difficulties as defined by this study.

Another weakness of the TATE study was the fact that the learning difficulty severity level was stated for only two of the participants. Aspinall (2007) described ten participant case studies. The only two case studies, for which the severity level of the participants was stated, were those of Sean with moderate learning difficulties (p. 44) and Jill with severe learning difficulties (p. 45). For the rest of the participants the degree of learning difficulty was not stated. Therefore all learning difficulty severity levels of the participants involved in the project cannot be known. From the two mentioned case studies it is obvious that at least one individual with moderate and another with severe learning difficulties were involved in the TATE project but the literature did not mention people with mild learning difficulties. The current study involved only people with mild learning difficulties.

Aspinall (2008) also stated that the TATE project involved people with learning difficulties and their carers in the design, implementation, and delivery of assistive technologies. However, like in the case of the Portland Partnership Project mentioned previously, the details of how the two groups were involved were not explained. Moreover, there was no mention of a methodology or research paradigm used to guide the research process.

The literature stated that people with learning difficulties were involved in the management of the research as well as the development of technology but there is lack of detailed description of how people with learning difficulties were involved in the management. Aspinall (2008) observed:

> "...it was decided that instead of having one Management Board the
> project would have two, with beneficiaries [people with learning
> difficulties] making up the membership of an Advisory Group
> which would report to the Management Board on all issues
> involving them… Meetings were chaired by the Project Manager
> and held two weeks before Management Board meetings so that the
> views of the Advisory Group could be relayed to the Management
> Board" (p. 54).

Therefore people with learning difficulties who comprised the Advisory Group were reporting to the Management Board offering their views on all issues that involved them but Aspinall (2008) did not give any details on what those issues were.

A number of key findings and conclusions from the TATE project were described without any evidence or data to support them. Aspinall and Nichols (2008) described in detail the case study of Jo, one TATE project participant with learning difficulties. Regarding Jo it was mentioned, "Using email has enabled her to develop her reading skills which have definitely improved since the beginning of the project" (p. 238) and "Since her involvement began her confidence has improved" (p. 238). However, the literature did not explain how reading skills and increased confidence were measured and/or it did not present any data to support the findings. Aspinall and Nichols (2008) stated that, "Case studies and more

information is available on the TATE website www.tateproject.org.uk" (p. 239) but as the website is not available it cannot be known if the supportive data was presented there.

According to Aspinall (2008) the objectives of the TATE project were to demonstrate how assistive technology could support independent living for people with learning difficulties, increasing their employability and allowing them to take a full, active part in the communities in which they lived. Moreover, the project tried to challenge the paternalistic culture for the support of people with learning difficulties and to empower individuals to take decisions in their lives (p. 54). Therefore the objectives of the TATE project were wider in scope and with a social dimension, compared to most of the other studies presented in this section which emphasised technology. However, despite the social orientation in the objectives of the TATE project they were different from the objectives of the current study which explored participation.

Dawe (2007a, 2007b) described a Participatory Design study which was conducted at the Department of Computer Science, the University of Colorado, USA. The study involved individuals with 'cognitive disabilities' and their family caregivers (without disabilities), as co-designers of technology. Five families and their adult children were involved with the following characteristics (Dawe 2007b, p. 181):

- Jake, age 21 and his mother; Jake had moderate to severe 'developmental delay' and might also been autistic.
- Both parents of Linsey age 25; Linsey had moderate to severe 'developmental delay.'
- Both parents of Margaret age 24; Margaret had Down syndrome and moderate 'cognitive disability.'
- Mark, age 19 and his father; Mark was autistic with moderate 'cognitive disability.'
- Alex, age 24 and this mother; Alex had Cerebral palsy with moderate 'cognitive disability'

Two different terms were used in the literature to describe the participants with disabilities, 'developmental delay' and 'cognitive disabilities.' Unfortunately the literature did not define the used terms and the difference between them was not explained. Developmental delay is not a term typically used to denote learning difficulties. The online Oxford Dictionaries (Oxford University Press, no date) defines developmental delay as "the condition of a child being less developed mentally or physically than is normal for its age." The online American Heritage Dictionary of the English Language (Houghton Mifflin Harcourt 2011) defines it as "A delay in the appearance of normal developmental milestones achieved during infancy and early childhood, caused by organic, psychological, or environmental factors." Dawe (2007b) described Jake and Linsey, two study participants, who were both over twenty years old as having moderate to severe developmental delay (p. 181). As described in Section 2.2.1 in the USA the term 'developmental disabilities' rather than developmental delay is typically used to refer to learning difficulties. It is not clear why the study used two different terms to describe the participants. However, as both the 'developmental delay' and 'cognitive disability' terms were used, the study must have considered those to be different disabilities, and therefore the terms should have either been defined or the difference between them explained.

To explore the problem area ethnographic and evolving 'technology probe' methodologies were used. According to Dawe (2007a):

> "Technology probes study a domain of human behaviour by
> providing simple, useful functionality, inspiring users to consider
> how technology can enhance their environment, and collecting
> extensive usage data through realistic use" (p. 2178).

Therefore, the study described by Dawe (2007a) used two methodologies in order to conduct research and develop technology for people with learning difficulties like the current study did.

The developed technology was based on a Windows mobile Personal Digital Assistant (PDA) style 'smart phone' with a touch screen which run a software from AbleLink Technologies specifically developed for people with learning

difficulties. Instead of developing something from scratch the study used this software as a base and implemented user interface modifications and additional features to it. The specially modified smart phones could send and receive calls through a picture and audio-based user interface and they supported remote communication functionality that was not typically found on regular mobile phones (Dawe 2007a).

Dawe (2007b) stated that one of the aims of the study was to understand the mobile phone requirements for young adults with learning difficulties, "The research presented in this paper identifies design requirements for mobile phone users with cognitive disabilities" (p. 180). However, part of the input for altering the design of the smart phones came from the family caregivers instead of the people with learning difficulties themselves. Dawe (2007a) observed, "The family caregivers co-designed a number of changes and additions to the probe (such as a missed call screen, and a screen lock function)" (p. 2181). Dawe (2007a) also stated, "A surprising outcome of the study method has been the ability to engage the participants with cognitive disabilities as co-designers" (p. 2181). As according to Dawe (2007a) the methodology used was successful in engaging the participants with learning difficulties, then the input on the necessary changes to make the smart phones accessible should had come directly from the participants with learning difficulties, not what the parents believed their children needed. The aim of the study was to make the technology accessible to people with disabilities and therefore the system requirements should had come from the participants with learning difficulties themselves.

A second objective of the study with a social rather than a technological orientation was to contribute to our understanding of how remote communication plays a role in increasing independence, safety, and social connection in the family-based care model (Dawe, 2007b). Despite the fact that the study did not concentrate solely on the design of accessible technology, its objectives were different from the objectives of the current study. The current study explored how people with learning difficulties can be involved in software development and aimed to demonstrate how software developers can approach this field, the issues

they will face and how they can be overcome. The input for the design of accessible technology for the current study came solely from the users with learning difficulties themselves, while in the study described by Dawe part of the input came from the family carers.

Grammenos, Savidis et al. described the development of universally accessible computer games using an inclusive and participative design methodology (Grammenos, Savidis et al. 2009, Grammenos, Savidis et al. 2006, Grammenos, Savidis et al. 2005). The study involved people from many different disability groups including "those with mild memory or cognitive impairment" (Grammenos, Savidis et al. 2009). Grammenos, Savidis et al. (2009) observed, "considering the broadest possible population during design and with representatives from as many categories as possible participating and providing input to all the development phases" (p. 25). The games developed were intended to support multiplayer sessions in which people with diverse abilities could play at once.

'Cognitive impairment' was defined as follows, "a very broad category, which roughly includes difficulties in the performance of mental tasks that can range from limited and focused problems affecting a very specific cognitive function (e.g., the ability to understand math), to severe cases (e.g., brain damage) where the individual is unable to take care of any of his daily living activities" (Grammenos, Savidis et al. 2005, p. 2). This is a rather broad and not typical definition which seems to include all learning difficulty severity levels, along with other disabilities such as people with Traumatic Brain Injury. Even though Grammenos, Savidis et al. (2009) stated that they considered the broadest possible population during design with representatives from as many categories as possible they could have described their participants more explicitly and give more precise definitions of each of the disabilities they included, something they did not do. However, they stated that they involved "those with mild memory or cognitive impairment" (Grammenos, Savidis et al. 2009, p. 8) and therefore the study was considered by the researcher as relevant to this inquiry.

In order to design universally accessible games a structured design methodology was followed based on the 'unified user interface design' (Savidis and Stephanidis 2004). According to the study this type of methodology was highly participatory with a user-centred iterative process due to:

> "(a) the direct involvement of several representative end-users (gamers) with diverse characteristics, as well as domain experts (usability, accessibility, gaming, etc) is promoted throughout the overall lifecycle in order to continuously assess the design outcomes in each step; and (b) it is possible to return to a previous design step in case, for instance, more information is required, some design artefacts have to be revisited, or the design parameters must be specialized further" (Grammenos, Savidis et al. 2009) p. 8).

The aim of the study was to create a discipline for the development of accessible technology that would overcome the limits of existing approaches (Grammenos, Savidis et al. 2009) p. 6). The only mention relating to the participation of the users was the following, "The outcomes of the case studies show that the accessibility and usability of games can be greatly improved through the employment of a user-centred participatory development process that integrates usability evaluation" (Grammenos, Savidis et al. 2009) p. 26). Therefore, the study had a different objective compared to the current study, which concentrated on exploring the participation of the users and how software developers can approach the field of learning difficulties. Grammenos, Savidis et al. (2009) observed that the only methodology used was a structured design methodology and this suggests that the emphasis of the study was on technology. The study also involved people from various disability groups as well as usability, accessibility and game experts. The current study involved only people with learning difficulties and from only one severity level.

AEGIS (www.aegis-project.eu) was a big European Union accessibility research project which sought to develop an Open Accessibility Framework (OAF) consisting of open source accessible interfaces and accessibility toolkits for

software developers. It started in September 2008 and finished in February of 2012 with the release of the OAF D1.2.1, even though as of this writing dissemination of the results is still continuing (AEGIS Project 2008, AEGIS Project 2012a). The OAF consists of the following (AEGIS Project 2012b) [online]:

- A document describing the framework of things needed for 3rd generation accessibility, as validated by user and developer feedback
- A collection of largely open source prototypes and code deliverables implementing various aspects of the OAF

The AEGIS project had a budget of around 12 million Euros and it involved well known partners from the industry (Sun Microsystems, Vodafone, AOL) along with a big number of European and Canadian universities. It adopted a comprehensive approach to accessibility encompassing desktop as well as rich Internet applications and mobile devices (AEGIS Project 2008).

AEGIS engaged two categories of end-users, developers of IT, as well as people with disabilities (referred as 'end-users') that were experiencing one or more of the following mild to severe impairments (AEGIS Project 2009):

- Blind and low-vision users
- Motor impairment users
- 'Cognitive impairment' users
- Hearing impairment users
- Speech impairment users

The definition of learning difficulties was stated in a project deliverable titled *User groups' and stakeholders' definition and UCD Implementation Plan* (AEGIS Project 2009) p. 11). The learning difficulty severity level of the users engaged was also stated in the same paper. AEGIS involved users from all severity levels (AEGIS Project 2009) p. 13).

AEGIS used a holistic User-Centred Design development methodology in order to identify user needs and interaction models for different user groups (AEGIS

Project 2009, Van Isacker, Slegers et al. 2009). All developments were iteratively tested with a significant number of end-users, developers and experts in three phases and four pilot sites in Belgium, Spain, Sweden and the UK (AEGIS Project 2012b).

The research objectives of AEGIS as listed on the project website were the following (AEGIS Project 2012b) [online]:

- To develop tools which will allow developers to easily create accessible applications which leverage sets of pre-built and accessibility enabled user interface components for desktop, mobile, and rich Internet applications.
- To develop a set of embeddable assistive technologies for mobile devices in order to deliver a satisfying experience to people with disabilities.
- To develop a set of user agents for desktop and mobile devices which leverage and translate a cross-platform accessibility Application Programmer Interface (API) in such a fashion as to give users with disabilities the same utility and accessibility with rich Internet applications as they have with accessible desktop applications.

In addition to the above AEGIS intended to address two of the key purposes for which people use IT, for creating accessible documents and information, and for communicating with other people in an accessible manner. For document and information creation the project embedded the latest research into a popular, open source office suite in order to assist people with disabilities. Further, AEGIS addressed the issues of accessible document creation by building direct support for DAISY digital talking books and Braille and large print to that office suite (AEGIS Project 2012b).

To aid people with hearing impairments in communicating with one another and with people outside of that community the project built into mainstream communication software the ability to communicate using real-time-text. For people with speech impairments, AEGIS developed and demonstrated affordable and open source Augmentative and Alternative Communication (AAC)

applications that could be embedded into future mobile devices and desktop systems (AEGIS Project 2012b).

The final, core objectives of AEGIS were to address the economic barrier to inclusion and describe a framework of things needed for 3rd generation accessibility. The project developed the entire infrastructure, developer's tools and the assistive technology prototypes under an open source software license. This allows device manufacturers to extend, complete, and embed these assistive technologies into their products at no cost. It allows desktop systems to include real-time-text communications that interoperate with those on mobile phones and Personal Digital Assistants (PDA) as well at no cost. It also allows developers to obtain the developer's tools and user interface component sets to create accessible applications again at no cost. This open source policy is expected to bring down the cost of developing accessible technology. Finally, the OAF describes the framework of things needed for 3rd generation accessibility, as validated by user and developer feedback (AEGIS Project 2012b).

AEGIS was a big multi-national research project with a very broad set of objectives, which involved many universities. The study managed to create a framework of things necessary to develop accessible IT on desktops, the Web and mobile devices, not just for people with learning difficulties but for a range of other disabilities. AEGIS therefore involved people from a number of different disability groups and people with learning difficulties from all severity levels. AEGIS also created a collection of open source code for software developers to easily create accessible technology and without cost. Despite this broad set of objectives there are differences between the objectives of AEGIS and this study. The current study concentrated on the participation of users with learning difficulties from only one severity level. The main objectives of the study were to explore how people with learning difficulties participate during the software development process and to demonstrate how software developers can approach the field, the issues they will face, and how they can be overcome. These aims were not part of the objectives of AEGIS.

A number of other studies involved participants from various disability populations rather than people with learning difficulties. ECHOES is an ongoing interdisciplinary, multi-partner project which developed a Technology Enhanced Learning (TEL) environment targeting 5 to 7 year old Typically Developing (TD) and children with Autism Spectrum Disorders (ASD). The child users can explore and improve social and communication skills through interacting and collaborating with semiautonomous virtual characters (agents) and digital objects in socially realistic situations. The TEL system combines interactive multi-touch screens, gaze tracking cameras and intelligent agent-based context-sensitive interfaces to create a multi-modal environment that are adapted to the needs of particular individuals. The agents inhabit a 3D virtual sensory garden filled with interactive objects that can become the focus of (joint) attention between them and the child user. Children manipulate the environment through touch via a large multi-touch display. The system's computer vision detects where the child is looking at any given point. The interaction between the child and the agents are facilitated by a combination of learning activities that are designed around specific learning goals and interactive narratives that relate to different forms of joint attention and free exploration of the virtual environment (Porayska-Pomsta, Frauenberger et al. 2012, Foster, Avramides et al. 2010).

The system can provide new ways of investigating and supporting the development of social skills in children. The ECHOES system provides developmentally appropriate goals and methods of intervention that are meaningful to the individual child, and prioritises communicative skills. The ECHOES computational tools can be used to explore both theoretical research questions of importance to the understanding of autism (in particular in relation to joint attention) and the effects of TEL interventions. Joint attention is considered a key developmental building block and a necessary precursor for theory of mind (Porayska-Pomsta, Frauenberger et al. 2012). Joint attention constitutes the main focus of the learning activities within ECHOES. The ECHOES system also serves as a tool for teachers, parents, and practitioners to better understand particular children's strengths and difficulties, and the ways in which these may be addressed through technological intervention. It provides a platform for exploring

research questions relating to cognitive development, user modelling, and multi-modal interaction (Porayska-Pomsta, Lemon 2012).

The ECHOES project served as a case study for its proposed research methodology and delivered specific conclusions that contribute to the practice, theory and culture of research in this field. It explored where different disciplines overlap, in principle and intent, and examined ways in which the most significant aspects of each can be combined within a single methodological framework. It also presented the application of an interdisciplinary research methodology. Whilst the individual methods used were not necessarily new in themselves, the novelty of the approach was the way in which the different methods and techniques were combined and applied in the context of the developed ECHOES technology (Porayska-Pomsta, Frauenberger et al. 2012).

ECHOES II is a succession of the original ECHOES project and it has the following four new research goals (Porayska-Pomsta, Lemon 2012) [online]:

- Establishment of a comprehensive set of learning objectives and interactive activities capable of supporting children who follow different developmental trajectories in their ability to engage in social interactions.

- ECHOES II aims to employ a participatory, learner-centred design methodology whereby children, and their carers and teachers when appropriate, act as design partners with the researchers.

- Implementation of the TEL environment capable of scaffolding children's exploration and learning of social interaction skills at a number of different levels of social engagement, and of adapting to the needs and preferences of individual children.

- Deployment of a framework for assessing the effectiveness of the learning activities.

The ECHOES system was developed using an interdisciplinary participatory methodology and by involving TD and children with ASD along with their carers, teachers and practitioners throughout the development process. The design methodology was derived from a combination of Action Research, Participatory Design and applied Artificial Intelligence (Porayska-Pomsta, Frauenberger et al. 2012). ECHOES also adopted the Persistent Collaboration Methodology (PCM) (Conlon, Pain 1996) which draws from Action Research and advocates active and continuing collaboration between researchers, practitioners and technology experts in both the design and evaluation of TEL. It involves phases of four unordered cycles: observation, reflection, design and action. Typically there are a number of iterations of these cycles, which may stop and start anywhere within the process but the division between them is unclear. Each of the collaborators contributes distinctive knowledge and skills to the process, and can influence, and be influenced by other stakeholders (Porayska-Pomsta, Frauenberger et al. 2012).

The ECHOES Participatory Design process involved a series of workshops with primary schools and specialised units working with ASD children. The process facilitated the sensory exploration and idea generation for the design of the ECHOES system and its elements. Knowledge elicitation workshops with practitioners also informed the design of the learning activities and the implementation of ECHOES' intelligence, including its user model and pedagogic component (Foster, Avramides et al. 2010). Internal evaluation tested the various system components within the implementation cycles of the respective technologies (Porayska-Pomsta, Frauenberger et al. 2012).

The ECHOES team is working towards a large-scale intervention study where the system will be tested in a number of different schools. This final evaluation will take place in the context of the Social Communication Emotional Regulation and Transactional Support (SCERTS) framework (Prizant, Wetherby et al. 2006), an educational model for children with ASD which uses assessments and interventions designed to support emotional regulation, social communication and transactional support in a child's daily routine (Foster, Avramides et al. 2010). The impact of the TEL system will be assessed using pre- and post-tests of

various sorts, along with analysis of the recorded interactions (Porayska-Pomsta, Frauenberger et al. 2012, Foster, Avramides et al. 2010).

The ECHOES project combined Action Research and Participatory Design methodologies for the creation of accessible e-learning technology and it involved final users like the current study did. In both ECHOES and the current study, the individual methods used were not necessarily new in themselves and the novelty of their approach was the way in which the different methods and techniques were combined and applied in the context of developing accessible technology. However, despite the similarities there are differences between the ECHOES and the current study.

The current study concentrated on the participation of adult users with learning difficulties from only one severity level. The people involved in the current study were also working together as an empowered team of Health Trainers. ECHOES involved TD and children with ASD therefore the conclusions and results from ECHOES do not apply to the community of users of the current study. ECHOES also involved technology experts, carers, teachers and experienced practitioners, from a range of backgrounds while the current study did not.

Finally, the main objectives of the current study were to explore how people with learning difficulties participate during the software development process and to demonstrate and explore how software developers can approach this field, the issues they will face, and how those can be overcome. ECHOES paid importance to exploring where different disciplines overlap in principle and intent, and tried to examine ways in which the most significant aspects of each can be combined within a single methodological framework. It explored theoretical research questions relating to the understanding of autism, in particular joint attention, and the effects of TEL interventions. The ECHOES technology also provides a platform for exploring research questions relating to cognitive development, user modelling, and multi-modal interaction (Porayska-Pomsta, Frauenberger et al. 2012). There are therefore differences between the goals of ECHOES and the current study.

Moffatt, McGrenere et al. (2004) described a participatory design study conducted at the University of British Columbia, Canada, which involved users with aphasia in the development of technology. The developed technology was an Enhanced with Sound and Images Planner (ESI) Planner for use on a PDA. The ESI Planner is a multi-modal daily planner designed to enable individuals with aphasia to independently manage their schedules. It incorporates images, sound and text to represent appointment data. This triple modality makes it easier for people with aphasia to comprehend the information presented within the planner. The need for a daily planner which allows this community of disabled users to independently manage their appointments was identified from interviews with aphasic individuals, their caregivers and speech-language pathologists (Moffatt 2004).

The research was conducted in two phases: a design phase during which the ESI daily planner was iteratively developed with input from aphasic participants, and an evaluation phase where an experimental study was conducted to assess the effectiveness of the planner. The first phase used a participatory design methodology and was conducted in four steps: brainstorming, low-fidelity paper prototyping, medium-fidelity software prototyping, and high fidelity software prototyping. This methodology ensured that the produced technology would suit the needs of the users and be more accessible (Moffatt 2004). The current study used a similar methodology for technology development incorporating two phases like the study described by Moffatt, McGrenere et al. (2004). In the first phase of the current study Evolutionary Prototyping a participatory design methodology was combined with Participatory Action Research, while in the second phase the developed technology was evaluated in relation to accessibility and usability.

During the first phase of the research described by Moffatt, McGrenere et al. (2004), the intended users were continually involved in the development of the technology. Initially there was one participant who motivated the ESI planner. Unfortunately this particular participant died before the completion of the preliminary design. Thus, three replacement design members were recruited to fill

the initial participant's role and ensure continued progress (Moffatt, McGrenere et al. 2004). According to Moffatt, McGrenere et al. (2004) due to the large variability in impairments across people with aphasia, none of the surrogate individuals had exactly the same difficulties as the original participant; however all of them felt that improvements could be made to text-only daily planners.

During the second phase an exploratory experiment was conducted to evaluate the ESI Planner's interface in relation to the goals of developing a usable application which would better support the needs of aphasic users. This was not a traditional laboratory study as it had to meet the challenges inherent in working with aphasic users. Some of the constraints of a traditional laboratory study, like maintaining a consistent experimental environment, had to be relaxed in order to accommodate the special needs of this population. During this phase the ESI Planner was compared with an equivalent text only electronic planner, NESI Planner (Not Enhanced with Sound and Images Planner). The study wanted to specifically test the hypothesis that an interface using images and sound would better support aphasic users in appointment management tasks (Moffatt, McGrenere et al. 2004).

Nine aphasic individuals participated in the evaluation part of the study. One of them was female while the rest were male. The participants were between 47 to 86 years old and they had a range of educational backgrounds from high school completion up to post-graduate education. None of the nine participants were part of the participatory design phase and there were no caregivers involved in the evaluation part as the ESI Planner was designed to be used independently by aphasic users (Moffatt, McGrenere et al. 2004). The current study involved the same Health Trainers for both the design and the evaluation of the developed technology.

The aims of the study reported by Moffatt, McGrenere et al. (2004) were to develop general guidelines for working with people with aphasia in the development of technology, and design guidelines for accessible handheld technology (Moffatt 2004, Moffatt, McGrenere et al. 2004). These aims differ from the goals of the current study which were to explore the factors and

challenges which people with learning difficulties faced during involvement in software development and software use. The current study also explored the issues and challenges faced by software developers involving users with learning difficulties in design and how they were overcome.

While exploring factors and challenges which affected the involvement of people with learning difficulties in software development and how the developer could overcome them, the current study produced a number of general software involvement and design guidelines for the specific population of people with learning difficulties. Moffatt, McGrenere et al. (2004) reported several guidelines which emerged from their work and are relevant to other researchers working with people with disabilities. The guidelines suggested by the Moffatt, McGrenere et al. (2004) study are however more appropriate and specific to people with aphasia as it involved only people from this disability community. Contrary, the current study involved only people with learning difficulties.

Prior (2011) at the University of Dundee, UK, involved four adults with Severe Speech and Physical Impairments (SSPI) in the design of AAC software using User-Centred Design (Prior 2011). Assistive Technology and in particular AAC software is a field which in the past had little experience of User-Centred Design (Waller, Balandin et al. 2005). Waller, Balandin et al. (2005) suggested that by using User-Centred Design in the development of AAC aids could improve their usability. Prior (2011) however, maintained that the literature mentions many challenges as to how to involve people with SSPI in software development. Prior (2011) investigated methods currently used in software development and how they could be adapted and tackled for use with people with SSPI. The study found that with careful planning it was possible to involve people with SSPI in User-Centred Design. The lessons from this study were translated into recommendations.

Although the aims of the Prior (2011) study overlap with those of the current study, Prior involved people with SSPI and the results are more appropriate for this specific population of users. The current study involved a different community of disabled users, people with learning difficulties who were working together as an empowered team of Health Trainers.

The current study also combined two different methodologies, Evolutionary Prototyping, a software design methodology and Participatory Action Research a social science methodology appropriate for working with excluded populations. Thus, the current study involved people with learning difficulties in both the research and the software design. Even though the individual methodologies used were not necessarily new in themselves the novelty of the approach was the way in which the two were combined and applied in the context of developing technology. Prior (2011) used only User-Centred Design, a design methodology. Finally, the current study also explored the issues and challenges which the software developer faced while involving users with learning difficulties and how those issues were overcome.

Waller, Prior et al. (2011) described Dundee University's 'The Straight-Talking User Group.' This is a user centre within the School of Computing which aims to create a place where adults with complex disabilities can meet and work with researchers to explore and develop technology. The aforementioned study conducted by Prior (2011) took place at the participants' day and residential support centres and it showed that these centres were not ideally suited for research work which involved people with disabilities. There were often difficulties in finding space to work with participants away from the activity of the main rooms in the centre. It also proved challenging to set up technology in these centres (Prior 2011). The Straight-Talking user centre eliminates these problems. The centre's aims are, to train members in becoming 'expert end-users,' to raise awareness of AAC in the wider community and to provide a social space for members to meet. Another aim of the centre is to provide students and researchers with access to disabled expert users (Prior 2011, Waller, Prior et al. 2011).

The members of the user centre develop their computer skills and also provide feedback for accessibility research. The User Group was established in September 2010 with five adult volunteers with SSPI. In order to investigate the feasibility for such a centre, a pilot study with 4 participants was conducted. The user group of the pilot study was composed of 3 females and 1 male. All the members of the pilot study had previously been involved in research projects within the School of Computing and were known to the research staff. All four participants had cerebral palsy, used motorised wheelchairs and various types of AAC devices (Prior 2011, Waller, Prior et al. 2011). The pilot study showed that the concept of such a user centre was welcomed by members, as no one had turned down the offer of a place. The users were keen to engage in a variety of activities and they brought their own skills to the group (Prior 2011).

The User Group has been involved in various projects. It worked with MSc students to identify requirements for a Human-Computer Interaction (HCI) project. It evaluated prototypes of a talking photograph album software system developed by a student. It provided feedback to a design team on a workshop plan for people with SSPI, and it worked with a PhD student to develop a communication device. The centre also had one commission from outside the School of Computing at Dundee. A visiting researcher from another university wanted access to disabled adults in order to trial design techniques with SSPI users. The User Group also provided consultancy on the design of health questionnaires (Prior 2011, Waller, Prior et al. 2011).

The centre faces many challenges including supporting a larger number of members, dealing with a wider range of abilities and ensuring continued funding. Staffing has been a challenge as running the group requires additional staff. Disabled participants need support and guidance to engage in software design activities. A staff member acts as manager while other staff members within the AAC research group volunteer to support participants. Part of their job is to keep a diary, arrange sessions and ensure that participants are not overused as the demand on the group is increasing. It is anticipated that when the centre expands

additional staff will be hired to provide personal care and communication support. The number of members admitted to the centre at any one time will unfortunately be restricted to ensure that personal care needs can be met and there are enough assistants available (Prior 2011, Waller, Prior et al. 2011).

A further challenge is finance. The participants cannot be paid for their work due to benefit constraints, however, travel costs can and should be reimbursed and they can be high. Other challenges relate to ethical issues. Obtaining consent for each different project is time consuming and frustrating for users (Prior 2011, Waller, Prior et al. 2011). The group currently meets in the older-adults user centre but this is not the ideal space for wheelchair users due to the amount of space and the height of desks. The next step will involve developing space for use by adults with SSPI. Existing technology labs will need to be adapted for use by a larger group and adults with mobility impairments (Prior 2011, Waller, Prior et al. 2011).

According to Waller, Prior et al. (2011) the user centre is still in its infancy, but the pilot study has shown that the concept of such a centre could be of benefit to researchers and developers as well as the participants themselves. In the ten months of running the centre, there was a marked change in the participants' self-esteem and self-confidence. The participants also showed an increase in communication ability and desire for inclusion in the community. They were motivated to engage in a variety of activities and brought their own skills to the group. The participants exhibited insight into the needs of other disabled users and were able to reflect on design issues from different perspectives. Providing a challenging environment for adults with SSPI has the potential to afford them with motivation and opportunity. Such an environment raises the expectations of both participants and social care professionals of what SSPI people are able to achieve.

Black, Waller et al. (2012) described a study in which children with cerebral palsy and Complex Communication Needs (CCN) were involved in the development of a voice output communication aid system. The "How was School today...?"

system helps children with CCN to create and relate oral narratives about their school day. The system uses data-to-text technology to generate narratives from sensor data. According to Black, Waller et al. (2012) all up to date systems faced the fundamental limitation that the narrative content had to be authored ahead of time by the user or a carer and this was a laborious process. The "How was School today...?" system overcomes this problem by authoring some draft content itself, based on data about the user's activities acquired from sensors and transactional databases.

Close collaboration with users in the design and implementation was essential in order to successfully develop this new way of supporting communication for children with CCN and in order for the technology to be embraced (Black, Waller et al. 2012). The development of the prototype system therefore followed a User-Centred Design process in which staff, parents and children from a special school were involved during all stages of the design process. The special school catered primarily for children with cerebral palsy, between the ages of 4 and 18. Observations, interviews and prototyping were used to ensure that stakeholders were involved in the design of the system (Black, Waller et al. 2012).

The information gathering process led to the identification of system requirements and design ideas. Black, Waller et al. (2012) described that after discussing the potential of using sensor data to generate narratives with school staff and parents, they engaged with them to understand the target users, their needs and their environment. This was achieved by creating participant profiles of potential users, observation and interviewing. The school therapists were asked to supply information about the capabilities and communication needs of potential participants in the study along with possible applications of the planned prototype. Parents were invited to provide input during parent council meetings. Ten parents responded to an invitation to attend a presentation about the project and were shown a demonstration of the concept prototype. A questionnaire was later sent out to the parents of three children who were identified as potential participants by staff. The questionnaire targeted both parents and siblings and included both multiple choice and open-ended questions. The three children included in the

sample had quadriplegic cerebral palsy with severe physical disabilities and were aged between 12 years 11 months and 14 years 11months. Two were non-speaking, while the third had intelligible dysarthric speech characterised by the use of stock phrases. The children were dependent on others to push their manual wheelchairs. All three participants had limited to no functional use of their hands and used a head switch with row/column scanning when accessing a computer and communication aids. Their literacy varied from non-reading over recognising familiar words to being able to type short sentences. All three children were able to recognise symbols. The two non-speaking children used symbol-based AAC systems to indicate needs and wants (Black, Waller et al. 2012).

The goal of the research study was to develop a new type of AAC device which supports the generation and narration of "oral personal narrative" for children who are developing language and who do not have functional literacy (Black, Waller et al. 2012). The "How was School today...?" project was undertaken to evaluate the potential of using data-to-text technology to support conversational narrative for children with severe speech and physical impairments.

The system was evaluated twice in order to assess the potential of the prototype to support interactive conversational narrative and to identify areas for further development. During an initial one-week evaluation two participants and school staff used the system with intensive technical and pragmatic support from the researchers. A more independent use of the system by three children, school staff and parents was evaluated during a second two-week period. Support by the researchers during the second evaluation was limited to occasional visits and problem solving.

During the first evaluation the system was used successfully to generate stories utilised in interactive communication sessions. During the second evaluation it became clear that the system was still far from being able to be used independently without intensive technical and pragmatic support or training. The evaluations however showed that the prototype system, which automatically

generates utterances, has the potential to support disabled individuals to participate better in interactive conversation (Black, Waller et al. 2012).

Black, Waller et al. (2012) reported success in the implementation and evaluation of a "proof-of-concept" system that not only enabled two nonspeaking individuals to tell people about their day at school but it was also used by a speaking child with cerebral palsy who was unable to relate experience due to memory difficulties. Despite the many issues that needed to be addressed, the results of the evaluations were very encouraging. The system enabled the children to engage in storytelling and control the conversation instead of being passive communicators who simply responded to questions. They were also able to initiate topics, provide relevant information, evaluate how they felt and respond to interventions by the communication partner. For nonspeaking children, this was a major achievement and one that has the potential to significantly enhance the quality of their life (Black, Waller et al. 2012).

There are obvious differences between the current study and the one described by Black, Waller et al. (2012) even though both involved people with special needs for the design of technology. Black, Waller et al. involved children with cerebral palsy and CCN. Two of the children were non-speaking, while the third had intelligible dysarthric speech characterised by the use of stock phrases. The children had physical disabilities and were dependent on others to push their manual wheelchairs. They used switch access to control a computer and their literacy varied from non-reading over recognising familiar words to being able to type short sentences.

The current study involved four adult users with learning difficulties who could both speak and write and could interface with a computer using a mouse and keyboard like most typical users. They did not have any physical disabilities and they were working together as an empowered team of Health Trainers. Therefore the conclusions and results of Black, Waller et al. do not directly apply to the people involved in the current study as the two samples were different. However,

in both studies some of the findings relating to work which involves people with special needs for the design of technology were similar.

Finally, the goals of the Black, Waller et al. (2012) study were to develop a new type of AAC device which supports the generation and narration of "oral personal narrative" and to evaluate the potential of using data-to-text technology to support conversational narrative for children with severe speech and physical impairments. These goals emphasise technology design, while the goals of the current study were to explore the participation of people with learning difficulties in software development and the challenges and issues which both the Health Trainers and the developer faced and how they were overcome.

As shown, the presented studies primarily had technology oriented objectives and most of them used only product design methodologies. Only the study described by Dawe (2007a) used two different methodologies, ethnographic and evolving technology probe, but the study had different objectives from the objectives of the current study. The current study combined two different methodologies, Evolutionary Prototyping a software engineering methodology which guided the development of the software system and Participatory Action Research used to guide the research process and work with people with disabilities. The major objectives of the current study were to explore how people with learning difficulties could participate in the software development process and how software developers can approach this field.

The TATE project described by Aspinall (2007, 2008) and the study described by Dawe (2007a) did not concentrate solely on technology and their objectives spread into the sociological domain. However, despite the social dimension, their aims were different from the aims of the current study. The aims of the AEGIS study were broader in scope compared to the aims of this study; however none of them tried to concentrate on how people with learning difficulties participate in software development. There is therefore a difference between the main objectives of all the above mentioned studies and the current study.

The current study concentrated on people with *mild* learning difficulties only, while the above presented studies involved people from a variety of severity levels. Moreover, some of the above studies involved users from a number of different disabilities instead of just people with learning difficulties. A number of scientists support that universal accessibility may not be an attainable goal, and that trying to concentrate on the creation of accessible technology for only one disability group like the current study did, may be a more realistic goal (Kelly, Sloan et al. 2005, Kelly, Nevile et al. 2009, Kelly, Nevile et al. 2008). On this Dickinson, Gregor et al. (2003) mentioned, "At the same time there is a need to recognise that 'design for all' and 'universal design' are by no means always desirable or attainable goals" (p. 67).

Additionally, some of the above studies involved people with learning difficulties along with their tutors, their family members or their carers, while the Grammenos, Savidis et al. (2009) study involved usability, accessibility and game experts as well. Therefore, in the presented studies the developed technology was not guided solely with the input of people with learning difficulties. The current study developed technology with the input of people with learning difficulties only.

2.10 Conclusion

Several studies already involved people with learning difficulties in software design and development processes. All the previously described studies however had different aims compared to the current study. None of the studies concentrated on the participation of the users itself. There is no literature that concentrates on the experience of involving people with learning difficulties in software development, which systematically studies how such users can be involved. There is also lack of research which tries to explore how software developers can approach the field of learning difficulties, the issues they will face and how those issues can be overcome. None of the reviewed literature presents a systematic account of the challenges that people with learning difficulties face during involvement or factors that affect participation like the current study does. There

is therefore lack of research that concentrates on the participation itself, and how people with learning difficulties can be involved in software development.

The involvement of people with learning difficulties in the software development process should not happen in a few research investigations only. Involvement should instead become more widespread including more research studies and possibly affect the whole software industry. In order to include people with learning difficulties as equal members of society most IT must become accessible to them and not just a few specialised applications. For this to happen, more researchers, developers and society in general must be convinced of the abilities of people with learning difficulties and how to include them in software development. This will remove the social barriers imposed regarding their involvement in software development processes. For these reasons the present study tries to answer the three research questions presented in Section 1.5.

Chapter Three: Methodology

3.1 Introduction

This chapter starts by examining positivism and interpretivism the two most important social science philosophical perspectives. This is done in order to contextualise Hammersley's 'subtle realism' the paradigm adopted for the present study. Hammersley's 'subtle realism' falls under a constructivist approach and therefore constructivism is also discussed. The chapter also considers Participatory Action Research, the methodology which the study adopted. A short history of Participatory Action Research is presented along with basic principles and criticism. Next, the sample and its limitations are described, followed by the ethical considerations that the study had to address. Finally, the data collection methods used and thematic content analysis are also described.

3.2 Design and Social Science Methodologies

The social sciences investigate society and social behaviour, or the relationship of individual members within society. Thus the social science researcher is usually located within a network of stakeholders who all have different understandings and ways of knowing about the world and the topic which is being investigated (D'cruz, Jones 2004). Given this fact it is important for the social researcher to be aware of any differences and tensions that may be generated through power and knowledge about the research being undertaken. Within social science the ethics and politics of the research are important (D'cruz, Jones 2004). An investigation into an area of the social world, for example, demands the adherence to a specific ethical code in order to guide the researcher and minimise the impact of the research on the participants (Kimmel 1988). Moreover, the conduct of research requires setting research agendas, developing research questions, gathering and analysing data and choosing evaluation methods. Therefore, social science researchers and the methodologies they use reflect on all the above.

Designers, however, follow a completely different perspective. There is a difference, for example, between how designers and how social scientists involve end-users. When designers involve users their primary aim is to create usable technology rather than to gather data to conduct research, and the methodologies they use reflect that. Newell and Gregor (2000) observed that User-Centred Design enables developers to focus on the users as the heart of the design process, and involving disabled people as a normal part of such design gives them the dignity of being treated in the same way as any other users of products. There is the possibility, however, of a tension between issues of research goals and design methodologies. Design methodologies typically do not deal with the ethical and other challenges of involving people with disabilities. They concentrate on technology development, and the role of the final users is limited to providing input in order to make the product more usable rather than to setting research agendas, developing research questions, or choosing evaluation methodologies (Newell, Gregor 2000).

As the purpose of the current study was both to design technology and to conduct research by involving people with disabilities, the researcher decided that a

software design methodology alone would not be sufficient. Instead two different methodologies were combined. Participatory Action Research, described in the following sections, was intended to guide the overall social research approach. (Certain real world limitations described in Section 3.4.6 were encountered while applying Participatory Action Research in practice). Evolutionary Prototyping, which is described in Section 4.4.1, was used to guide the software design and development process.

3.3 Research Paradigms

This section examines the two main social science philosophical positions and their implications for both the researcher and for the actual research undertaken. The set of assumptions about the social world or the paradigm of the researcher is a very important issue for any research study. This paradigm will determine the methods used and even affect the research questions. Johnson and Duberley (2000) define a paradigm as a set of beliefs shared by a community and which "specifies the character of the world and its constituent objects and processes and which acts as a 'disciplinary matrix' by drawing the boundaries for what the community's work is to look like" (Johnson, Duberley 2000).

Guba and Lincoln (1999) summarise an 'Inquiry paradigm' as made up of three fundamental questions (p. 37):

1. The ontological question, or the form and nature of reality: 'What is there that can be known about?'

2. The epistemological question, 'What is the nature of the relationship between the knower or would be knower and what can be known?'

3. The methodological question, 'How can the inquirer go about finding out whatever he or she believes can be known?'

Although Guba and Lincoln divide an inquiry paradigm into three distinct questions, these concepts are strongly inter-related. Morgan and Smircich (1980)

recognize an ontology *continuum* ranging from those who support an objectivist perspective and view social reality as a concrete structure (Positivist) to those who view reality from a subjectivist stance seen as a projection of the human imagination (Interpretivist). The continuum is separated into six identifiable stages as shown in Figure 3.1. Those occupying different places on this ontological continuum are therefore likely to possess different views as to the nature of reality and true knowledge.

Continuum of core ontological assumptions

Reality as a concrete structure	Reality as a concrete process	Reality as a contexual field of information	Reality as realm of symbolic discourse	Reality as a social construction	Reality as a projection of human imagination

POSITIVIST   INTERPRETIVIST
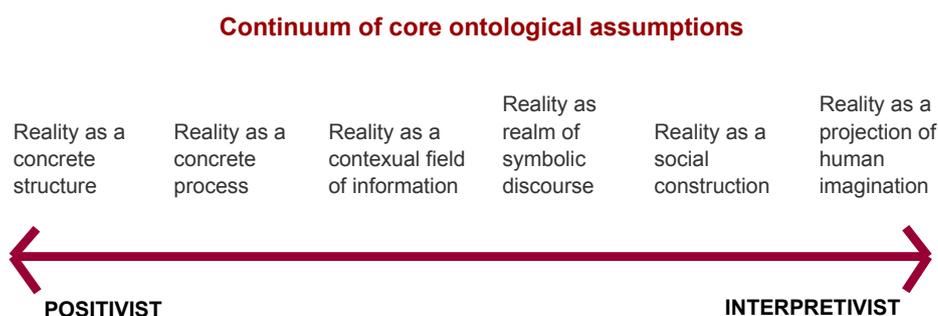
Source: Adapted from Morgan and Smircich (1980)

Figure 3.1 - Morgan and Smircich's six stage ontology continuum (Source: Adapted from Morgan and Smircich, 1980).

These ontological and epistemological issues linked to the philosophy of the research, influence the various methodologies and methods in social science research. Morgan and Smircich (1980) contended that "the choice and adequacy of a method embodies a variety of assumptions regarding the nature of knowledge and the methods through which that knowledge can be obtained, as well as a set of root assumptions about the nature of the phenomena to be investigated" (p. 491).

Most scientific debates focus predominately on which of these two extremes, positivism or interpretivism, is the most appropriate when investigating the social world (Lincoln, Guba 1985, Collis, Hussey 2003) although many would argue that such a debate is stale and unnecessarily polarised (Pawson, Tilley 1997). At the one end positivism assumes that the social world is a concrete structure of determinate relationships between its constituent parts, which can lend itself to accurate measurement and observation. Observation must be objective, value-free, neutral, capable of and subject to, empirical testing (Lincoln, Guba 1985, Collis,

Hussey 2003). As in the natural sciences the aim of a positivist approach is to generate causal relationships or laws that allow scientists to predict or control their environment. It is, however, questionable that such an approach to the social sciences achieves a satisfactory level of understanding. The social sciences deal with human behaviour and interactions and depend on human character and beliefs. The use of techniques invented for the study of the natural world is not always appropriate (Guba, Lincoln 1999, Ritchie, Lewis 2003).

At the other extreme end of the ontological continuum lies an interpretivist perspective. Researchers who adopt an interpretivist paradigm assume that social reality is merely a creation of consciousness. Such a methodology differs from positivism in that human or social action should be distinguished from the movement of physical objects and that such action is seen as inherently meaningful (Collis, Hussey 2003). The philosophical thought it therefore embraces attempts to explain the social world from the point of view of the actors within it. Table 3.1 adapted from Collis and Hussey presents the main features of the positivist and interpretivist paradigms, although as already suggested, it is helpful to think of them as being on a continuum.

Table 3.1 - The main features of the positivist and interpretivist paradigms (Source: Adapted from Collis and Hussey, 2003).

Features of the two main opposing paradigms	
Positivistic Paradigm	Interpretivist Paradigm
• Tends to produce quantitative data • Uses large samples • Concerned with hypothesis/theory testing • Data is highly specific and precise • The location of the research is artificial (i.e. lab) • Reliability is high • Validity is low • Generalises from sample to population	• Tends to produce qualitative data • Uses small samples • Concerned with generating theories • Data is rich and subjective • The location of the research is natural • Reliability is low • Validity is high • Generalises from one setting to another

A positivistic paradigm attempts to ensure that any concepts used can be described in such a way that they can be measured. As a consequence of the need to conduct statistical analysis large samples are used quite often. The results from a representative sample can then be generalised to a whole population. Positivism also expects researchers to be objective and external to the process and that they typically formulate hypotheses. Researchers that follow a positivistic paradigm in their analysis generally seek associations and/or causality (Lincoln, Guba 1985, Collis, Hussey 2003, Guba, Lincoln 1999).

Alternatively researchers that follow an interpretivist paradigm typically examine small samples. The aim is to acquire deep understanding of the phenomenon under consideration and it is possible to conduct research even with a sample of one (Collis, Hussey 2003). An interpretivist approach may use a number of different research methods in order to obtain different perceptions of the phenomena and in the analysis look for patterns which may be repeated in other similar situations (Collis, Hussey 2003, Guba, Lincoln 1999).

The normal process under a positivistic paradigm is to establish an appropriate theory or construct a hypothesis, which is then tested using statistical analysis. With an interpretivist approach typically there is no relevant existing theory and the investigation is carried out in order to construct one to explain the phenomena or to describe different patterns which emerge in the data (Collis, Hussey 2003, Ritchie, Lewis 2003).

In a positivistic paradigm, it is essential that the data used is highly specific and precise. Therefore the data collected will be mainly quantitative. Considerable rigour is applied in order to ensure the accuracy of the measurement, because measurement is an essential element of the research process under this paradigm. Under an interpretivist paradigm, the emphasis is on the quality and depth of the data, therefore the data collected will be mainly qualitative. The data is often referred to as being rich because it captures the richness of detail and nuance of the phenomena under study (Lincoln, Guba 1985, Collis, Hussey 2003, Guba, Lincoln 1999).

The location of the research in a postitivistic paradigm is quite often artificial like for example in a laboratory where a controlled experiment can be conducted. By placing the research in a laboratory it is possible to isolate, control and measure the specific variables under investigation. Under an interpretivist paradigm, the research typically takes place in a natural setting, in the field where the phenomena under investigation take place. Typically the researcher does not attempt to control any aspects of the phenomena (Lincoln, Guba 1985, Collis, Hussey 2003).

Repeating a research study to test the reliability of the results is known as replication. In positivistic studies, like in the natural sciences, reliability is very important and the endeavour is for it to be high. Under an interpretivist paradigm the criterion of reliability may not be given so much status, or it may be interpreted in a different way. It is not important whether qualitative measures are reliable in the positivistic sense but whether similar observations and interpretations can be made on different occasions and / or by different observers (Collis, Hussey 2003, Guba, Lincoln 1999).

Validity is the extent to which the research findings accurately represent what is really happening in a situation (Collis, Hussey 2003). Research errors such as inappropriate procedures, poor samples and inaccurate or misleading measurement may occur which may undermine validity. Because a positivistic paradigm concentrates on the precision of measurement and the reliability of the results, there is always a danger that validity may be very low. Conversely, an interpretivist paradigm targets at capturing the essence of the phenomena and extracting data rich in its explanation and analysis. The researcher's aim is deep understanding and full access to the knowledge and meaning of those involved in the phenomenon, consequently validity is high under such a paradigm (Collis, Hussey 2003, Guba, Lincoln 1999, Ritchie, Lewis 2003).

In social science research generalisability is the extent to which you can come to conclusions about a population based on information drawn from a sample (Vogt

1993). Positivistic studies use statistics in order to generalise results from a sample to a population. Therefore samples are chosen very carefully so that the characteristics found in the sample will be present in the population from which the sample has been drawn (Gummesson 1991).

However, using statistics to generalise from a sample to a population is just one type of generalisation (Gummesson 1991). In an interpretivist study a researcher may be able to generalise from one setting to another (Collis, Hussey 2003). Norman (1970) supported that it is possible to generalise from a very few cases, or even a single case, if your analysis has captured the characteristics and interactions of the phenomena under investigation. This type of generalisation is concerned with the patterns, concepts and theories which have been generated in a particular environment and whether they can be applied in other environments. To do this a researcher must have a comprehensive understanding of the activities and behaviour under study.

3.3.1 Research Position Adopted in this Thesis

The aim of the present work was to explore how people with learning difficulties get involved in software development and if they could use a software system developed with their involvement. The literature review has shown that there is lack of research in this area therefore the present study is *exploratory* and *inductive* in nature. The aim was to look for patterns and ideas and the focus was on gaining insights and familiarity with the phenomenon. The research was concerned with establishing and searching for evidence of phenomena in terms of user involvement, rather than making claims about absolute truths or causality. As a result, it was necessary to gain deep understanding and give meaning to the phenomena. Therefore the study adopted an interpretive paradigm and the methods used were qualitative in nature.

A constructivist approach was adopted which sees the social world as constructed through social interaction. There is not a single truth or reality but only interpretations of reality, "people construct the world, both through their

interpretations of it, and through the actions based on those interpretations"
(Huberman, Miles 2002).

Within a constructivist paradigm there are, however, a number of different
perspectives. On the one extreme, constructivism takes a relativist view on the
realist/idealist debate spectrum and supports that there is no external reality
independent of our beliefs and understanding (Ritchie, Lewis 2003). This view at
the idealist end of the debate spectrum also holds that there is no single shared
social reality, but rather a series of alternative social constructions and that each of
these perspectives is equally valid (Ritchie, Lewis 2003).

At the other end of the debate spectrum is the extreme realist view, a positivist
view known as 'naive realism' which makes a clear distinction between beliefs
and understanding about the world and an external reality (Ritchie, Lewis 2003).
The researcher finds this view to be unsustainable as he believes that knowledge
of the social reality is contextual and constructed by scientists within a cultural,
economic and political context.

Between these two extremes there are a number of other intermediate positions.
The researcher is inclined towards Hammersley's 'subtle realism' (Hammersley
1992, Hammersley 1990). Subtle realism supports that all research involves
subjective perceptions and observations. It admits that different methods and
different researchers will produce different pictures of the participants being
studied, however, this position is not taken to the extent of the extreme relativists
(Duncan, Nicol 2004). Subjective perceptions and observations do not exclude the
existence of independent phenomena and that objects, relationships and
experiences can be studied (Hammersley 1992).

Subtle realism falls under an interpretivist position (Guba, Lincoln 1999), and this
is the driving force behind the choice of methodology and methods for the present
inquiry. As subtle realism supports that all research involves subjective
perceptions and observations, reflexivity is very important, as indeed it is in all
interpretivist approaches (Flick 1998). The researcher's personal experiences,

knowledge and beliefs could affect his understanding and interpretation of the data and influence the findings. The researcher tried to be reflexive in order to minimise these. During the whole process of data gathering he was keeping a research journal in which among other things he was also recording his feelings and how they might bias and affect his understanding of the phenomena. Similar reflexive notes were also kept along with his observation notes. During the analysis of the data the researcher considered the above mentioned reflexive notes. Another important aspect of the study was that part of the data was analysed by the Health Trainers as described in Section 3.7.2. The emerging findings were also made available for critical inspection and validation by the participants according to reflexivity requirements.

The philosophical approach explained above is also consistent with the evolving model of disability. As presented in Section 2.4 initially the medical model of disability had focused on the impairment itself. This model was replaced with the social model of disability which supported that even though an individual's medical condition is important and disabling, it is also important to recognise that society itself disables a person (Barnes 1991, Oliver 1996, Oliver 1990). According to Shakespeare (2001) however, later writers supported that the social model of disability should evolve further maintaining that everyone is impaired at some point in their lives even if it is only for a short period of time. The fact that we can change the way we view disability from one model to another, a perspective change which affects our behaviour and understanding, is evidence that social reality is indeed a construction of the mind, something which interpretivists support. The above general philosophical approach to a social science inquiry is also consistent with Participatory Action Research the adopted methodology of the study.

3.4 Participatory Action Research

In this section Participatory Action Research will first be put in context by presenting its history. The methodology will then be defined and its basic

principles along with criticism for it will be discussed. Finally, a description of why it is appropriate for this research study will be presented.

3.4.1 Short History

The origins of Participatory Action Research are usually traced to work in the fields of education by John Dewey, on race relations by John Collier and in psychology by Kurt Lewin and Eric Trist (McNiff, Whitehead 2006, O'Brien 1998). Dewey supported the democratisation of education and knowledge creation, urging educators not only to teach facts but also how to think and how to actively collaborate in personal knowledge creation. He was among the first to apply participatory methods to solve practical social problems and was committed to issues of participative democracy (Pasmore 2001). Dewey recommended five phases of reflective thinking used to deal with practical problems: suggestion, intellectualization, hypothesizing, reasoning and experimentation. These five phases lead to conceptual inquiry as a cyclical process and are a precursor to the cyclical process of *plan*, *action* and *evaluation* later described by Lewin (1951).

John Collier was a community development activist who became Commissioner in the United States Bureau of Indian Affairs (BIA) from 1933 to 1945 (Pasmore 2001). The major responsibility of the BIA was to improve the relations between native and non-native Americans (Pasmore 2001). Collier concluded that neither legislation nor the observations produced by traditional research could lead to changes in the beliefs of study participants and resolve issues. Therefore, he advocated engaging members of the affected communities in research activities whose purpose was to find acceptable solutions (Pasmore 2001). In 1945 Collier established the Institute for Ethnic Affairs whose charter proposed that social scientists should engage in Action Research. He described Action Research as having been the key organising principle of the BIA in its efforts to address race relations (Pasmore 2001).

Kurt Lewin, a German social and Gestalt psychologist, is described as the intellectual father of Action Research and of contemporary theories of applied behavioural science and planned change (O'Brien 1998, Cooke 1999). He was

concerned with social problems in the beginning half of the twentieth century and focused on participative group processes for addressing crises, conflict and change, primarily within organizations. He was initially associated with the Centre for Group Dynamics at the Massachusetts Institute of Technology (MIT) but later went on to establish his own National Training Laboratories (O'Brien 1998). Lewin was the first to construct a theory of Action Research which described the process cycle of *plan*, *act* and *reflect* (Figure 3.2) (O'Brien 1998, Lewin 1951). This was the precursor to all subsequent models and it made Action Research an acceptable and legitimate approach to research inquiry (McKernan 1991).

The Participatory Action Research Cycle
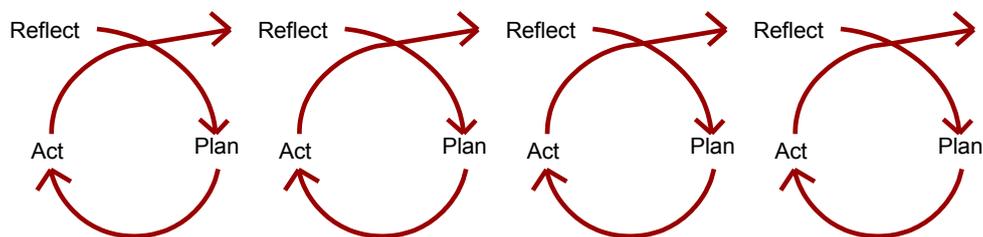
Figure 3.2 – The Participatory Action Research cycle of plan, act and reflect (Source: Author created)

Eric Trist was another major contributor to the field during the immediate post-war era. He was a social psychiatrist at the Tavistock Institute of Human Relations in London. He and his group engaged in applied social research, initially for the repatriation of German prisoners of war and tended to focus more on large scale and multi-organizational problems (O'Brien 1998).

Koch and Kralik (2006) also observed the work of Paolo Freire with oppressed people in Brazil, in the latter half of the twentieth century. Paolo Freire was an educationalist who broke with the tradition of gathering data on oppressed people and instead carried out research with participant involvement. By placing capabilities in the hands of disenfranchised people he encouraged them to transform their lives. The methodology that Paolo Freire developed was considered a threat to the establishment and he was forced to leave Brazil for

twenty years. With his work however he helped to empower countless impoverished and illiterate people (Koch, Kralik 2006).

Participatory Action Research has its origins in social justice, international development, educational philosophy and psychology. From its beginnings Action Research as a practice, has been adopted in a number of disciplines including community development, education, business and management, organizational development, public health and the social sciences (Reason, Bradbury 2001). The family of Participatory Action Research approaches are characterised by a cyclical inquiry process along with practical knowledge and action outcomes. This type of approach to research is typically undertaken to give a voice to and to recognise the expertise of the people experiencing the research problem (Reason, Bradbury 2001).

Today Participatory Action Research is a well known and established social research methodology. There is an increasing number of Action Research like processes and methodologies in various disciplines and professions which are known under a plethora of names such as Action Science, Appreciative Inquiry, Soft Systems Methodology, Constructivist Research, Collaborative Inquiry, Emancipatory Research, Action Learning, and Contextural Action Research (O'Brien 1998, Reason, Bradbury 2001). In rural community development it is commonly referred to by such terms as Rural Rapid Appraisal, Participatory Rural Appraisal or Farmer Participatory Research (Selener 1997, Chambers 1997) and there is a growing community of action researchers interacting through and contributing to several dedicated journals and an annual World Congress (Dick 2004).

3.4.2 Definition

In the plethora of terms used the most common are Action Research, Participatory Action Research and Participatory Research. These terms are often used interchangeably and share similar characteristics (Israel, Schurman et al. 1992). They differ however, "…in the degree of participant influence over the research process and in the emphasis on action relative to research and theory building"

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(Israel, Schurman et al. 1992, p. 75). Action Research stresses action and reflection throughout the research process, Participatory Research stresses community participation and Participatory Action Research contains elements of both (Loewenson, Laurell et al. 1995, Barnsley, Ellis 1992).

There is not a single and universally accepted definition established for Participatory Action Research (Loewenson, Laurell et al. 1995) but the different definitions are all variations on the same theme. While theoretical differences sometimes do exist, there are three elements generally understood to be common to Participatory Action Research related approaches: research, participation, and action (Greenwood and Levin, 1998, p. 7).

Macauley's (1999) definition is the following:
> "Participatory Action Research attempts to negotiate a balance between developing valid generalisable knowledge and benefiting the community that is being researched and to improve research protocols by incorporating the knowledge and expertise of community members" (p. 774).

O'Brien (1998) defines Action Research as:
> "Action research...aims to contribute both to the practical concerns of people in an immediate problematic situation and to further the goals of social science simultaneously. Thus, there is a dual commitment in Action Research to study a system and concurrently to collaborate with members of the system in changing it in what is together regarded as a desirable direction. Accomplishing this twin aim requires the active collaboration of researcher and client, and thus it stresses the importance of co-learning as a primary aspect of the research process" (p. 2).

Ritchie (1996) acknowledges that the main difference between Action Research and Participatory Research,

"...lies in the description of the relationship between the instigating researcher and the other participants. In action research with teachers and managers the instigator is most likely to be one of their own kind, with shared values and similar use of language. In participatory research, the instigator may be from a different sub-culture if that person is better resourced and more highly educated than the participants" (p. 207).

Even though the various definitions are slightly different especially among the three different terms observed, all of them agree that Action Research participatory approaches have the following common characteristics: They attempt to develop valid knowledge in order to further the goals of social science and at the same time benefit the community that is being researched by finding solutions to practical problems or concerns that the participants face. This is done by the active involvement of the community and by incorporating the expertise of the people experiencing the research problem because they are seen as the experts on the field.

3.4.3 Basic Principles and Characteristics

The family of Participatory Action Research methodologies are characterised by a cyclical inquiry process (Figure 3.2) with practical knowledge and action outcomes. A primary purpose of Participatory Action Research is to produce knowledge with practical applications and which is useful to people in the everyday conduct of their lives (Reason and Bradbury, 2001). In the current study for example, action is taken as people with learning difficulties are discriminated against by the software industry. Even though this type of action was decided by the researcher and the supervisory team instead of the Health Trainers (for the reasons described in Section 3.4.6), they suggested that one reason they decided to volunteer was, because the study would benefit their community. It was hoped that the actions of the inquiry would work towards making Information Technology (IT) more accessible to people with learning difficulties and thus produce knowledge with practical applications.

Another practical application useful to the Health Trainers was the development of a specific software system that they needed to enhance the service they provided. The result was an accessible system which offers practical benefits and is utilised in the Health Trainers' occupation. Through the process the Health Trainers gained the skills to use this and potentially other similar systems.

Another principle of Participatory Action Research is that people are more likely to modify their behaviour when they have understood the circumstances through involvement in the identification and analysis of problems they face. Furthermore, they are more likely to positively respond to decisions that they have been involved in taking (Reason and Bradbury, 2001). In the case of this inquiry for example, they identified problems they face when trying to use a software system and as a result they managed to overcome them by offering input for the development of an accessible system. As the software system was developed with their involvement they were more willing to use it.

Participatory Action Research also intends to be democratic, equitable, liberating and life enhancing (Reason and Bradbury, 2001). Some other themes that characterise it are collaboration through participation and social change (Reason and Bradbury, 2001). According to Stringer (1996) it is a collaborative approach to inquiry enabling participants to systematically investigate problems and issues that are important to them, to build up accounts of their situation and to plan and take action to deal with the problems. In practice the cycle of research starts with at least one group of stakeholders who have a concern and then participants are facilitated through cycles of planning, action and reflection (Stringer, 1996). Action researchers acknowledge that theory alone has very little power to create change and that there actually needs to be interplay between theory and practice. The interaction between theory and practice is necessary in order to bring about change (Reason, Bradbury 2001).

The cycling between action and reflection is also needed in order to find a balance between excessive theorizing and unfocused activism. As Reason and Heron

(2010) put it, "Too much time in reflection is just armchair theorizing; too much time in action is mere activism" [online]. This cyclic nature helps responsiveness and rigour because the early cycles are used to help decide how to conduct the later cycles. In the later cycles the interpretations developed in the early cycles can be tested, challenged and refined (Dick 2000).

The traditional role of the external researcher, which is to determine objective truths, must be changed because the nature of the problem is not yet known. The researcher becomes a facilitator or co-researcher working with the participants' pursuit of understanding and consensus for action in order to find solutions to their situation (Stringer, 1996).

Another parameter of Participatory Action Research observed in the literature is the fact that it is emancipatory or empowering because research participants are partners in the process. Reason and Bradbury (2001) describe "empowerment through consciousness raising" and the "production of knowledge and action directly useful to a community" as one of two primary objectives of this approach (p. 187). This is particularly important for marginalised groups such as people with learning difficulties. However empowerment is a challenging concept and not a guaranteed outcome of participatory research. Johnson and Mayoux (1998) warn against the idealisation of the empowering capacities of participatory methods. Many researchers aim for their research to be emancipatory but question whether they really do achieve this ideal (Johnson, Mayoux 1998).

3.4.4 Criticism

Participatory Action Research has undoubtedly gained considerable acceptance in fields where the production of new knowledge also leads to practical solutions to issues of concern (Greenwood, Levin 1998). However, the central importance given to local community experts who possess insider knowledge and their involvement in the research process, which is an important distinction compared to conventional research, has raised criticism. The major concerns include those of quality and validity. This criticism is based on claims that the approach is not

'scientific,' and that it is value laden, subjective and not generalisable (Herr, Anderson 2005, McTaggart 1998, Feldman 2007).

The claim that Participatory Action Research is not scientific is based on the positivist / interpretivist debate. Participatory Action Research is positioned within a constructivist paradigm which supports that science or the positivistic methodologies, are valid forms of inquiry under certain circumstances, like for example, when studying the natural world but not when dealing with the complex social reality. For validity, Brydon-Miller, Greenwood et al. (2003) contended that knowledge outputs from Action Research are tested by the people who have the greatest stake in the issue under investigation and this is not generally the case in other conventional approaches to social science (Brydon-Miller, Greenwood et al. 2003).

According to Reason and Bradbury (2001) quality relates to process and it is subject to variation in any research approach regardless of the paradigm. Therefore quality can be an issue in all types and forms of research practice and it is managed by attention to and reflection on established methods and procedures and evaluation of outcomes. Dick (2000) supports that the cyclic nature of Participatory Action Research aids rigour. "The early cycles are used to help decide how to conduct the later cycles. In the later cycles, the interpretations developed in the early cycles can be tested and challenged and refined" (Dick 2000).

Another important criticism of Participatory Action Research is the way that it is sometimes reported through narratives, which do not fit the positivist model for data collection and presentation (Koch, Kralik 2006, Stringer 1996). Action researchers contend that when this type of presentation is chosen the generated accounts have to be in narrative form in order to be true to the process. Even within traditional social science there is a growing recognition that social reality and socially constructed meaning quite often grow out of dialogue and narrative and therefore the narrative provides much power for gaining deep understanding and constructing meaning (Koch, Kralik 2006, Greenwood, Levin 1998).

3.4.5 Justification for Use

The researcher and supervisory team decided that Participatory Action Research was the most appropriate methodology for the study for many reasons. People with learning difficulties are today excluded from the use of IT, the main reason being the fact that the software industry discriminates against them by imposing social barriers (Lewis 2005, Gregor, Dickinson 2007, Czaja, Lee 2007, Keates, Adams et al. 2007). The primary aim of the study was to explore how people with learning difficulties could be involved in software development. If this could be shown then it was hoped that it would make a case towards convincing advocacy groups, the software industry and the research community to engage more people with learning difficulties in software development processes. This would make software systems more accessible and promote the inclusion of this community as equal members of society. Participatory Action Research was considered appropriate for this aim because it is an activist methodology which is often used to give a voice to marginalized and oppressed groups, to empower them to solve their problems and develop themselves and their communities (Collis, Hussey 2003, Cornwall, Jewkes 1995).

Participatory Action Research attempts to develop valid new knowledge to further the goals of science and at the same time take action in order to benefit the participants by finding solutions to practical problems or concerns they face (O'Brien 1998, Reason, Bradbury 2001). The aims of the study were both to create new knowledge and at the same time make a case for convincing the research and practitioner communities to stop discriminating against people with learning difficulties. In the course of the study a usable software system would be created and this would benefit the Health Trainers further by enhancing the service they provided. Participatory Action Research was appropriate for these goals.

One successful and widespread method for creating usable software systems is by involving the final users in design and development (Lopresti, Mihailidis et al. 2004). User-Centred and Participatory Design methodologies for software

development are based on the active involvement of users to improve the understanding of user and task requirements and they use iteration cycles between design, development and evaluation (Mao, Vredenburg et al. 2005, Lopresti, Mihailidis et al. 2004). As presented in Section 3.2 the intention of these methodologies is the design of usable systems and not the conduct of research though. Therefore, adopting a software design methodology alone would not suffice for the needs of the study. Consequently Evolutionary Prototyping, a Participatory Design paradigm which involves the final users (described in Section 4.4.1) and Participatory Action Research were combined in order to satisfy the needs of the inquiry.

Participatory Action Research was chosen as an appropriate accompaniment to Evolutionary Prototyping because it involves the stakeholders in the research. The iterative cyclical inquiry process of plan, act and reflect (Figure 3.2) which characterises Participatory Action Research is compatible with Evolutionary Prototyping which also uses iterative cycles between *design*, *development* and *evaluation*. The aim of Evolutionary Prototyping is incremental system development (Bischofberger, Pomberger 1992). The iterative development strategy starts with a prototype that serves as an initial basic system, which end-users evaluate providing feedback. The feedback (new system requirements) is then incorporated into the prototype in order to refine it. This iterative process of prototype refinement is continued until a satisfactory system is finally developed (Bischofberger, Pomberger 1992, Pressman 2001).

Participatory Action Research methodologies are characterised as being flexible in contrast with the rigid and linear design of most conventional research (Cornwall, Jewkes 1995). The researcher decided that this flexibility would offer advantages when working with people with learning difficulties who have specific needs. During the course of the inquiry the Participatory Research Team was able to change procedures in order to fit the needs of the Health Trainers. When a need was identified in one Participatory Action Research cycle, the team could change the procedure in the next cycle adapting it accordingly.

Finally, Cornwall and Jewkes (1995) asserted that Participatory Action Research allows flexibility to the degree of participation as well. They observed that there are different levels of participation, from shallow to deep, and that the participation degree is not fixed. A researcher and/or the participants can choose from those for their study. "In practice, movement from one mode to another may take place at different stages of the research and for different purposes" (Cornwall, Jewkes 1995). The researcher decided that this type of flexibility would be helpful for the study. There was variation in the skills of the Participatory Research Team and depending on the stage of the research different participants could participate at different levels. At certain technical stages for example, like the programming of the software system, the Health Trainers could not get involved at all.

3.4.6 Applying Participatory Action Research in Practice

For the current study there were challenges applying Participatory Action Research in practice. Participatory Action Research was considered the most appropriate methodology for the reasons observed in Section 3.4.5. This was a PhD study which had to adhere to specific bureaucratic procedures though, and consequently was forced to deviate from the following typical Participatory Action Research route.

According to Hagey (1997) in Participatory Action Research methodologies the 'problem' typically originates within the community or workplace itself. The community participants are involved in controlling the entire research process and the research aim is to fundamentally improve the lives of those involved while creating new knowledge. Therefore, in the typical practice of Participatory Action Research the participants have a specific concern which they want to address and they therefore initiate the process themselves. As a result the participants own the research and they set the research agenda and the research questions.

This inquiry deviated from the typical Participatory Action Research procedure for the following reason. As a PhD study it followed the appropriate academic

procedure during which the researcher with the supervisory team first submitted a research proposal which included specific research questions. After the proposal was accepted the researcher and supervisory team decided that Participatory Action Research was the most appropriate methodology for this type of research. As a consequence of this procedure that had to be followed, the researcher and the supervisory team initiated the process instead of the community participants. The Health Trainers with learning difficulties were approached later. The result was that the research was not owned by the Health Trainers and they did not have an active role in setting the research agenda and research questions. When the decision for Participatory Action Research was taken the researcher misjudged the importance that the specific methodology places on who sets the research agenda, research questions and who owns the research. The researcher's previous education is in computing rather than the social sciences. He did not have previous experience with Participatory Action Research and was learning about it as he was proceeding with the study. Therefore at the time that the decision for Participatory Action Research was taken he was not familiar with the importance that the methodology places on research ownership.

Hagey (1997) stated:

> "The most common abuse of Participatory Action Research is using
> its good reputation, gained from its ethical relations and practices,
> while conducting research within the conventional sets of relations.
> The obvious motivation is to retain control of research and to be
> accountable to one's bureaucracy, which calls for efficiency in
> research. Participatory Action Research, being in community
> control, may not appear to be efficient and may ignore institutional
> deadlines" (p. 2).

As this inquiry was a PhD it was impossible to disregard the bureaucratic procedures set by the University of the West of England under whose auspices the research was happening. The study could not, for example, ignore institutional deadlines and not try to be efficient. These facts pushed the study in a specific direction affecting the extent of involvement of the Health Trainers and the level of Participatory Action Research achieved, which in certain areas were not the

anticipated. The level of Participatory Action Research achieved is discussed further in Section 6.7.1.

3.5 Sample

The current study decided to recruit participants from a group of students with learning difficulties who were trained at the University of the West of England to become Health Trainers. The sample used was chosen due to its convenience. This is not a traditional sampling approach but this type of sampling was appropriate mainly because the study was exploratory in nature and followed an interpretivist paradigm.

Health Trainers provide support and advice on an individual basis and try to help people to address some of the underlying causes of ill health specifically when a bad lifestyle is followed. They help community members to identify and achieve their own health goals and to make healthier lifestyle choices. In most cases these are in the areas of healthy eating, physical exercise, smoking and alcohol abuse (DH 2010).

Health Trainers often come from, or are knowledgeable about, the communities they work with and in most cases they work from locally based services and offer support from a wide range of local community venues. Since 2006 they have facilitated behaviour change and provided motivation and practical support to individuals in their local communities (DH 2010).

Based on the aforementioned model of the generic Health Trainers, the idea of Health Trainers with learning difficulty who would work with other people from their community was conceived in September 2006 by people in the University of the West of England, and the Bristol Primary Care Trust (PCT). The 'Bristol Health Trainers with Learning Disabilities' project, as it was called, was the first such project in the United Kingdom (UK) and it recruited people with learning difficulties to act as Health Trainers.

The project offered the Health Trainers opportunities for additional education and employment. The Health Trainers were trained at the University of the West of England (UWE) and were then employed part-time by the National Health Service. According to the Health Trainers their training and education offered them more life opportunities and a job. These factors increased their self-esteem and independence. As a result of having an income, three out of the four Health Trainers were able to afford to live independently away from their families. The fourth Health Trainer lived with her parents at the initial stage of the study but later reported that she was also able to live independently. The fact that the Health Trainers were part-time employed and could live away from their family home, empowered them to take decisions about their own lives. On these issues the Health Trainers reported the following:

> Researcher (to Roy): "…Yeah! Why, do you feel that if you could you would like to do a PhD or study further?"
>
> Roy: "Because going to school…" (pause)
>
> Researcher: "Education?"
>
> Roy: "Yes, education makes you feel, more confident about things."
>
> Tanya: "Yeah, it definitely gives you more opportunities, doesn't it? Like life opportunities."
>
> Researcher: "What do you think of the training you receive as Health Trainers then?"
>
> Roy: "Oh, that's great."
>
> All: "Yes."
>
> Researcher: "So you all agree? Why do you feel that it is so great?"
>
> Brenda: "Because we can have a job."
>
> …
>
> Researcher: "Can we go back to what you said earlier Roy, that education increases your confidence, I believe that is how you put it, do you feel, I am asking all of you now not just Roy, do you guys feel that your training as Health Trainers, for becoming Health

Trainers I mean, at UWE, does that make you feel confidence, or like affect your self-esteem? How does that education, training make you feel? Who wants to talk about this?"

Bonnie: "Yes it does."

Researcher: "How, eh why?"

Bonnie: "When I go, to see my clients, and I talk to them, they listen to me, like they listen to what I tell them because… I have trained to know these things, about healthy living."

Researcher: "You mean they see you as an expert on this subject? …on health, on the subject of health?"

All: "Yes."

Researcher: "And how does that make you feel?"

Tanya: "Important, personally it makes me feel important."

Bonnie: "Yes."

After some discussion about the importance of employment Brenda and Tanya reported:

Brenda: "I like living away from home because I can do whatever I like, you know, I do not have to get permission about things, and if I feel like doing something I can do it."

…

Tanya: "Most people I know, especially people with no learning difficulties, do have a job, so personally I feel good when I say I have to go to work today..."

The fact that the people involved in the study were trained to become Health Trainers and were also part-time employed had an effect on their confidence, self-esteem and independence. As the Health Trainers put it, being employed made them feel more socially included. Section 6.6.5 discusses how these empowering factors affected the Health Trainers participation in the study and in software development.

The Health Trainers with learning difficulties were first approached by one of their instructors at the University of the West of England who asked them if they would be interested to take part in the study. They replied positively. Later the researcher met the Health Trainers at the university during a training session and discovered that they were a convenient sample for the needs of the study. The Health Trainers had the following characteristics:

- All the Health Trainers had mild learning difficulties (Figure 3.3, defined in Section 2.2.3). This was confirmed by the learning difficulties advisory group to the current study who knew the Health Trainers.

- The Health Trainers reported that they had basic computing skills. Computing skills were necessary for participation as the study involved them in software development.

- All the Health Trainers lived and worked in the Bristol area and this made it easy for them to attend the study meetings. According to Ambler (2011), "When stakeholders aren't regularly involved with a project team the chance that the team will build the wrong thing increases. With continuous stakeholder participation the feedback cycle is reduced, improving overall chances of project success" [online].

- The Health Trainers showed enthusiasm when the study was explained to them.

Learning Difficulties Severity Continnum

This study engages participants from this severity group

Mild	Moderate	Severe
Can live independently	Need help with daily living	
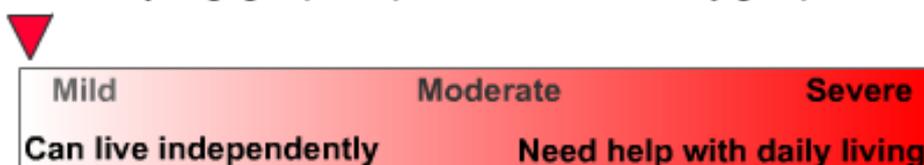
Figure 3.3 – Severity of the Health Trainers' learning difficulties (Author created).

Initially six Health Trainers signed the consent forms but later two of them decided to withdraw. No explanation was given for the Health Trainer's withdrawal. During the meeting in which the study was presented and the consent forms handed out, the researcher made it clear that the Health Trainers could withdraw from the study at any time without an explanation or any consequences. When two of the Health Trainers withdrew the Participatory Research Team respected this ethical agreement and did not ask for an explanation for their decision to withdraw. The withdrawal happened when four of the Health Trainers became National Health Service (NHS) employees while the other two remained working at a self advocacy, non-profit organisation which supports the rights of people with learning difficulties. The four that became NHS employees stayed committed to the study while the two that continued their employment at the non-profit organisation decided not to continue. It is not clear if this change in employment circumstances affected their commitment to the study.

3.5.1 Demographic Characteristics

As previously stated the present study is exploratory in nature and used convenience sampling. The study does not seek generalisation of the results to the greater population of people with learning difficulties. It is however important to describe some of the Health Trainers' characteristics in order to explain the findings of the study. Table 3.2 presents a summary of the demographic characteristics of the four Health Trainers that remained committed to the study until its end.

Table 3.2 – The demographic characteristics of the Health Trainers. Each column represents one Health Trainer. The column heads contain the pseudonyms used to replace the Health Trainers' real names.

	Brenda	Bonnie	Tanya	Roy
Gender	Female	Female	Female	Male
Race/Ethnicity	White	White	White	White
Age Group	20 – 30	20 – 30	40 – 50	40 - 50
Years of education	13	11	11	11
Employed	Part time	Part time	Part time	Part time

Work hours per week	19	19	21	21
Level of income	Approximately £6500/annum	Approximately £6500/annum	Approximately £7200/annum	Approximately £7200/annum
Living conditions	Lives independently in private housing	Lives at home with parents (In the last meeting the Health Trainer reported living independently)	Lives independently in council housing	Lives independently in council housing
Marital Status	Single	Single	Single	Single

Of the four Health Trainers, three were female and one male. All of them are white British and none of them were married. Brenda and Bonnie were aged 20 - 30 years old, while Tanya and Roy were aged 40 – 50 years. Tanya said that she had eleven years of regular state funded school because she was not diagnosed as a person with learning difficulties until she was thirty-seven years old. Brenda reported that she had thirteen years of education. The first eleven years she attended state funded school for people with special needs. Brenda also attended two years of college for people with special needs. Bonnie and Roy stated that they had eleven years of state funded education in schools specifically for people with special needs.

 All Health Trainers were working together in a big one-room common office as NHS employees. The two younger female Health Trainers indicated that they worked nineteen hours a week while the two mature ones worked twenty one hours a week. Their level of income was approximately £6500 to £7200 per year. Finally, Roy and Tanya indicated that they lived independently in council housing; Brenda also lived independently but in private housing while Bonnie still lived at home with her parents. During the last Participatory Action Research Meeting, Bonnie reported that she moved out of her parents' home and was living independently in private housing.

3.5.2 Computing skills

As the present study tried to explore involvement of people with learning difficulties in software development, it was deemed important to form a picture of the Health Trainers' computing skills before the study started. For this reason specific open ended questions were prepared and posed to them at one of the first Participatory Action Research Meetings. Table 3.3 presents a summary of the answers in tabular form.

Table 3.3 – Summaries of answers to questions relating to the computing skills of each Health Trainer at the start of the study.

Question	Brenda	Bonnie	Tanya	Roy
Do you own a personal computer? (At start of study)	Yes	Yes	No	No
Did you have official computer training? (At start of study)	Computer classes at secondary school between the ages of eleven to sixteen.	Computer classes at secondary school between the ages of eleven to sixteen.	'Computing for beginners' class specifically for people with special needs. Once a week for an hour each session. Attended for several months but class was cancelled.	'Computing for beginners' class specifically for people with special needs. Once a week for an hour each session. Attended from September to June of next year (one academic year).
Do you use a computer at work?	Yes	Yes	Yes	Yes
Which software applications do you use?	Word, e-mail (Outlook), Web browsing (Internet Explorer). Other simple applications. Applications	Word, e-mail (Outlook), Web browsing (Internet Explorer). Other simple applications. Applications	Word, e-mail (Outlook), Web browsing (Internet Explorer).	Word, e-mail (Outlook), Web browsing (Internet Explorer).

	to download and process photos from digital camera, MP3 music.	to download and process photos from digital camera, MP3 music.		
Can you browse the Internet?	Yes	Yes	Yes	Yes
Do you play computer games?	Yes	Yes	No	No
Do you use social network engines (i.e. Facebook)?	Yes	Yes	No	No
Did you ever post anything on a wiki or a blog?	No	No	No	No

Roy reported that he attended a state funded 'computing for beginners' class specifically for people with special needs. This class took place once a week for an hour each session and it lasted for one academic year (September to June of next year). Tanya indicated that she started the same class which Roy attended and that it was run for several months but was later cancelled due to funding cuts. Tanya was also told that she would be notified when a place was available at a future class but this did not happen. Bonnie and Brenda reported that because they were of younger age, computing was taught at secondary school starting at age eleven to sixteen so they did not have to attend after school classes like Roy and Tanya did.

Bonnie and Brenda reported that they owned personal laptop computers which they used at home and that sometimes they also brought them to work. Roy and Tanya did not own personal computers at the start of the study (at some point during the study Roy acquired his own laptop). There were, however, three desktop computers with Internet connection at their common office room which all of them used mainly for e-mailing, preparing simple accessible brochures for their clients in Microsoft Word and for browsing the Internet. Tanya indicated that

sometimes she was challenged using these three applications. Roy said that he could use computers but he did not feel comfortable using them. In the later stages of the study when Roy acquired his own computer he reported that he started feeling a little more comfortable with computer use.

Brenda and Bonnie, the two younger Health Trainers, reported that they also used their personal laptops for other common tasks such as to download and touch up pictures from a digital camera, to download music from the Internet and put it on their portable music players and to print pictures. Roy and Tanya, the two more mature Health Trainers, indicated that they used a computer only at work.

Bonnie and Brenda reported that they also played computer games and they both used social networking websites like Facebook to socialise with their friends. Roy and Tanya the two more mature Health Trainers indicated that they did not engage with such activities. All of the Health Trainers indicated that they had never posted anything on a wiki or a blog.

In order to compare the computing skills of the Health Trainers the researcher asked them in turn to perform a list of computer tasks while he was observing them (Table 3.4). These tasks were compiled by the researcher for the needs of the study and were operations involving two of the software applications which all the Health Trainers reported they were using at work, MS-Word and Internet Explorer. The researcher felt that in order to be able to compare the computing skills of the Health Trainers, the list of tasks should relate to applications which all of them used. The researcher tried to find a standardised test appropriate for comparing the computing skills of the particular group of Health Trainers but was not successful. All the standardised tests which the researcher reviewed involved many tasks beyond the three applications with which all the Health Trainers reported they were familiar. The researcher was therefore forced to devise his own test for the specific needs of the Health Trainers and the study, along with a customised computing skills measuring scale. The researcher decided that the measuring scale should only contain three computer skill levels, *basic*, *good* and *very good*. Three levels were judged sufficient as the test would compare the

computer skills of only four people and it would involve only eight basic tasks. The achieved computing skill level would be decided primarily by how many tasks each Health Trainer performed with no help.

Table 3.4 – The computer tasks that were executed by each Health Trainer and how they performed them.

performed Task	Brenda	Bonnie	Roy	Tanya
Start Microsoft Word	Could do it	Could do it	Could do it	Could do it
Type a sentence in Word: "I am a Health Trainer and I enjoy my work."	Could do it	Could do it	Could do it	Could do it
Start a new document in Word	Could do it	Could do it	Could do it	Could NOT do it
Copy and paste in Word	Could do it	Could do it	Could do it	Could NOT do it
Save the Word file	Could do it	Could do it	Could do it	Could do it
Try to find where you saved the file	Could do it	Could do it	Could NOT do it	Could NOT do it
Start the Web browser	Could do it	Could do it	Could do it	Could do it
Go to www.microsoft.com	Could do it	Could do it	Could NOT do it	Could NOT do it
Tasks completed:	8 out of 8	8 out of 8	6 out of 8	4 out of 8
Familiarity with computers at start of study, using the researcher devised scale described above.	*Very Good*	*Very Good*	*Good*	*Basic*

By observing the Health Trainers perform the tasks listed in Table 3.4 the researcher compared their computing skills. Brenda and Bonnie, the two younger female Health Trainers, had very good computing skills and felt quite comfortable with computer use. They performed all the tasks of the test without any help. They worked comfortably within Word, knew exactly what to do in order to copy and paste and knew where to find a file after it was saved in another folder other than the one they typically used. They also knew that in order to go to the Microsoft website they had to type the www.microsoft.com address, at a specific place in the Web browser and then press the 'enter' key.

Tanya knew how to start Word by double clicking a shortcut on the desktop but after she typed a sentence in it the researcher closed the document and asked Tanya to start a new one. Tanya said, "I remember that I have done this before but I do not remember how to do it now." She also forgot how to copy and paste. Tanya also knew how to click on the save button in order to save a file but when asked to find the saved file she did not know where the file was saved and could not find it. Tanya also knew how to start the Web browser by double clicking a shortcut on the desktop but then when asked to go to www.microsoft.com she did not know that she had to type the address in the browser and was instead searching to find it under the favourites (bookmarks) menu.

Roy knew how to start Word and type a sentence in it. After the researcher closed the document he managed to start a new document by clicking on the appropriate icon on the toolbar of Word. Roy also managed to copy and paste some text after taking time to do some thinking, but after he saved the file he reported that he could not remember where the file was saved. Using the 'File Open Dialogue Box' in Word Roy browsed to the folder where the Health Trainers typically saved their work documents. As the file was saved somewhere else Roy could not find it. Roy also knew how to start the Web browser but he tried to Google www.microsoft.com.

These computer use observations were indeed very useful as they showed that there was a difference in the general computing skills of the two younger and the two more mature Health Trainers. At a later meeting the researcher presented and discussed the above computing skills conclusions with the Health Trainers. The Health Trainers commented that the main reason for the difference in their computing skills was the fact that the two younger ones were taught computing for several years at secondary school. When the two more mature Health Trainers attended secondary school computing was not taught. Therefore, regarding computing skills, the sample of the study could logically be divided into two groups of Health Trainers. In the one group were Roy and Tanya, the two mature Health Trainers who belonged to a generation of people less exposed to

technology developments and who therefore had less developed computing skills. In the other group were Bonnie and Brenda, the two younger Health Trainers whose generation was exposed more to technology and thus had better computing skills.

3.5.3 Limitations of the Sample

According to Mencap only 1 in 3 people with a learning difficulty take part in some sort of education or training program (Mencap 2011). All the participants of the present study had training to become Health Trainers and therefore fall under the minority of those who are better educated, at least on the subject of healthy living.

Mencap also asserts that less than 20% of people with learning difficulties work (Mencap 2011). All the participants of the present study were employed as part time Health Trainers, so again they do not fall into the unemployed majority division of their community.

People with learning difficulties often have a combination of learning along with a variety of other physical and/or sensory impairments (DH 2001). The Health Trainers when asked did not report any physical or sensory impairment in addition to their learning difficulties.

Some authors contend that learning difficulties themselves are also highly variable even within a single individual (McGrenere, Sullivan et al. 2006, Fischer, Sullivan 2002). Fischer and Sullivan (2002) asserted that "each person with cognitive disabilities represents a 'universe of one,' preventing the technology designer from thinking in terms of typical 'user classes'" (p. 194). However, a number of other authors contend that all of us depict variation in our cognitive abilities and thus this phenomenon is not unique to people with learning difficulties. Newell, Carmichael et al. (2002) observed:

"It should always be borne in mind, however, that in 'real world'

situations, there is no marked distinction between that which is 'normal' and that which is not. In other words, everyone has some limits to their cognitive ability. Some have a highly specific impairment, some more diffuse problems, and there are also some that experience interrelated constellations of impairments" (Newell, Carmichael et al. 2002).

They also added,

"It is also worth noting that within the context of 'normal' cognitive systems, there is significant diversity among people in regard to differential preferences for types of material and ways of approaching and processing information. For example, some people may be considered primarily 'verbal' and will tend to excel in language-based tasks, relative to those considered 'visuospatial' " (Newell, Carmichael et al. 2002).

Moreover, even if this was a unique phenomenon among people with learning difficulties it would be practically impossible to separate participants with specific cognitive deficiencies therefore it would be impossible to choose a sample representative of all possible combinations.

Finally, the sample of the present inquiry was restricted to four people which may not seem an optimum size for certain types of research. This was a small scale exploratory study with an interpretivist inquiry paradigm and as such a small sample is acceptable (Collis, Hussey 2003, Malhotra, Birks 2006). The aim of the study was deep understanding rather than statistical inference so the fact that the sample consisted of only four Health Trainers did not affect its objectives.

3.6 Ethics

Ethics relate to moral standards considered to be general principles of how people should behave. For social research they are expressed as agreed codes of behaviour and are usually particular for each academic discipline. These codes guarantee that there is a balance between effective scientific research and the need

to respect the rights of research participants (Kimmel 1988).When engaging users, ethical codes are a method of ensuring that protocols for participation are recognized.

> "Although sociologists, like other researchers are committed to the advancement of knowledge, that goal does not, of itself, provide an entitlement to override the rights of others" (Smyth, Williamson 2004, p. 10).

Relationships with people with learning difficulties are central to ethical practice and supporting them can create a number of moral issues and dilemmas. In England, provision for people with learning difficulties is rooted in the principles of inclusion, rights, independence and choice. This is a set of principles by the Department of Health expressed in codes of conduct (DH 2001). These principles express the value base in seeking to work for the benefit of people with learning difficulties and provide direction and guidance in the decision making of both the individual and services (Northway 2011).

Additional to the set of values by the Department of Health are many other ethical perspectives and theories which can be referred to when seeking to examine a moral issue. Two important perspectives offering different understandings of an ethical situation are those of deontology and utilitarianism. Deontology is concerned with people acting as a result of binding duty and moral obligation, regardless of the consequences of their actions (Baggini, Fosl 2007, Mauthner, Birch et al. 2002). The concept of 'duty' is one most people working in learning disability services should be familiar with. Workers of these services typically speak of being 'on duty' or having a 'duty of care' (Northway 2011).

Utilitarianism is a consequentialist theory dealing with what makes consequences good or bad. It argues that virtue is based on utility, and that conduct should be directed toward promoting the greatest happiness for the greatest number of people. The morally correct course of action consists in the greatest good for the greatest number without regard to the distribution of benefits and burdens

(Kimmel 1988, Mauthner, Birch et al. 2002). This is particularly relevant to the community of people with learning difficulties, as they are a minority group within society and policies which are designed to achieve the greatest societal good could result in them being disadvantaged (Northway 2011, p. 78). Utilitarianism is different from deontology as it is concerned with the consequences rather than the motivation of actions. However, Edwards (2009) suggested that practitioners should consider both perspectives when they seek to address moral issues as it is necessary to take into account not only of what we do but also understand why we do it and what will be the outcomes. More specifically, it is important to consider both duties and the consequences as both are relevant to the ethical justification of acts (Atherton, Crickmore 2011, Edwards 2009).

When people with learning difficulties participate in research studies, the issue of power typically arises. Most research studies in the field of learning disability are typically started by non-disabled researchers, who involve people with learning difficulties in their work. Therefore, people with learning difficulties are rarely fully in control of the research process they are involved in. This was the case of the current inquiry. Researchers try to include people with learning difficulties in their studies but often the real power lies with the non-disabled people. Consequently, the issue of power and how it is played out within such studies is a frequent theme in the debate about inclusive research (Tarleton, Williams et al. 2004).

Participatory design and research methodologies are not just about acquiring requirements for system development or advancing knowledge. They also include an ethical dimension for giving participants a voice in technology or in research (Newell, Gregor 2000). People with learning difficulties are often marginalised in these processes and participatory methodologies promote mutually respectful relationships with stakeholders. This also leads to an immersion of the researcher or the software developer in the participants' world and allows for a more empathetic interpretation of their contributions (Porayska-Pomsta, Frauenberger et al. 2012, Porayska-Pomsta, Lemon 2012).

Participatory Action Research is a democratic methodology in which the participants can also be the researchers and the separation between them is more difficult, compared to conventional methodologies. Within studies using participatory methodologies it is more difficult to separate who has the power. If there are research supporters, they should always be endeavouring to share their power with the participants (Smyth, Williamson 2004). This was the case in the current inquiry as Participatory Action Research was the adopted methodology.

Participatory methodologies promote the sharing of power and thus it is easier for the research supporter to act ethically towards the participants. However, the current study involved people with learning difficulties, a community of users who are more vulnerable. People with learning difficulties are frequently undervalued and this places them at risk of being subjected to negative and degrading treatment (Northway 2011, p. 75). Therefore, even though the study implemented a more democratic methodology supporting the distribution of power, the researcher could be in a position of power if he chose to. The researcher therefore had to make a conscious effort to respect the rights of the Health Trainers and to act morally. "The dilemmas inherent in the support role are very much to do with power struggles." (Tarleton, Williams et al. 2004, p. 85) "The subtle skill required to actually achieve this stance is worth considering" (Tarleton, Williams et al. 2004, p. 83) and one which software developers are not academically trained to do.

Tarleton, Williams et al. (2004) argued that within inclusive research the question of the supporter's skills is not just about the technical trick of 'doing support' (p. 83). The question also has to be considered in light of the ethical issues such as identity and power. Research supporters operate in diverse ways, and the assistance required by people with learning difficulties also varies among individuals. However, a central characteristic of good support should be that the supporter does not dominate. That should be the goal towards which a research supporter should constantly be working towards. Tarleton, Williams et al. (2004) maintained:

"The ideal would be for the disabled person to truly control his or her supporter, asking for the help that he/she needs to accomplish a particular task. That is the goal towards which one is constantly working. In my experience, however, the difficulty arises in attempting to achieve this stance while also ensuring that the research gets done" (p. 84).

"My own experience as a supporter was that the struggle was often about desperately trying to hand over power. It would have been far easier for all the team if the supporter could simply tell them what to do!" (p. 85).

 "A true sense of power will emerge only when people with learning difficulties are proud of their own distinctive identities" (pp. 85 – 86).

Typically appropriate committees give or reject ethical approval by considering the research design submitted to them (D'cruz, Jones 2004). The Department of Health has research governance regulations specifically for health and social care researchers. These are described in the Research Governance Framework for Health and Social Care (DH 2005).

When the Health Trainers with learning difficulties were approached in March of 2008 in order to participate in the study they were still under training at the University of the West of England and were at the same time employed by a non-profit self-advocacy organisation. In October of 2008 they were expected to become NHS employees though, so the study explored the possibility of acquiring ethical approval from the Department of Health by submitting the research design to the National Research Ethics Service queries service (please see Appendix 2). This service replied that the type of involvement described in the research design did not require ethical review by the NHS Research Ethics Committee.

The study also applied and was granted ethical approval from the Faculty of Health and Social Care Ethics Sub-Committee at the University of the West of

England. The Sub-Committee approved the ethics application with a number of stipulations:

- That no pain, discomfort, distress, inconvenience or change of life-style would be caused as a result of participation
- That interviews / questionnaires would not be embarrassing or upsetting
- That the methods of the research would be explained
- To explain how the results of the study would be reported and disseminated
- To explain how the potential participants would be identified approached and recruited
- That the participants would be informed and explained that withdrawal is possible
- That destruction of the appropriate data would be possible in case a participant withdrew
- That informed consent would be obtained
- That a written information sheet would be given to the participants
- That arrangements would be made for the research and the information sheet to be explained
- That arrangements would be made in case the participants had communication or other problems understanding the explanation of the research
- That the participants would be given an amount of time to decide whether to take part or not
- That a signed record of consent would be obtained
- That potential benefits to the participants would be explained
- Have arrangements in place which would enable the researcher to refer problems to be dealt with in case they were identified
- To have arrangements in place which would ensure the protection of the researcher
- That health and safety aspects would be considered
- That the results of the research would be made available to the participants
- To inform the participants that they would be audio recorded

- That measures would be taken in order to ensure the confidentiality of personal data
- That measures would be taken for the protection of the data and limit access to it
- That the data would be destroyed three years after the study was finished

An accessible information sheet and consent form, were produced and discussed with the Health Trainers and informed consent was obtained. Both the information sheet and consent form were prepared with the help of an advisory group which was qualified in preparing accessible information for people with learning difficulties. There was an initial meeting with the Health Trainers during which the researcher presented the study and discussed the information sheet. During this meeting there was a qualified person standing by to help, if necessary, with communication. The information sheet explained the following points:

- Why the research was taking place
- Why the Health Trainers were chosen
- The fact that participation was voluntary
- The fact that they could stop at any time without any consequences
- What would happen to them if they chose to participate
- The fact that they would be audio recorded
- That anonymity and confidentiality would be observed

During the meeting the Health Trainers were told that they could take the information sheet and consent forms with them and discuss its contents with a carer if they wanted to and that they could reply in two weeks time. Out of seven Health Trainers six of them signed the consent form immediately at the end of the meeting. The seventh Health Trainer said that she wanted to discuss the whole matter of participation with her parents and when the meeting finished she took the information sheet and consent form with her. After two weeks her response was that she decided not to take part in the study.

For confidentiality purposes it was agreed that all information which was to be collected during the course of the research was to be kept strictly confidential according to the Data protection Act (1998) and the Faculty of Health and Social care Data Protection Guidelines. Personal data would only be available to the researcher and the supervision team and that any issues that could arise regarding the data would only be discussed with the study supervisors. All data would be computer password protected and no individuals would be identified in reports or other means of dissemination. It was also agreed that the data, including audio recorded and computerized data, would be destroyed within three years from the end of the study. These stipulations were agreed with, and the researcher adhered to them during the length of the study.

Anonymity was assured by using pseudonyms instead of the Health Trainers' real names. However, although the ethics application and the information sheet referred to anonymity, the study developed in such a way that the identity of the Health Trainers became an essential part of the work.

As stated in Section 3.5 one reason the current study is original is because it explored the involvement of people with learning difficulties in software development within the context of an empowered and innovative project such as that of the 'Bristol Health Trainers with Learning Disabilities.' The 'Bristol Health Trainers with Learning Disabilities' was the first such project in the United Kingdom (UK) and it recruited a very small number of people making anonymity more challenging. During the Participatory Action Research Meetings the people with learning difficulties who were involved in the study reported that their training to become Health Trainers and the fact that this training offered them part-time employment had an effect on their independence, confidence and self-esteem. These facts were part of the findings and thus the Health Trainers identity became an important aspect of the study.

3.7 Data Collection and Analysis

3.7.1 Data Collection

Participatory Action Research is a holistic approach to research and problem-solving rather than a single method for collecting and analysing data (O'Brien 1998). Thus it can use different data collection methods and research tools and the methods chosen must lend themselves to the capabilities of the participant community and the problem solving and action oriented focus of Participatory Action Research (Greenwood, Levin 1998). For example, methods that separate the researcher and the researched or methods that are beyond the resources of the people involved are not suitable for participatory research (Reason, Bradbury 2001). Participatory Action Research most often uses qualitative methods which make it more accessible (O'Brien 1998, Loewenson, Laurell et al. 1995). Most of the common qualitative research data gathering tools such as structured and unstructured interviewing, keeping a research journal, participant observation recording, document collection and analysis, panels, taped interactions, critical incidents, narrative accounts, focus groups and case studies can be used (O'Brien 1998, Koch, Kralik 2006, Hills, Mullett 2000). Quantitative methods such as questionnaire surveys can also be effectively used within Participatory Action Research projects (McNiff 2002).

While similar methods may be used in both standard and participatory approaches, the research process of Participatory Action Research is rather different in the fact that the community is involved in the study. As a result the research methods chosen may be affected by the needs of the community rather than being purely academic or scientific (Watterson 1994). One reason this research study used only qualitative methods was because the data produced was more accessible to the Health Trainers with learning difficulties. This type of qualitative data has been successfully utilised before in research studies involving people with learning difficulties (Scottish Human Services Trust 2002). Moreover, on the topic of involving people with learning difficulties in participatory research Tony Gilbert (2004) stated:

"Participatory research involves people with learning disabilities in the research process with the support of sympathetic non-learning-disabled people. This type of research focuses on the experiences of people and is qualitative in approach" (p. 301).

3.7.1.1 The Participatory Action Research Meeting

This section describes the Participatory Action Research Meeting, the main method used by the study to gather data. During a Participatory Action Research Meeting the Participatory Research Team discussed and worked on aspects relating to the research and to software development. Each Participatory Action Research Meeting was divided by breaks into various sessions. During each session the Participatory Research Team tried to concentrate either on software development or matters relating to the research. Therefore sessions could logically be divided into two types: the sessions during which the Participatory Research Team concentrated and worked on the software development, and the sessions during which the team concentrated and worked on matters relating to the research. For example, during a session which the work concentrated on research the Participatory Research Team analysed part of the gathered data, while during a session which concentrated on software development the Health Trainers offered input and ideas on how to make the software system accessible.

During the Participatory Action Research Meeting the members of the Participatory Research Team were free to talk with other group members. From time to time the researcher asked the Health Trainers specific semi-structured, open-ended questions on which they were encouraged to expand in an interactive group setting. Following this unstructured approach the researcher was free to take-up leads, explore issues raised by the respondents and tried to uncover layers of meaning and perception. The meetings happened over a long period of time allowing the researcher to form a long term relation with and get to know the Health Trainers well. The Health Trainers knew each other well as they worked together.

As the main aim of the study was to explore how people with learning difficulties can be involved in software development, the whole experience during the software involvement sessions was important. For this reason during software involvement sessions the researcher tried to record down as many aspects of that experience as possible and these recordings were used as data. Examples of such data notes are the changes and input which the Health Trainers suggested for the software system under development (software requirements) and observation notes written down by the researcher while observing the Health Trainers perform tasks for system use evaluation.

Data was gathered from all Participatory Action Research Meetings and from all sessions. The following types of data were recorded down:

- Sound recorded and transcribed dialogue
- The researcher's own observation notes, written down either at the time of the meeting or immediately afterwards and journal entries written down later
- Input and changes which the Health Trainers requested for the developed system (system requirements), noted down during the Participatory Action Research Meeting along with observations about them
- Notes written down while observing the Health Trainers during system use evaluation
- Communications between the Participatory Research Team, such as emails, and notes about telephone conversations

The recorded dialogue was transcribed verbatim, and entered into NVivo, a qualitative data analysis software package. During the meetings the researcher also kept observation notes. Immediately after the meeting the researcher added to or expanded his observation notes. This was deliberately done immediately after the meeting, usually in the researcher's car and before driving away, because events were still fresh in his mind and he wanted to write them before he forgot them. The researcher was also keeping a research journal in which he was writing down any other thoughts and ideas he had about the study. Relevant e-mail

messages exchanged between the Participatory Research Team members were also imported into NVivo as data, and notes about telephone conversations were added into the researcher's research journal.

Sheets of paper separated into two columns were prepared and taken to the meetings with the Health Trainers. The paper was used specifically for writing down the system requirements that the Health Trainers asked. In the first column the researcher used to write down the requirement and in the second column his personal comments, like the reason that the Health Trainers asked a specific requirement or how exactly they asked for it. All the system requirements along with the researcher's notes are presented verbatim in Appendix 3. Some requirements were extracted later by listening to the recordings. During the system use evaluation the same type of specially prepared paper was used to write down the researcher's observations for each task that the Health Trainers performed while using the system, as described in, Section 4.7.

Between June, 2008 and June of 2011 there were a total of fourteen Participatory Action Research Meetings as shown in Table 3.5. In the first two meetings all six Health Trainers who signed the consent forms were present. In September of 2008 two of the Health Trainers informed the researcher that they decided to withdraw, so the study was left with only four participants. Those four Health Trainers remained committed to the study until its end.

Table 3.5 - Dates, number of Health Trainers, venue and short description of the Participatory Action Research Meetings organised for the needs of the study.

Group Num.	Date	Attending Health Trainers	Venue	Description
1	25/06/08	6	UWE classroom	Presented study and handed out consent forms.
2	16/07/08	6	UWE classroom	Explained Participatory Action Research. Overview of Web 2.0 technologies.
3	16/09/08	4	UWE classroom	Ideas on what the Health Trainers need. Ideas for a new system. Decided to develop a wiki. Initial software

					requirements.
4	17/03/09	4		Health Trainers'office	Observed Health Trainers perform basic computer operations to get a sense of their computing skills (on a one-by-one basis).
5	23/03/09	4		Health Trainers' office	Input and ideas on the first software system prototype. Findings evaluation. First Participatory Action Research cycle ends. Ideas on how to improve the next cycle.
6	22/06/09	4		Health Trainers' office	Input and ideas on the second software system prototype. Findings evaluation. Second Participatory Action Research cycle ends. Ideas on how to improve things in the next cycle.
7	07/07/09	4		Health Trainers' office	Input and ideas on the third software system prototype.
8	24/08/09	4		Health Trainers' office	System considered ready for evaluation. System use evaluation: observed Bonnie while using the system.
9	28/09/09	3		Health Trainers' office	System use evaluation: observed Brenda while using the system. Findings evaluation. Third Participatory Action Research cycle ends. Ideas on how to improve things in the next cycle.
10	21/10/09	2		Health Trainers' office	System use evaluation: observed Tanya and Roy while using the system (on a one-by-one basis).
11	25/11/09	2		Health Trainers' office	System available online. Helped Tanya and Roy with system use difficulties.
12	14/04/10	4		Health Trainers' office	Gathered data for research question three, how have the Health Trainers used the system over time. Findings evaluation. Fourth Participatory Action Research cycle ends. Ideas on how to improve things in next cycle.

| 13 | 11/05/11 | 4 | Health Trainers' office | Gathered data for research question three, how have the Health Trainers used the system over time. |
| 14 | 01/06/11 | 4 | Health Trainers'office | Findings evaluation. Fifth Participatory Action Research cycle ends. |

The date and time of the Participatory Action Research Meetings were arranged after discussion within the Participatory Research Team so that all team members could attend. The software development progress was another factor that affected the date of some of the meetings.

The first three meetings took place at University of the West of England immediately after the Health Trainers had finished their class. The venue of these first three meetings was the classroom where the training took place. It was a place with which the Health Trainers were familiar and this was important in order to create a comfortable atmosphere where they would be ready to reveal their thoughts.

At the beginning the researcher attempted to gain the Health Trainers' trust and friendship by offering them refreshments. The researcher was hoping that this would establish a friendly relationship with the Health Trainers in order to communicate their knowledge and their views about the research issue (Mauthner, Birch et al. 2002). Later the Health Trainers offered to buy refreshments for the researcher and this was interpreted as evidence that a good relationship was built.

In October 2008 the four Health Trainers who remained committed to the study became NHS employees and acquired their own office. After discussion, the Participatory Research Team decided to use the Health Trainers' new office as the venue where all the meetings would take place. This was a place where the Health Trainers would continue to feel comfortable with and it also helped as they did not have to travel because they spent three days every week in their office for their duties. This arrangement made meeting times more flexible.

The Health Trainers were very reliable and responsible about attending our meetings. None of them were absent without a good reason on any of the arranged meetings. The fourteen meetings were divided into five Participatory Action Research cycles. During each cycle the collected data was analysed. The Health Trainers informed the Participatory Research Team that they could not afford the time to work on the analysis of all the data. Therefore, part of the data was analysed with the participation of the Health Trainers while the remaining data was analysed by the researcher as described in Section 3.7.2. All the findings were discussed and evaluated with the Health Trainers at each Participatory Action Research cycle. The results of the analysis of the previous cycle drove the focus of the Participatory Action Research Meetings of the following cycle.

3.7.2 Thematic Content Analysis

The gathered data was analysed qualitatively to allow the themes and categories to emerge using Burnard's framework (Burnard, Gill et al. 2008, Burnard 1991, Burnard 1994, Burnard 1996, Burnard 1998, Burnard 2004). Burnard's method is appropriate for qualitative data which has been transcribed to text (Burnard 1991, Burnard 1994). The Participatory Action Research Meetings used in the study produced textual qualitative data, therefore rendering Burnard's method appropriate.

Burnard (1991) described his method as an adaptation of thematic content analysis from Glaser and Strauss''grounded theory' and from various works on content analysis (Babbie 1979, Berg 1989, Bryman 1988, Couchman, Dawson 1990, Field, Morse 1985, Fox 1982, Glaser, Strauss 1967, Strauss 1986). Burnard (1994) also observed that it is similar to the process known as phenomenological analysis (Giorgi 1985, Kvale 1983). Thematic content analysis, on which Burnard's method is based, is appropriate for exploratory and inductive research like the one described in this thesis (Elo, Kyngäs 2008) and this is another reason why Burnard's framework was chosen. The method was also simple enough to be described to the Health Trainers.

The approach offers a systematic method of analysing textual data by breaking the text down into units of meaning or themes, developing a category system and grouping together ideas of a similar type. The aim of the analysis is to produce a detailed and systematic recording of the themes and issues addressed in the data and to link the themes and interviews together under a reasonably exhaustive category system. This enhances the understanding of the data (Burnard 1991, Burnard 1994, Elo, Kyngäs 2008). According to Burnard (1991, 1994) the analysis is done in a number of stages.

The first stage of the analysis is to clean the text from 'dross.' The term dross is used by Field and Morse (1985) to describe material which does not relate directly to the topic or material which is repetitious or peripheral. In the present study deciding on what did or did not constitute dross was not easy and was done by the researcher. Only text which definitely did not help towards the understanding of a Health Trainer's point of view was omitted. If there were any doubts about whether something should be deleted or included then it was left in. Once the data was cleaned from repetitions and irrelevant references to other things, then the process of separating the text into themes (meaning units) could begin (Burnard 1991, Burnard 1994).

In the case of transcripts, each transcript was carefully read through and the text divided up into meaning units (themes) as follows. A meaning unit is a discrete phrase, sentence or series of sentences which convey one idea or one related set of perceptions (Mostyn 1985). For example, in interview data a researcher may be looking for similarities in responses. Each meaning unit should stand on its own but it is very likely to relate to the theme that precedes it and/or the one that follows it (Burnard 1994). The process of dividing the text this way took time and it was often necessary to go over a piece of data several times in order for the various meaning units to emerge. The entire data set of the study was worked through this way separating the text into meaning units. Each meaning unit was separated and tagged in NVivo. Themes which conveyed the same idea or related set of perceptions were assigned the same electronic tag. Within NVivo these tags

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can be called nodes, labels or codes. Each NVivo label can be a single word or a short phrase representative of the meaning unit.

The next stage was to develop a category system within which to group the themes. The purpose was an exhaustive category system which included all the identified themes (Burnard 1994). According to Burnard (1994) the researcher is always looking for patterns within the data. An exhaustive category system helps distinguish these patterns. The use of a category system also allows for the presentation of the findings from the data (Burnard 1991, Burnard 1994).

Once all the themes were separated out and labelled, the researcher worked through the labels to find ways to group them together into a category system. Themes with the same label were grouped together and if necessary reduced. Reduction involved crossing out repetitions and similar labels. As the labelling was done electronically in NVivo this could easily be done. In NVivo for example it is very easy to rename a label to something else.

Next all the themes that belonged to the same category were brought together. Burnard (1996) described a manual, paper based method that this can be done where each theme under the same category is highlighted with the same colour highlighter. The paper is then cut up according to the colours and the pieces of paper with the same colour, which represent the same category, are collected together and pasted onto pages of A4 paper. This way the researcher is left with the themes pasted together on sets of paper according to their category.

The present study did not have to use this manual method as it used a software system which automated the procedure. NVivo allows the user to create hierarchical trees of nodes. The top tree node (branch) can be a category while the nodes gathered below it (leaves) can be the different themes that belong to it. If NVivo users need to move a theme to a different category, all they have to do is drag and drop it. By double clicking on a category name NVivo brings together and lists the text from themes that belong to it. This way themes spread in various different documents (i.e dialogue transcriptions from different meetings) can be

brought and displayed together. Once this was done the study was left with the whole data set grouped into an exhaustive category system that contained all the identified themes. This categorisation illustrated particular points, ideas or perceptions and it allowed patterns to emerge in the data, which could be used to answer the research questions of the study.

For the needs of the study the Health Trainers were first instructed on data analysis. A specific transcript of one of the Participatory Research Team's meetings was chosen and was used during the tutorial. Using the transcript the Health Trainers were shown how to choose and manually (on paper) highlight themes. The manual method was used only for instruction. After the tutorial the software package NVivo was used. During the tutorial Tanya suggested that data analysis was time consuming and the rest of the Health Trainers agreed. The Participatory Research Team discussed how long the Health Trainers could spend on data analysis. It was decided on one session of around forty to fifty minutes for each Participatory Action Research cycle. It was also decided that the rest of the data analysis should be done by the researcher. Thus the Health Trainers participated in the data analysis only partly. The procedure for data analysis used during the Participatory Action Research Meeting was the following:

- Before the meeting the researcher would choose a specific piece of data to be analysed within the Participatory Research Team. In all cases the piece of data was transcribed dialogue. The piece was transcribed by the researcher before the meeting and entered into NVivo. The researcher also cleared the transcription from dross.
- The laptop on which NVivo was running was then taken to the Participatory Action Research Meeting and connected to a bigger computer screen.
- The researcher sat in front of the laptop/monitor on which NVivo was running while two of the Health Trainers sat on his left and the other two on his right. The researcher verified that all Health Trainers could see the screen well.
- The researcher would then read the transcript and the Health Trainers were encouraged to stop him suggesting themes. The transcript was sometimes

read more than one time until some themes emerged. The researcher was also suggesting themes.

- A discussion on the suggested theme would then follow. If the Participatory Research Team agreed on the theme it was labelled into NVivo by the researcher.

Even though the researcher analysed most of the data of the study, a few of the themes presented in the thesis emerged from the Participatory Research Team's analysis. The grouping of the themes into categories was done by the researcher.

3.7.2.1 Findings Validation

Burnard (1994) asserted that it is important for the category system to remain true to the text that is being analysed. The category system should 'emerge' out of the data and should offer a clear and true representation of the things that were talked about in the interviews. There are at least two methods of checking the validity of this type of analysis. In the first method the researcher can return to the participants and show them the analysis. The method of categorisation can be talked through with them and ask their opinion about the degree to which the category system does or does not represent the participants' intentions. In the second method the researcher can ask a colleague or another researcher to develop his or her own category system from a sample of the data transcripts. Ideally there should be a reasonable match between the two people reviewing the category system although in practice slightly different categories are usually created (Burnard 1994).

For the current study the first validation method was chosen. There were five Participatory Action Research cycles and at the end of each cycle both the category system and the results of the analysis were discussed with the Health Trainers in order to validate if indeed they represented their world view on the topic. Additionally the interpretations developed in the early cycles were tested,

challenged and refined in the later cycles. This cyclic process added rigor and validity to the analysis (Dick 2000).

The procedure followed for the findings validation was the following:

- The emerged category system from the analysis of the data collected during the previous or the present Participatory Action Research cycle was first described to the Health Trainers.
- The Health Trainers were then asked to comment on the category system.
- Each theme was then presented to the Health Trainers with the supportive data, like for example a specific abstract of transcribed dialogue. The Health Trainers were asked to comment on each theme.
- Depending on the Health Trainers response for the theme appropriate decisions were taken for the next cycle. For example if the Health Trainers expressed reservations about a theme the Participatory Research Team decided if it should be discarded completely as wrong or if it should be left as pending in order discover if the theme re-emerges from data gathered in the following cycles.
- In the last evaluation session the Health Trainers confirmed that the final findings represented their world view.

Before an evaluation session the researcher always prepared for the language that would be used to describe and discuss the findings with the Health Trainers. The language had to be simple in order for the Health Trainers to understand it and not embarrassing to them. The researcher had to describe the category system and themes that emerged from the data that he personally analysed outside the Participatory Research Team. It was probable that the description of some findings could make the Health Trainers feel uncomfortable or even embarrassed. The researcher felt that it was his moral obligation to avoid embarrassing the Health Trainers and he therefore tried to use appropriate language. For the researcher discussing and evaluating the findings with the Health Trainers was one of the most difficult aspects of the study.

Chapter Four: Software Development

4.1 Introduction

The present study concentrated on the experience of participation and explored the possibilities of involving people with learning difficulties in the development of software systems. To do this a Web 2.0 application was developed with the participation of Health Trainers with learning difficulties. This chapter starts by describing Web 2.0 technologies and the wiki software system developed for the needs of the study. It then continues to describe Evolutionary Prototyping, the methodology used for software development, along with the reasons it was chosen. The procedure followed during software development sessions is described along with the system requirements and design. The procedure used for system evaluation is also described along with evaluation conclusions and system limitations.

4.2 Web 2.0

The term Web 2.0 is associated with Web applications that facilitate Web-based collaboration, content creation, online networking and participatory information sharing. Types of technologies that fall under this term include tools and systems such as wikis, blogs, RSS feeds, social bookmarking, video sharing sites, and social networking sites where users can, among other things, present themselves and socialise online with their friends. These systems enable users easily to present and share their ideas and knowledge with a huge Web audience. They also allow users to collaborate online and create their own content either from scratch or by editing, aggregating or remixing other people's work. With the use of these tools the Web has been transformed from what was once a 'Read Only Web' to a 'Read/Write Web.' The Web changed from being a medium in which information was only transmitted and consumed 'Web 1.0,' into being a platform in which typical users can easily create, remix, repurpose and share content (Boulos, Maramba et al. 2006). The term 'Web 2.0' was used for the first time at an

O'Reilly Media conference in 2004. Since then this term has been used to describe the above observed types of Web applications. Even though the name seems to suggest a technology upgrade this is not the case. It is rather a sociological upgrade. It is about enabling the users to participate, create and share content on the Web instead of just consume it (O'Reilly 2005).

During the initial meetings the Participatory Research Team discussed various technologies that could be useful and could enhance the service which the Health Trainers provided. Part of this discussion was spent on Web 2.0 technologies. Some Health Trainers did not know all the Web 2.0 technologies mentioned during the discussion, therefore the researcher prepared and presented a tutorial for them during which Web 2.0 technologies (wikis, blogs and social networking) were shown. In the following meetings the Health Trainers decided that the system that would enhance and benefit their work the most would be a wiki (discussed further in Section 4.5.1).

4.3 The Developed System

A wiki is a Web based application that runs through a browser like Internet Explorer or Mozilla Firefox. Wikis are typically used to create websites and they allow visitors of a site to edit or add content to it. Editing rights are typically governed by a user account scheme. Some wiki websites allow anyone, even anonymous visitors, to add or change the content. Other sites require visitors to register first, while still others restrict these privileges to specific users only. Wikis also allow the linking of Web pages using Web hyperlinks. As a result of the afforded editing facilities, wikis can be seen as an easy and quick way to create a website. The word 'wiki' in Hawaiian means 'fast.' It was first used in the Web 2.0 context by Ward Cunningham, the developer of the first such software system, which he called 'WikiWikiWeb' (Cunningham, Leuf 2002). Wikis are typically used to create collaborative and community websites, as knowledge management and e-learning systems, in corporate intranets and even for Web based personal note taking.

The wiki developed for the needs of the study enabled the Health Trainers to collaborate online in order to post health related information on the Web as an additional service to their clients. Initially the Health Trainers had asked that the system should have the capability to allow their clients, as well as themselves, to be able to edit and add information to the wiki. However this proposal was relinquished for security reasons. The Information Technology (IT) services of the University of the West of England where the wiki was hosted pointed out that this would be contrary to the policy of the university. The IT services of the university suggested that if any visitor could add or change content there was the danger of some people posting abusive language and this would be upsetting to both the Health Trainers and other users of the system. Later the issue was discussed within the Participatory Research Team and the Health Trainers agreed that this feature could be taken out. Instead the Participatory Research Team decided that only the Health Trainers and specific users should be allowed to change and add to the content of the wiki. The specific users who would be allowed to edit the contents of the wiki should be approved and registered to the system by one of the Health Trainers. This meant that if some clients wanted to add or change information on the wiki the Health Trainers had to first approve it and then add them into the system as Registered Users.

For visitors, the Health Trainers' wiki looks like a typical website. The first thing visitors see is the Home Page which briefly describes the Health Trainers along with their contact information (Figure 4.1). On the right margin there is a multi-modal Help system (video and textual) which describes what the site is about and how to use it. At the very top there is a search facility. This comprises of a text-box and a button next to it with the caption 'Click to Search.' Visitors can type keywords in the text-box and then click the 'Click to Search' button in order to search the site. Below the search facility there is a horizontal menu system. For visitors there are only four items on this menu, 'Go to Home Page,' 'List All Pages,' 'Websites,' and 'Your Ideas.' Visitors are basically expected to find the health information that interests them, either by doing a search or by listing all the

pages that exist on the site. The pages can be listed by clicking on the menu item 'List All Pages.' Each page is on a different health topic.
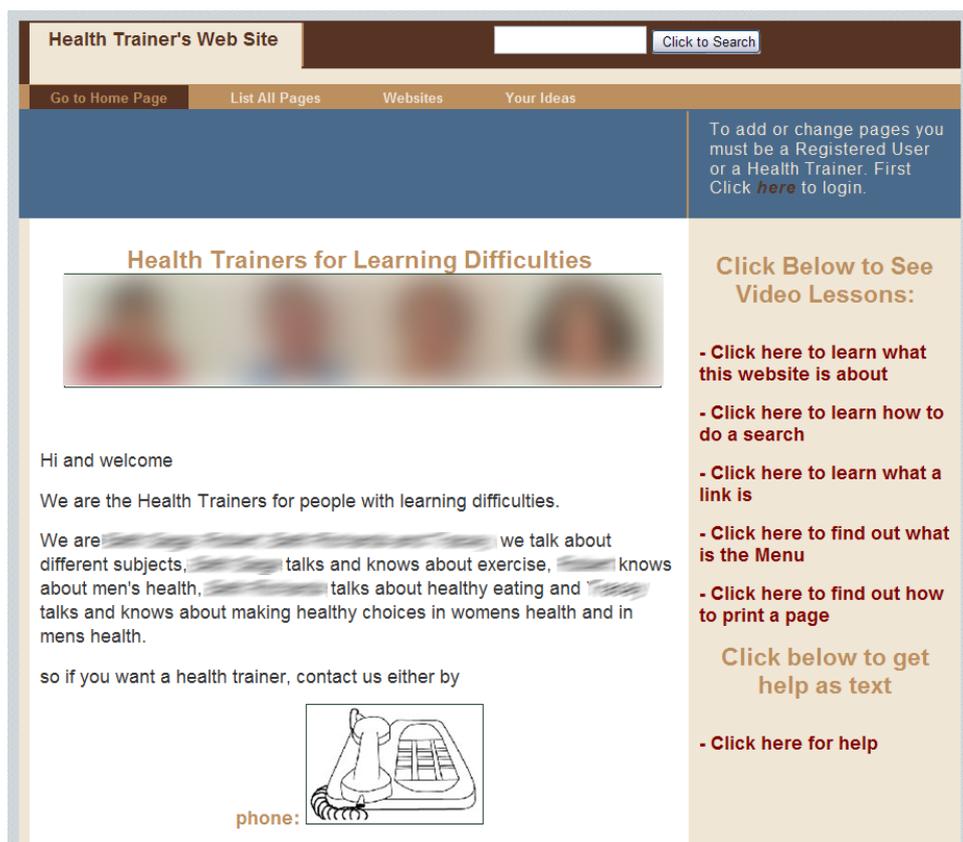
Figure 4.1 – The Home Page of the Health Trainers' wiki based website. The images and real names of the Health Trainers are blurred to hide their identity.

Visitors do not have editing privileges on the site; by contrast a Health Trainer has to first log into the system (log-in) in order to have access to the editing capabilities. The log-in facility is on the top right corner of the site (Figure 4.1) which clearly says 'To add or change pages you must be a Registered User or a Health Trainer. First Click *here* to login.' Health Trainers and Registered Users log-in to the system using a user-name and a password. After they log-in the horizontal menu at the top of the site expands to seven items instead of the four that visitors see (Figure 4.2). The additional menu items allow the Health Trainers to edit the site. Registered Users and the Health Trainers also have access to a variety of other buttons which also allow them to edit different aspects of the website. The buttons are located at different places on the system's Graphical User Interface (GUI), and they are not available (hidden) to non-registered visitors.

Figure 4.2 - How the horizontal menu expands to seven items after Registered Users or the Health Trainers, log-in the developed system. The extra menus allow editing of the site.
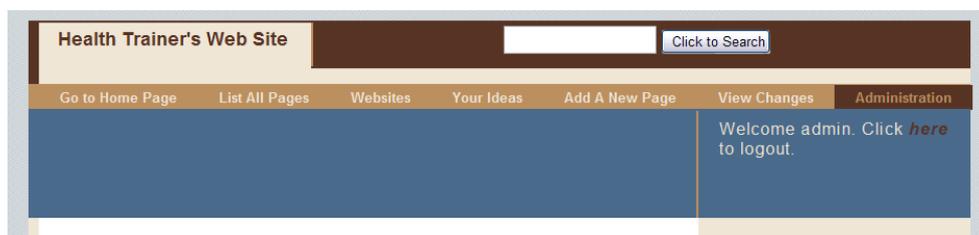
The wiki application developed was deployed online and at the time of writing continues to be available to be visited by Web users. The Web address cannot be disclosed in this public document as the Health Trainers have included personal details on the site whose disclosure would constitute a breach of the confidentiality and anonymity promised in the process of gaining ethical approval (discussed in Section 3.6).

4.4 Methodology

The software development methodology chosen was Evolutionary Prototyping and is described in the following section. Evolutionary Prototyping is an Agile Development methodology which uses iterative and incremental cycles (Larman, Basili 2003). During each cycle the user requirements are refined and are incrementally incorporated into the software application in order to construct a system of increasing fidelity. In the present work, meetings with the Health Trainers were used to refine the requirements. The deployed product was evaluated qualitatively by observing the Health Trainers while using the system.

4.4.1 Evolutionary Prototyping

Agile Development methods have had a long gestation, but their principal characterisation was not codified until 2001 at the Snowbird, Utah, workshop which resulted in the publication of the *Manifesto for Agile Software Development*

(Beck, Beedle et al. 2001). Some of the principles of agile development are highly relevant to the current study (Beck, Beedle et al. 2001)[online]):

- Our highest priority is to satisfy the customer through early and continuous delivery of valuable software.
- Welcome changing requirements, even late in development. Agile processes harness change for the customer's competitive advantage.
- Deliver working software frequently, from a couple of weeks to a couple of months, with a preference to the shorter timescale.
- Business people and developers must work together daily throughout the project.
- Build projects around motivated individuals. Give them the environment and support they need, and trust them to get the job done.
- The most efficient and effective method of conveying information to and within a development team is face-to-face conversation.
- Working software is the primary measure of progress.
- Agile processes promote sustainable development. The sponsors, developers, and users should be able to maintain a constant pace indefinitely.
- Continuous attention to technical excellence and good design enhances agility.
- Simplicity-the art of maximizing the amount of work not done-is essential.
- The best architectures, requirements, and designs emerge from self-organizing teams.
- At regular intervals, the team reflects on how to become more effective, then tunes and adjusts its behaviour accordingly.

Software prototyping is the activity of creating prototypes or incomplete versions of software systems that are being developed. A prototype normally simulates only a few aspects of the final system and may be completely different from the actual implementation. Prototyping offers several benefits. By allowing the users to interact with the prototype the software designers can get valuable input early in the project. The client and/or the users can compare if the software under

construction matches the specifications requested. It allows the software engineer some insight into the accuracy of the initial project estimates and whether the deadlines and milestones proposed can be successfully met (Bischofberger, Pomberger 1992). This process is in contrast with the linear and monolithic development paradigm which builds the entire program first and then works out any inconsistencies between requirements and implementation and which in turn lead to higher software costs (Connell, Shafer 1989). Therefore prototyping can avoid the great expense and difficulty of changing a finished software system.

The unique purpose of a prototype is to allow end-users of the system to evaluate the design by actually trying it out rather than having to interpret and evaluate the design based on descriptions and/or paper mock-ups or other models. Prototypes can also be employed by end-users to describe and prove requirements that designers have not considered. Interactive design in particular makes heavy use of prototyping (Connell, Shafer 1989). Prototyping design models try to overcome the inherent process of incomplete requirements specification by cycling through several designs, incrementally improving the system with each pass. This type of iterative development process has advantages over linear/monolithic processes especially for interactive system design in which it is difficult to ensure that all user requirements are clearly specified at the beginning. In order to overcome this problem Evolutionary Prototyping and other prototyping models, place special emphasis on the rapid building of a prototype system with which the end-users can interact early and provide feedback. Following an evaluation of such an interaction with the end-users the designers can improve the system making it more usable (Connell, Shafer 1989, Rubenstein, Hersh 1984).

The process of prototyping involves the following steps (Rubenstein, Hersh 1984).

1. Identify basic requirements, details such as for example security can be ignored.

2. Develop an initial prototype which typically includes the user interface and basic functionality.

3. The end-users examine the prototype and provide feedback on additions or changes that need to be done.

4. Revise and improve the prototype using the feedback from the end-users. If changes are introduced then a repeat of steps 3 and 4 may be necessary.

Software prototyping has many variants, though all the methods are essentially based on two major types, Throwaway Prototyping and Evolutionary Prototyping (Bischofberger, Pomberger 1992, Pressman 2001). Throwaway Prototyping also known as close-ended prototyping creates a model or a number of models that will eventually be discarded rather than become part of the final implementation.

The aim of Evolutionary Prototyping which was adopted in the current study is incremental or successive system development. A prototype is first developed from a set of initial user requirements and requirements stemming from problem domain and environment analysis. The result serves as an initial system with which the end-users can interact and give feedback for the succeeding iterative cycle during which the new user requirements are integrated into the prototype in order to refine it. The iterative process of prototype refinement is continued until a satisfactory system is finally developed (Figure 4.3) (Bischofberger, Pomberger 1992, Pressman 2001). In Evolutionary Prototyping prototypes are not viewed as throwaways but they are instead successively elaborated towards a final product. This type of approach does not differentiate between prototype and final product, yet the prototype designation is appropriate because the initial versions certainly cannot be viewed as the final system nor is the deployed system necessarily final (Bischofberger, Pomberger 1992).

Evolutionary Prototyping process
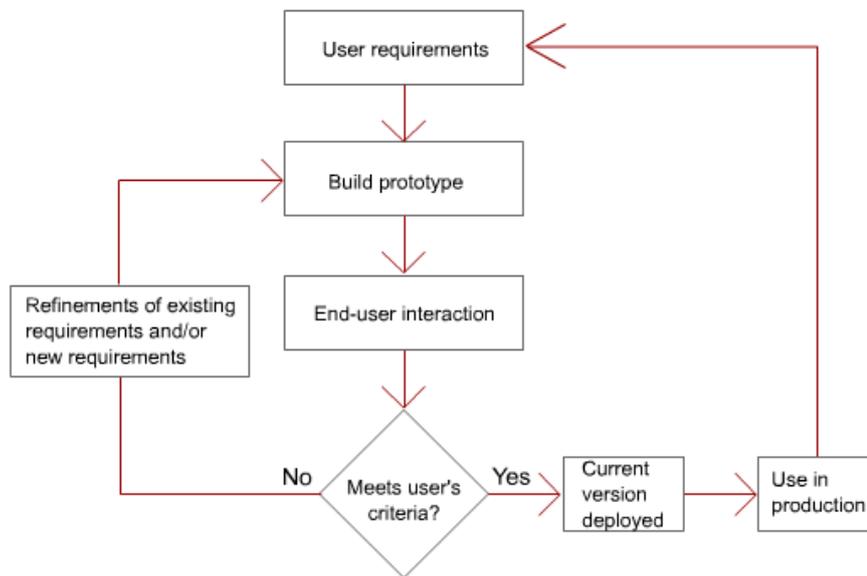
Figure 4.3 – The iterative process of Evolutionary Prototyping (Author created).

The Evolutionary Prototyping methodology was chosen for the needs of the study for a variety of reasons:

- It allowed the involvement of the end-users in the process and this was compatible with Participatory Action Research the adopted research methodology
- The iterative process of Evolutionary Prototyping is compatible with the *plan*, *act* and *reflect* cyclical process of Participatory Action Research
- The basic task requirements (functionality) of a wiki were known at the onset because wikis existed for several years before the study started. This allowed the use of an open source product as the initial prototype, instead of developing one from scratch which saved a considerable amount of development time
- It had an advantage over Throwaway Prototyping in that the initial prototype was already a functional system which was refined instead of discarded

- Prototyping is especially good for designing interactive interfaces (Connell, Shafer 1989). To make a system accessible to a specific group of end-users most of the work done is typically on the interactive user interface

Bischofberger and Pomberger (1992) observed that the most important disadvantage of Evolutionary Prototyping is the fact that sometimes as the process progresses a complete redesign may be necessary instead of just refinements. As this may not be economical, redesign may not occur and instead developers continue making minor changes. If this happens then the result may be low quality system architecture. This type of drawback did not affect the system developed for the current study because a fully functional open source system was used as the initial prototype and its architecture was already in place. Most of the work done to make the initial prototype of the study accessible to people with learning difficulties, were user interface and functionality simplifications. These types of changes did not affect the architecture of the system.

4.4.2 Procedure Followed

System development happened in a period of approximately seventeen months, between June of 2008 and November of 2009. This process included meetings to familiarise the Health Trainers with Web 2.0 technologies as they were unfamiliar with them. The involvement of the Health Trainers in software development was integrated into the Participatory Action Research Meetings (described in Section 3.7.1.1). The Participatory Action Research Meetings were used both to conduct the research and to develop the software system. Out of fourteen meetings organised for the needs of the study, eleven of them concentrated mostly to software development as shown in Table 4.1. The meetings were divided into five Evolutionary Prototyping iteration cycles.

Table 4.1 – The meetings which concentrated mostly on the development of the system.

Group Num.	Date	Attending Health Trainers	Venue	Description
1	25/06/08	6	UWE classroom	Discussed different technologies that could be developed
2	16/07/08	6	UWE classroom	Tutorial on Web 2.0 technologies, wikis, blogs and social networking. Asked Health Trainers to think about technologies that could benefit their Health Trainer role.
3	16/09/08	4	UWE classroom	Ideas for a new system. Decided to develop a wiki. Initial software requirements.
4	17/03/09	4	Health Trainers' office	Observed Health Trainers perform basic computer operations to get a sense of their computing skills (on a one-by-one basis).
5	23/03/09	4	Health Trainers' office	Tutorial on how to use the first prototype of system. Gathered input and new requirements on the first software system prototype. Evolutionary Prototyping iteration one.
6	22/06/09	4	Health Trainers' office	Gathered input and new requirements on the second software system prototype. Evolutionary Prototyping iteration two.
7	07/07/09	4	Health Trainers' office	Gathered input and new requirements on the third software system prototype. Evolutionary Prototyping iteration three.
8	24/08/09	4	Health Trainers' office	All system requirements implemented. System considered ready for evaluation. Evolutionary Prototyping iteration four. System use evaluation begins. Observed Bonnie while using the system.
9	28/09/09	3	Health Trainers' office	System use evaluation, observed Brenda while using the system.
10	21/10/09	2	Health	System use evaluation,

			Trainers' office	observed Tanya and Roy while using the system (on a one-by-one basis).
11	25/11/09	2	Health Trainers' office	System available online. Helped Tanya and Roy with system use difficulties. Evolutionary Prototyping iteration five.

The requirements gathering procedure used during the software development sessions was discussed and agreed within the Participatory Research Team and was the following:

- The researcher sat in front of the computer on which the wiki system was running while two of the Health Trainers sat on his left and the other two on his right. At this stage, the researcher verified that all Health Trainers could see the screen well.

- The researcher then showed the Health Trainers how to use the system step-by-step, and on each step encouraged the Health Trainers to stop him and suggest changes which would make the system more usable and accessible.

- Sometimes the researcher would point at an interface element to draw the Health Trainers' attention there and ask them a non-leading question such as 'what do you think of this control?'

- From time to time a Health Trainer would sit at the computer where the system was running and try something in order for the rest of the team to observe how the user was using it. While being observed the user was encouraged to speak aloud of what she/he was doing or describe the type of challenges if any, she/he was facing.

Some of the things that the researcher was pointing at and some questions that he asked were prepared before going to the meeting. The researcher was always careful so that both the prepared questions and the questions asked during the meeting were not leading questions. For example instead of asking 'do you think we should change this button?' he used to say something like 'what do you think

of this button?' The session had an informal atmosphere and the Health Trainers had time to talk between themselves.

The sessions were audio recorded and the researcher was also writing down requirement and other observation notes. As soon as the session finished, the researcher would complete or write more observation notes in his car before driving away. The audio recordings were transcribed verbatim. Some system requirements were extracted from the transcribed recordings. After the meeting the system requirements were implemented into the system by the developer, to be shown at the next meeting for further feedback from the Health Trainers.

In later iterations where previous requirements were already implemented into the system, at least two Health Trainers, would in turn sit at the computer and try the specific interface controls that were changed. While using the specific interface control the users were encouraged to vocalise their thoughts or any difficulties they were facing. The rest of the Participatory Research Team observed if the user could use the control after the required changes were implemented. This was done in order to find out if the interface control changes were satisfactory to the users. During this procedure the researcher was keeping separate notes for each individual interface control that was being used by the Health Trainer.

At the start of system development the Participatory Research Team had a discussion on using a different procedure which was suggested by the researcher. Later the team decided to adopt the above described procedure as it met the Health Trainers' needs better than the suggested one. This issue is discussed further in Section 6.8.1.

The team work described above and the process of co-design, implementation and evaluation was iteratively repeated until all the Health Trainers' requirements were incorporated into the system. As described in Section 4.8, a very small number of requirements could not be implemented due to limited resources. As shown during the evaluation of the system (please see Section 4.7), the limitations did not affect the usability or accessibility of the system.

4.4.3 The Methodology Used

The needs of the current study required the development of an accessible software system, the conduct of research as well as the involvement of people with learning difficulties in both research and software development. Therefore, Evolutionary Prototyping was used, which was adapted to the needs of the study, by including elements from Participatory Action Research (described in Section 3.4). As portrayed in Section 4.4.1, Evolutionary Prototyping falls under the User-Centred Design (UCD) class of methodologies. User-Centred Design is an umbrella term used for participatory design processes which has been standardised by the International Organization for Standardization (International Organization for Standardization (ISO) 2010, International Organization for Standardization (ISO) 1999). It is recognised by both the academic and practitioner communities as the best way to improve system usability (Mao, Vredenburg et al. 2005).

When building software systems, User-Centred Design recommends an iterative process, the active involvement of users and multi-disciplinary design teams (International Organization for Standardization (ISO) 1999). It also proposes four software development stages (International Organization for Standardization (ISO) 1999):

1. To understand and specify the context of use,
2. To specify the user and organisational requirements,
3. To produce design solutions,
4. To evaluate the system design against the requirements.

The ISO 13407 (International Organization for Standardization (ISO) 1999) has in 2010 been replaced by a newer more detailed standard, the ISO 9241-210:2010 (International Organization for Standardization (ISO) 2010). The newer standard provides more detail on most aspects of the process and turns many of the recommendations into necessary criteria which must be fulfilled in order for a process to be classified as User-Centred Design (International Organization for Standardization (ISO) 2010). For example, ISO 13407 suggested that 'iteration' be conducted during the evaluation phase, but in ISO 9241-210:2010 iteration is a required criterion and should be carried out in every phase of the process. Also, it

is now required, not recommended, that the design of a software system be driven and defined by the users' feedback. These required criteria mean that a software system has to be developed through several cycles, and the end-users must be taking part in the development and have a greater impact on the end result (International Organization for Standardization (ISO) 2010). One reason for this is the fact that end user requirements and recommendations are being returned to continually.

As stated previously, the first stage of software development proposed by User-Centred Design is to understand and specify the context of use. The context of use looks at who are the stakeholders, for example who will be using the software, the motivation for using it and the environment in which it will be used. When this stage is complete, the development team must be able to provide details on the stakeholders, including the end-users and their goals, the tasks the system should be able to provide, and the environment in which the system will be used. The stakeholders/users should be involved even at this very first stage because their needs have to be understood within the context of use (International Organization for Standardization (ISO) 2010).

The focus of the second stage as proposed by User-Centred Design is to specify the user and organisational requirements. The requirements stage should be on what the stakeholders and users want to achieve and not how the system will provide this (International Organization for Standardization (ISO) 2010). The requirements should also include any constraints imposed by the context of use and how those will be addressed. If there are conflicts between the different requirements these must be resolved at this stage. The standard also requires that developers record how these conflicts will be resolved so that if necessary they can be referred back to later (International Organization for Standardization (ISO) 2010).

During the third development stage suggested by User-Centred Design, 'to produce design solutions,' the users must be involved in the process and shown the proposed solutions because this may encourage further system requirements. As the process progresses the designs must become more concrete by using

scenarios, simulations, mock ups or prototypes. The standard also emphasises interaction between the users and the system and the users and the developers (International Organization for Standardization (ISO) 2010).

According to the latest ISO 9241-210:2010, in the final User-Centred Design suggested stage, the evaluation of software systems is a required rather than a recommended activity (International Organization for Standardization (ISO) 2010). There are two main evaluation methods, heuristic and user-based testing. When heuristic based evaluation takes place, experts use guidelines (i.e. usability and accessibility) to evaluate the system prototype. There are a variety of guidelines available like for example the Web Content Accessibility Guidelines of the World Wide Web Consortium for developing accessible websites (W3C 2008). Dix (2004) and Nielsen (1993) specify a number of other software usability guidelines against which software systems can be evaluated (Nielsen 1993, Dix, Finlay et al. 2004., Dix, Finlay et al. 2004.). According to the User-Centred Design standard, heuristic based testing should not be the sole evaluation method though, but it should be used to eliminate major issues before user-based evaluation (International Organization for Standardization (ISO) 2010).

In user-based evaluation the users perform system tasks and report their thoughts about the software and any problems they encounter (International Organization for Standardization (ISO) 2010). The system should also be checked against the users' requirements given during previous stages of the software cycle and ensure it meets all of them. To achieve conformance with ISO 9241:210 a process must meet the above mentioned recommendations and requirements or it must be explained why some of them have not been followed (International Organization for Standardization (ISO) 2010).

User-Centred Design places special emphasis on the participation of the final users during all four User-Centred Design stages. Therefore software designers/developers can use various social science methods in order to facilitate user involvement. For example, during the first software development stage, User-Centred Design recommends to understand and specify the context of use. Most software developers have limited experience of people with learning difficulties

and the environments in which they live or work, (i.e. care centres) (Waller, Balandin et al. 2005). Software developers could therefore use ethnographic methods in order to meet this specific community of users in the environments they spend most of their time and observe how they could use a potential software system.

During the last two decades ethnography has become an accepted process in Human-Computer Interaction (HCI) (Prior 2011, Dix, Finlay et al. 2004.). The two main methods within the ethnographic process are observations and focus groups and both can be used within User-Centred Design processes (Prior 2011, Weng, McDonald et al. 2007). By using observation methods, software developers can understand the context surrounding the software system's location and its users (context of use) during stage one of the User-Centred Design process. Focus groups can be used during any of the four User-Centred Design suggested stages. For example, focus groups are often used during system evaluation or for requirements gathering to identify the needs of different stakeholders and discuss any conflicting wishes in the design (Pressman 2001, Tomayko, J. E.,Hazzan, Orit,, 2004).

Another social science method, which can be used within any User-Centred Design stage, is interviewing. Interviewing methods involve the developer and the user/participant discussing topics and engaging with one another in an interactive manner. Interviews are useful as they allow the developer to probe into why a user or participant thinks in a certain way. There are three main forms of interviewing: structured, semi-structured and unstructured (Ritchie, Lewis 2003, Huberman, Miles 2002). Structured interviews are constituted by predetermined questions from which the interviewer does not deviate. Unstructured interviews take the form of a general discussion around a specific topic and tend to be exploratory in nature, whereas semi-structured interviews will have a combination of both open and closed questions (Ritchie, Lewis 2003, Huberman, Miles 2002).

Another method which can be used by software developers within User-Centred Design are survey style questionnaires. Questionnaires are similar to interviews in

that they can be formed by both open and closed questions and they can be used at any stage of the development cycle but they are not interactive. They can for example be administered without the presence of the developer/researcher. This can sometimes be an advantage because users may feel more comfortable answering personal questions. The disadvantage is that the developer cannot clarify any queries which the users may have or probe into why they think in a certain way (Huberman, Miles 2002, Holliday 2002).

Finally, within User-Centred Design, developers can use most other methods available to social scientists and some less common ones like role-play and video which are discussed in Section 6.7.3. All the previously mentioned tools are used by social scientists and they can also be employed within User-Centred Design. User-Centred Design places special emphasis on multi-disciplinary design teams and the involvement of the final users in the software development process. Therefore software designers and developers should be familiar with the use of social science methodologies. However software designers and developers are typically not trained in the use of social science methods.

As discussed in Section 3.2 software developers and social scientists follow completely different perspectives. There is a difference, for example, between how designers/developers and how social scientists involve end-users. When software developers involve users their primary aim is to create usable technology and the methodologies they use reflect that (Newell, Gregor 2000). Conversely, social scientists understand that they are located within a network of stakeholders, who all have different understandings, ways of knowing about the world and the topic which is being investigated and possess different political powers (D'cruz, Jones 2004). Given this fact it is important for the social scientist to be aware of any differences and tensions that may be generated through knowledge and power about the topic under investigation. For example, in a focus group it can be difficult to get all of the members to participate and often one or two can dominate the discussion. If a person of power (i.e. boss) participates in a focus group it may affect how some of the participants express their views (Huberman, Miles 2002).

Within the social sciences the ethics and politics of the research are important (D'cruz, Jones 2004). An investigation into an area of the social world, for example, demands the adherence to a specific ethical code in order to guide the social scientist and minimise the impact of the research on the participants (Kimmel 1988). Furthermore, social scientists are trained to be reflexive attempting to recognise any biases they themselves may have about the phenomenon under investigation. Software developers typically are not academically trained about the specific social science concepts unless required during their graduate studies (Tomayko, J. E.,Hazzan, Orit,, 2004, Hazzan 2010).

Participatory design and research methodologies are not only about acquiring requirements for system development or advancing knowledge. They also present an ethical dimension for giving participants and users a voice in technology or research. Participatory methodologies are democratic as they support the sharing of power between the participants and the researcher or the developer. In Participatory Action Research the researcher as a trained specialist supports the participants to conduct their own investigation. Thus the researcher shares power and knowledge with the participants. The participants own the research and they are empowered to make and implement decisions.

The requirement of User-Centred Design to involve the final users and the emphasis which the software development community puts on this standard necessitates that software developers be academically trained to the specific ideas from the social sciences. At the moment this does not happen to the extent that it should (Tomayko, J. E.,Hazzan, Orit,, 2004, Hazzan 2010). Social scientists and the methodologies they use reflect on all these issues while software developers are typically not educated about them. Software designers and developers see themselves as specialists and they are challenged when they have to share power with users. Therefore, the current study used Evolutionary Prototyping but adapted it by including elements from Participatory Action Research in order to consider the above mentioned issues.

4.5 System Requirements

Most software systems start with a need that a client has. The software system itself is created by designers/developers, and the completed system finally used by the end-users. Thus there are three major parties interested in a new system: the client, the designers/developers, and the end-users. In the case of the current study the researcher and supervision team of the study who specified what should happen acted as the client, while the researcher was also the developer and the Health Trainers were the end-users of the developed system.

The requirements for the system that will satisfy the client and the needs of the users have to be communicated to the developer. Sometimes the client and users do not understand software or the software development process though, and the developer might not understand the client's problem, the application area or the users' needs. Therefore, there might be a communication gap between the stakeholders involved in the development process. A basic purpose of requirements engineering is to bridge this communication gap so that the stakeholders have a shared vision of the software being built. This is especially true for linear or monolithic software development processes which are not iterative and typically use the waterfall model (Jalote 2008). Agile and iterative processes maintain a closer contact with the client and end-users; therefore the communication gap is less of an issue (Pressman 2001). The requirements engineering provide the appropriate mechanism for understanding what the client and users want, analysing need, assessing the feasibility of the system, negotiating a reasonable solution, specifying the solution unambiguously and managing the requirements as they are transformed into an operational system (Pressman 2001).

Bahill and Dean (2009) define a requirement as, "a statement that identifies a capability or function needed by a system in order to satisfy a customer need." (Bahill, Dean 2009)p. 209). All software development methodologies require requirements to be specified. Agile software processes similar to the one used in the study, require only high-level requirements to be specified in written form. In agile processes detailed requirements are elicited through interaction with the

customer and the users, which in the iteration they are implemented directly in the software system (Rubenstein, Hersh 1984, Jalote 2008). For linear or monolithic software processes all the requirements must be gathered, analysed and documented in advance before development begins and they must be specified precisely. For this type of processes the aim of the requirements activity is to produce a precise Software Requirements Specification (SRS) document which describes what the proposed software should do without describing how the software will do it (Jalote 2008). For linear/monolithic models the requirements process typically consists of three tasks, problem or requirement *analysis*, requirements *specification*, and requirements *validation* (Jalote 2008, Leffingwell, Widrig 2003).

During the analysis stage the problem domain and the environment are typically modelled in an effort to understand the system behaviour, constraints on the system, its inputs and outputs. The purpose of this activity is to obtain a comprehensive understanding of what the software needs to provide. Typically during analysis, the analyst will have a series of meetings with the clients and end-users. In the early meetings, the clients and end-users will explain their work, their environment, and their needs as they understand them. Any documents describing the work or the organisation may be given to the analyst, along with outputs of the existing methods of performing the tasks. In these meetings, the analyst is basically a listener, absorbing the information provided. Once the analyst understands the system to some extent, he then seeks clarifications of the parts he does not understand. The information is documented and some models may be built that show what the system should do. In the final meetings, the analyst essentially explains to the client what he understands the system should do and uses the meetings as a means of verifying if what he proposes the system should do is indeed consistent with the objectives of the clients and the users (Pressman 2001, Jalote 2008).

In a typical scenario of software system development the client approaches the developer with a specific need or a specific system in mind. The developer then performs an analysis as described above in order to understand what type of

system should be developed. In the case of the current study it was suggested by the researcher and the supervision team that it should be explored how people with learning difficulties could be involved in the development of a software system based on Web 2.0 technologies. The purpose of the study was to conduct research during the process of which a system would be developed. The requirements analysis stage was therefore somehow different in the following ways. The client (supervision team and researcher of the study) did not know how the Health Trainers worked and did not have specific ideas on the functionality of the system. That was left for the Health Trainers to decide. Therefore, the Health Trainers (end-users) themselves were asked to decide about the functionality of the system. The system could be anything that would support the Health Trainers' duties and it should probably be based on Web 2.0 technologies (the requirements analysis stage is described in more detail in Section 4.5.1). Finally the Health Trainers asked for a wiki for which its basic functions and boundaries were already known and the analysis only revealed specific features that this system should have.

In linear software processes the aim of the requirements specification phase is to produce a precise Software Requirements Specification (SRS) document which describes what the proposed software should do (Jalote 2008). As already observed previously, agile software processes similar to the one used in the current study, require only high-level requirements to be specified in written form. Therefore the current study did not require a precise SRS document. The understanding obtained about the required system during the initial meetings with the Health Trainers formed the basis of a requirements document which described the high-level requirements. This document was expanded during the following Evolutionary Prototyping iteration cycles (Appendix 3).

Finally, requirements validation is more appropriate for linear/monolithic software development processes which use the waterfall model and it focuses on ensuring that what have been specified in the SRS are indeed all the requirements of the software. This is necessary because in linear processes, development does not start unless all the requirements are finalized (Pressman 2001, Jalote 2008).

Prototyping design models like the one used in the current study try to overcome the inherent process of incomplete requirements specification by cycling through several designs, incrementally improving the system with each pass (Rubenstein, Hersh 1984).

4.5.1 Analysis and Initial Requirements

During the first Participatory Action Research Meeting the Participatory Research Team discussed different types of Web 2.0 technologies that could be developed in order to improve or enhance the service that Health Trainers provided. The researcher also asked the Health Trainers if they had a software system in mind which could help them in their role. During the discussion some of the Health Trainers observed that they were not familiar with some of the Web 2.0 technologies mentioned, wikis, blogs and social networking (Facebook). All the Health Trainers stated that they did not know what wikis or blogs were and Roy and Tanya mentioned that they never used Facebook either. Two of the Health Trainers were familiar with Facebook. Consequently the Participatory Research Team decided that during the next meeting the researcher would try to book a computer lab to present a tutorial on common Web 2.0 technologies.

In the second Participatory Action Research Meeting the Participatory Research Team spent approximately two hours on a tutorial in which the researcher presented three common Web 2.0 technologies, wikis, blogs and social networking. At the end of the tutorial the Participatory Research Team discussed types of technologies that could be helpful to the Health Trainers. The team ran out of time and therefore decided to continue the conversation in the next meeting.

The conversation was followed in the third Participatory Action Research Meeting during which the Health Trainers suggested that they liked one of the systems shown to them during the previous meeting. Then Tanya and Roy asked the researcher to repeat the tutorial on Web 2.0 technologies again in order to refresh their memories. During the meeting the Health Trainers indicated that the system

they liked and believed could help them improve the service they provided was a wiki.

During the same meeting the Participatory Research Team had scheduled a discussion about the Health Trainers' duties as part of the software requirement analysis. The Participatory Research Team went ahead and discussed the Health Trainers' duties even though they had already indicated that they would like a wiki to be developed. A discussion about the Health Trainers' duties was still important to understand the environment in which they would be using the wiki. The Participatory Research Team also contemplated that by discussing the Health Trainers' duties they might gain new insights into specific features that the wiki could have.

Tanya described their Health Trainer duties as follows:

> "What we are doing is showing or sending them [the Health Trainers' clients] by post accessible information about health, from when we went to the conference they [clients] were there as well, like healthy information day. Then we split up into groups and we ask them what they thought of the day and what information they wanted us as Health Trainers to send them or if they wanted to come and see us, and they said things like healthy eating, exercise, so that we have to make like a handout and make it on the computer, like pictures of fruit and things like that and also [Tanya names their instructor] made a health action plan and they don't have to pick everything out that they want to know about, it could be just two things from the health action plan, and we need to try to get them to improve their health."

During the discussion the Health Trainers stated that a major part of their duties was to prepare accessible hard copy brochures for their clients using Word. Each one of them prepared brochures on a specific topic. A number of those brochures were presented in a previous meeting and the researcher was allowed to take them off-site for further study. The Health Trainers suggested that with a wiki they could make the information contained in their brochures available on the Internet.

From the discussion several initial requirements started to emerge. The Health Trainers asked the researcher specific questions such as if they could upload their health action plans or recorded voice or even video on the wiki. During the discussion about the Health Trainers' duties, they also stated that some of their clients could not read and that the Health Trainers sent them recorded information. The following conversation on information supplied in different formats took place:

> Researcher: "So, if the person that you are advising cannot read you prepare a tape for him?"

> Tanya: "Yes, or pictures. Maybe he or she might understand things better with pictures…"

> Researcher: "…What if you wanted to record something on a tape or video?"

> Tanya: "We have little recorders, they are like mobile phones, but they are like the same size…"

An initial requirement that the Health Trainers asked was to be able to upload sound files on the system. Another requirement that emerged from the discussion was that even though each Health Trainer would be preparing wiki pages relating to his or her specialisation, they preferred to be able to edit anybody's pages.

During the same meeting the researcher recommended that two Health Trainers try to use a typical wiki and describe their experience while using it to the rest of the team. Roy and Brenda in turn sat in front of the computer to try to edit an article in the Simple English version of Wikipedia while the rest of the Participatory Research Team was observing them. Wikipedia was the most famous wiki on the Web and it was shown to the Health Trainers during the tutorial part of the meeting.

In editing mode Wikipedia, and most other common wikis, used a user interface which was not WYSIWYG. WYSIWYG is an acronym for 'What You See Is What You Get.' It is a computing term used to describe a system in which content

displayed during editing, appears very similar to the final output. For example, in most of today's word processing applications when a user highlights a paragraph and clicks the 'bold' button the paragraph is immediately presented in bold form. This is an example of a WYSIWYG editor. Wikipedia did not work like this. When users tried to format a section of text in the Wikipedia editor instead of seeing the results immediately, the text remained the same and two cryptic tags appeared at the beginning and the end of the highlighted section. The two tags indicated that the specific part of the text was formatted. This was confusing to both Roy and Brenda who tried to edit the article in Wikipedia. As a result, another initial requirement for an accessible wiki was to get rid of the tags and make the editing WYSIWYG like it was in Word, a software application with which the Health Trainers were familiar.

After the third Participatory Action Research Meeting the developer had the initial system requirements and could start development on a wiki system. Between the Participatory Research Team's third meeting when the decision for a wiki was taken and initial requirements gathered and our fifth meeting during which the first prototype of the new wiki was presented there was a period of approximately six months. During that period the developer looked at several open source wikis which could be used as a base for the Health Trainers' system. Dotwiki (described in Section 4.6) was chosen as it was developed in a computer language that the developer was familiar with and could therefore change it. Dotwiki also had several other features which the Health Trainers were looking for, like for example a WYSIWYG editor which could be adapted further. Other than the editor the rest of Dotwiki's features, functionality and user interface were very typical. By starting with an existing wiki which had already been used by typical users as a first prototype the possibility of general design flaws that may not relate to learning difficulties was eliminated. This foundation system was then changed accordingly to accommodate the Health Trainers' accessibility requirements.

Dotwiki was installed and made to work on a laptop computer so that it could be taken to the Health Trainers' office. The open source wiki was then presented to the Health Trainers and the rest of the requirements were gathered during the

software development cycles that followed. The user requirements that the Health Trainers asked in the following development cycles are presented in the next section.

4.5.2 The Rest of System Requirements

The rest of the system requirements were gathered between March and August of 2009 in four Evolutionary Prototyping iterative cycles as shown in Table 4.1. During each cycle the collected requirements were implemented into the system and then shown to the Health Trainers for feedback at the beginning of the next cycle. The following paragraphs present a summary of the requirements that the Health Trainers asked.

A major requirement that was asked several times was for a large font size (at least 14 points or bigger) both on the system interface but also in other places like the Help system. Another common requirement was for information to be short and in simple language. The Health Trainers for example asked that the topics of the Help system to be short, simple and to the point, not long and boring. The video tutorials should also be short and to the point. They requested simple (non-complicated) subjects that do not need serious thinking, the elimination of irrelevant material and the elimination of useless information which users would have to read or go through in order to get to the important parts.

Another main requirement was for the interface itself to be as simple and un-cluttered as possible. The Health Trainers found interfaces that were cluttered with too many buttons, too much text or too many commands confusing. They showed preference to simple interfaces with few buttons and a few descriptive commands.

The caption on the interface controls such as buttons or menus should not be a single keyword like for example 'print' or 'delete.' Instead the Health Trainers always asked for descriptive captions like 'click here to print this page' or 'click here to delete this page.' The control caption should describe what the control did.

The Health Trainers also showed preference to common vocabulary and no technical jargon. A common requirement was to remove uncommon and technical words from the interface and other places like the Help system. For example, instead of 'create page' they asked for 'add a new page,' the 'edit page' button to become 'click here to change this page,' and the 'index' menu to become 'list all pages.' They also asked for the word 'wiki' to be removed where it occurred and that H1 should become 'Heading 1,' H2 should become 'Heading 2' etc.

Outlining the system requirements it can be observed that the most important changes requested were simplifications, user interface changes to make the system easier to learn and multimodality in the Help system. Most system requirements asked by the Health Trainers related either directly or indirectly, to the 'learnability' or the simplicity of the system. Learnability is defined as "the ease with which new users can begin effective interaction and achieve maximal performance" (Dix, Finlay et al. 2004.)p. 260). The system changes requested were not drastic in extent and relatively easy to implement. These observations have implications which are discussed in Sections 6.8 and 7.3.

4.6 System Design

As already stated the system developed for the study was based on the project DotWiki. The DotWiki project and source code are licensed under the open-source license (Correa 2010). The open-source license relates to source code that is available to the public free of charge, to use, copy, modify, distribute or sub-license. Open source code is often improved, enhanced and adapted for the specific purposes of interested programmers. Under the license agreement, the revised versions of the code are also made available to the public (OSI 2010). The source code of the DotWiki project was adapted in order to meet the needs of the Health Trainers according to their requirements.

The system was implemented using Microsoft Visual Studio 2008, ASP.NET, C# and the Javascript programming languages. The layout of the various Web pages were developed using HTML, Cascading Style Sheets (CSS) and Javascript. As a backend for data storage it used the Microsoft SQL-Server 2005 database.

4.6.1 System Architecture

The system was based on 3-tier architecture (Figure 4.4). Tier-1 was comprised of a number of Web pages which contained HTML and Javascript code and which run in the Web browser on the client's machine.

Figure 4.4 – The 3-tier architecture on which the developed system was based (Author created).
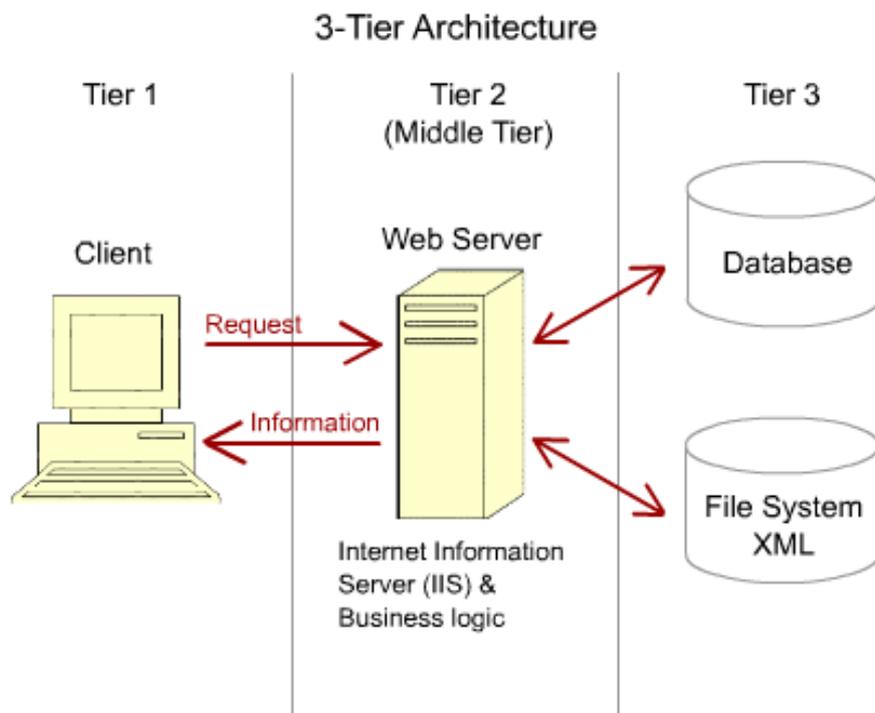
Tier-2 or the middle-tier comprised by the Web server (the Health Trainers' system used the Microsoft Internet Information Server – IIS) which, when requested by the browser, transferred the system's Web pages to the client and run

the business logic of the application. The middle-tier also ran the logic which communicated with tier-3, the database and the file system.

Tier-3 was comprised by the SQL-Server database which was holding the system content, the text of the various Web pages created in the wiki. The file system was also part of tier-3 because resources such as images or sound files resided on the file system.

4.6.2 Class Structure

The Health Trainers' wiki project contained three main groups of classes (Figure 4.5):

- A build in MS-Visual Studio class (System.Web.UI) employed in order to instantiate the various Web pages used to display and edit topic information
- A number of business services classes (Topic, TopicList, TopicInfo, TopicHistoryList, TopicHistoryInfo) that read and saved data from and to the database. These classes were based on the open source CSLA business object framework (Lhotka 2010)
- A parser class (TopicParser) that performed translations on the text coming from the database before the text was displayed on a Web page

Figure 4.5 – The main groups of classes which the developed system contained (Author created).
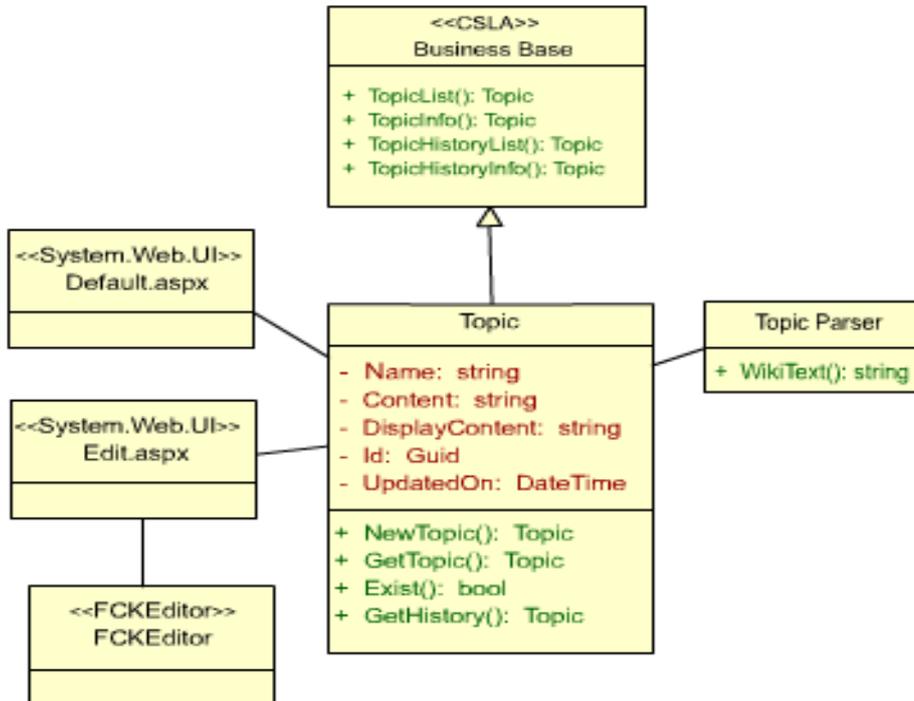
4.6.3 Tier-1 The Web pages

Tier-1 was comprised by a number of Web pages which run in the client's Web browser. The Web pages contained HTML and Javascript code which were responsible for the page's display layout and most of the interface's interactive functions. The most important Web page of the system was the Default.aspx Web page. Default.aspx was the first page loaded when a user visited the website. It displayed topic information and also allowed authorised users to edit the content.

The Default.aspx Web page had two different modes *view* and *edit*. In view mode (Figure 4.6) the wiki assigned the topic information read from the database and the file system to a display interface control on the page so that the browser could display the information. The view mode of the page also made the 'Click here to change this page' (edit) button visible and hide the 'Save this page on the Web' and 'Cancel changes' buttons.

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Figure 4.6 - A topic of the Health Trainers' wiki in view mode.
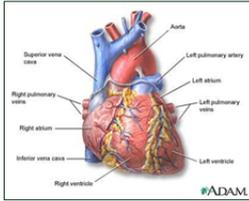
In edit mode (Figure 4.7) the system read the content from the database and/or the file system and assigned it to the CKEditor (formerly FCKEditor). The 'Save this page on the Web'and 'Cancel changes' buttons were also made visible. The CKEditor was a free Web based editor licensed under the open source license (OSI 2010). It was used in the system because it allowed the users to edit the pages in a WYSIWYG environment (Knabben 2011).

Figure 4.7 – A topic of the Health Trainers' wiki in edit mode.
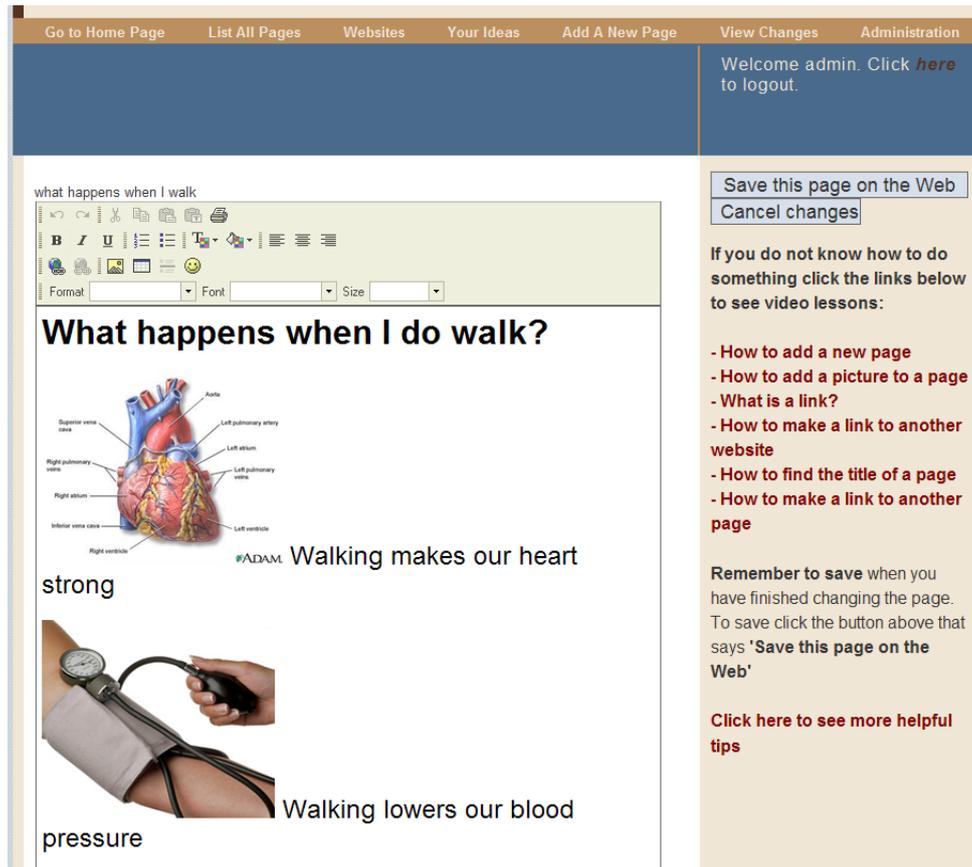
Some other important pages that provided functionality to the system's tier-1 included an 'Index' page that displayed the list of topics in the database, a 'Search' page that allowed users to look for information stored in the database, a 'Feedback' page that allowed visitors to send input and comments to the Health Trainers, a 'NewTopic' page that allowed users to add a new topic and an 'AddUser' page that allowed the Health Trainers to add someone as a Registered User.

4.6.4 Tier-2 Business Services

The code within the Web pages of tier-1 had rather limited functionality and they had to interact with the functionality of the system middle-tier and the business services classes in order to complete most of the tasks. Although users saw and interacted with Web pages when they visited the Health Trainers' wiki, in fact most of the work happened at the tier-2 level. Some of the services performed by the tier-2 classes were, to receive requests from the Web pages, to communicate with the database and file system in order to read and write data, and to pass the results to the Web pages.

For example, when users visited the Health Trainers' wiki, the system loaded the Default.aspx page which in turn used the functions in the business classes to load a topic from the database and the file system. When a user clicked on a link inside a topic, the page called the business objects to load the appropriate record corresponding to the clicked link. Before the content was passed to the page to be rendered the TopicParser object was called in order to process the content and put it in the appropriate format.

When a user clicked the 'Click here to change this page' (edit) button, the Default.aspx page switched itself to edit mode and used the business classes to get the appropriate data from tier-3 in order to display the content of the topic in the WYSIWYG Editor. Then the user could make modifications. When the user finished the modifications and clicked the 'Save this page on the Web' button, the page passed the new modified text to the business objects which in turn sent the text to the database, and finally the Default.aspx Web page switched itself back to view mode. Figure 4.8 illustrates how the different pages and classes interacted with each other as a user visited the Health Trainers' wiki system.

Figure 4.8 - Interaction diagram which shows how the different objects of the system collaborate (Author created).
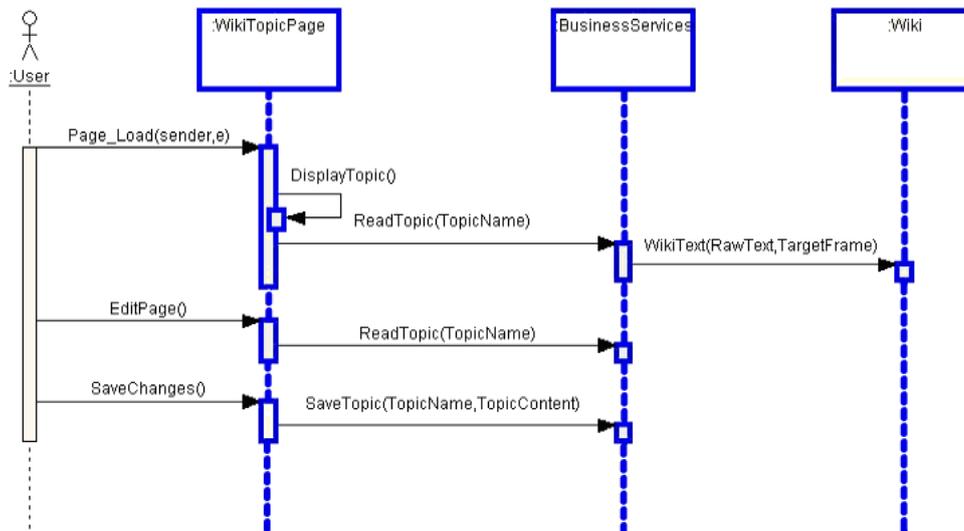
Another important class of the business services was the TopicParser. TopicParser basically parsed text coming from the database and returned a 'browser friendly' version of the text passed to it. For example, the database record for a Web page could contain the following text:

"What you eat affects your health. Go to the [[[Healthy eating]]]

page to read information about how to eat healthy."

When a visitor requested the page which contained the above section of text the text would first be read from the database and then passed to the TopicParser before being send to the browser. TopicParser would analyse the text and in the case above it would replace the phrase contained within the three square brackets with a hyperlink. Three square brackets mean an internal link to the Health Trainers' wiki system but not to a browser. As three square brackets are not a standard HTML tag the browser would not recognise them as a link, therefore the text had to be parsed. In the Health Trainers' wiki the TopicParser parsed the text replacing the three square brackets with the appropriate standard HTML tags which an Internet browser understands, as shown below:

"What you eat affects your health. Go to the <a
href="Default.aspx?topic=Healthy+eating">Healthy eating
page to read information about how to eat healthy."

This way the text and the link would be displayed correctly in the client's
browser.

4.6.5 Tier-3 Database

The Health Trainers' system stored all text information in a database, while the
different media, like images and sound files, were stored on the server's file
system. There was no limit on the number of topics created by the users and no
limit on the number of words used for each topic. Despite this, the database of the
wiki was simple in design and contained only two tables, 'topic' and
'topichistory' (Figure 4.9). Each record in the 'topic' table stored the content
information for one Web page. The topichistory table stored the previous versions
of each of the topics in the database in case a user wanted to go back to an older
version or undelete a page. When users clicked the appropriate button to edit a
page, the system copied the current version from the 'topic' table to the
topichistory and then wrote the new edited version in the 'topic' table. This way
the most recent version of each Web page was always stored in the 'topic' table.

Figure 4.9 - An entity relationship diagram of the two tables that make up the Health Trainers' wiki database (Author created).
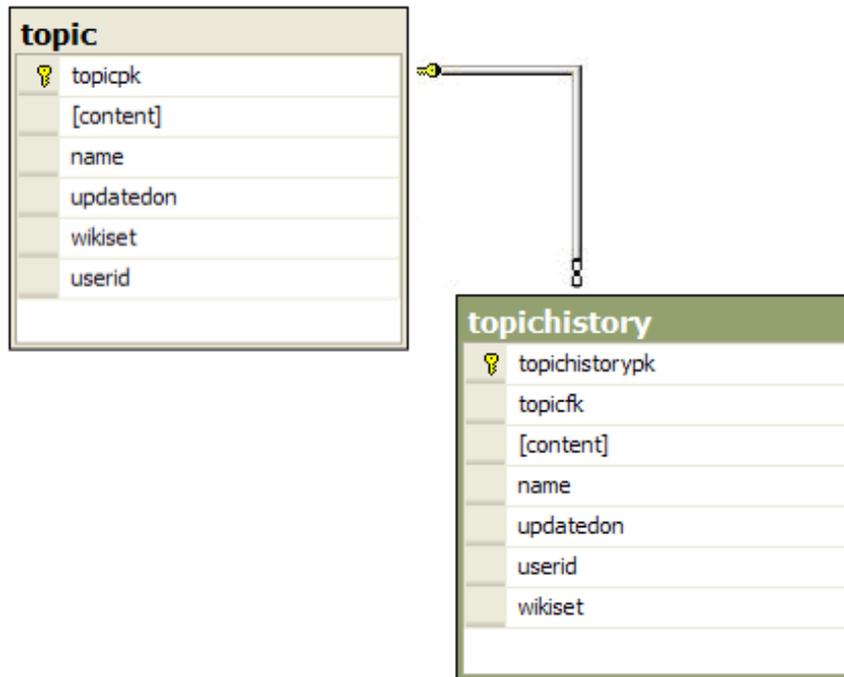
Table 4.2 - The Structure Query Language (SQL) statements used to create the two tables of the developed system's database.

```sql
CREATE TABLE [dbo].[topic] (
       [topicpk] [uniqueidentifier] NOT NULL ,
       [content] [text] COLLATE SQL_Latin1_General_CP1_CI_AS NULL ,
       [name] [char] (50) COLLATE SQL_Latin1_General_CP1_CI_AS NULL
,
       [updatedon] [datetime] NULL ,
       [wikiset] [char] (20) COLLATE SQL_Latin1_General_CP1_CI_AS
NULL,
       [userid] [uniqueidentifier] NULL
) ON [PRIMARY] TEXTIMAGE_ON [PRIMARY]
GO

CREATE TABLE [dbo].[topichistory] (
       [topichistorypk] [uniqueidentifier] NOT NULL ,
       [topicfk] [uniqueidentifier] NOT NULL ,
       [content] [text] COLLATE SQL_Latin1_General_CP1_CI_AS NULL ,
       [name] [char] (50) COLLATE SQL_Latin1_General_CP1_CI_AS NULL
,
       [updatedon] [datetime] NULL ,
       [userid] [uniqueidentifier] NULL,
       [wikiset] [char] (20) COLLATE SQL_Latin1_General_CP1_CI_AS
NULL
) ON [PRIMARY] TEXTIMAGE_ON [PRIMARY]
GO
```

As all the data of the Health Trainers' Web pages was stored in a database rather than the file system, text searches were very easy. The Health Trainers' wiki provided a search facility (Figure 4.10) with which users could enter one or more keywords they wanted to search for. The system then passed the search request to the FetchSearch method of the TopicsList class which built a Standard Query Language (SQL) SELECT statement using the LIKE operator in the WHERE clause. For example, if a user entered the word 'food' in the search facility the FetchSearch method would built a SQL SELECT statement that looked like this:

```
SELECT name
    FROM topic
    WHERE name LIKE '%food%' OR
        content LIKE '%food%'
```

This very powerful SQL SELECT statement would find the word 'food' present in either the title ('name' field) or the main content ('content' field) of all the topics. However, LIKE was a very expensive operator. In a query like the one presented above, SQL Server should perform a full table scan on the topics table and read through all the text in the name and content fields to try to find the word 'food.' If there were not many records in the topics table this should not be an issue. If the system had a rather large number of topics though, then there would be performance problems especially if many users performed many searches and therefore many full table scans.

Figure 4.10 – The search facility of the system developed for the Health Trainers.
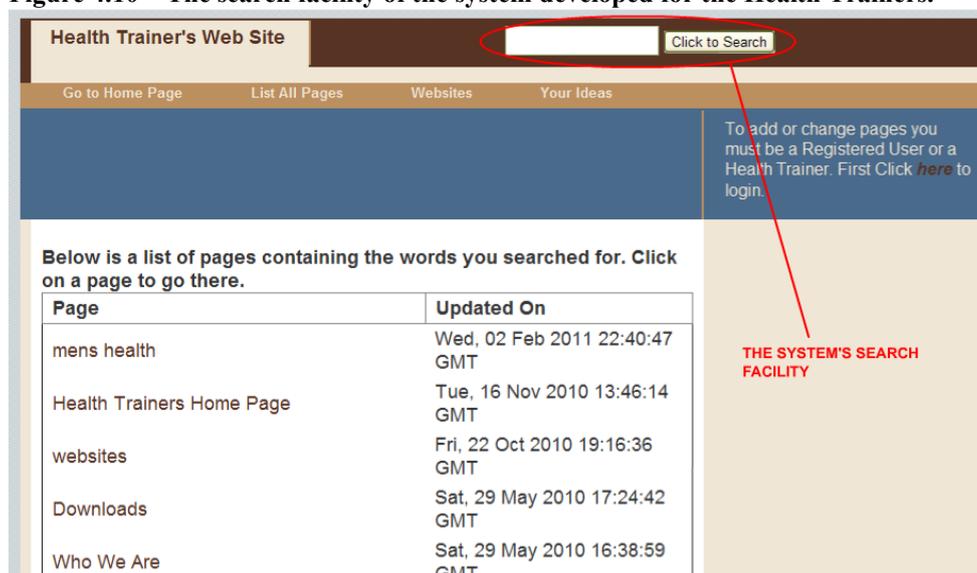
In order to overcome this problem an SQL Server facility was used. SQL Server provided a Full-Text-Search service that offered a better approach for performing searches in text fields, because it was optimized for large blocks of text. This service was especially useful for a system like the Health Trainers' because its database was basically a collection of large blocks of text. When the Full-Text-Search was used SQL Server created a separate index for each of the text fields and optimized these text indexes for text searches. With this facility search on text fields did not force SQL Server to perform a full table scan. This was another advantage of storing the content of the system in a database rather than directly on the file system.

4.7 System Use Evaluation

The final developed system was evaluated with respect to usability and accessibility. This was done by observing the Health Trainers (who took part in the development) while using the system one after another. The data gathered during system use evaluation was also used to answer research question two. After the software application was evaluated by the Health Trainers on a local machine it was deployed online and became available on the Internet.

Usability evaluation methods can assess accessibility to ensure that software systems are usable by people with disabilities. A software developer does not have to be a usability professional and does not have to follow formal usability testing protocols to include people with disabilities in evaluation. Short informal evaluation can gather valuable feedback from people with disabilities without the rigor of formal usability testing (Henry 2011b).

"In most cases, including users in evaluation involves:

- finding a few people with disabilities,
- asking them to complete tasks on prototypes,
- observing them interact with the prototype,
- discussing accessibility issues with them

Projects rarely have the time and money resources to do thorough
usability testing with a wide range of participants with disabilities.
The number of usability test participants with disabilities included
in a given usability test is usually determined by limited project
resources" (Henry 2011a)[online]).

System use evaluation started after the fourth Evolutionary Prototyping iteration
cycle, when the Health Trainers decided that the system meets their most
important criteria. These criteria were met with the implementation of all the
requirements requested by the Health Trainers as described in Section 4.5. The
evaluation happened in three different meetings over a period of approximately
two months as shown in Table 4.1.

Before the evaluation observations begun the Health Trainers did not have the
chance to sit in front of the system to systematically try to use all its functions.
This was so as the Health Trainers had only a limited amount of time that they
could offer for the study. Evaluating the complete system in each Evolutionary
Prototyping cycle would probably be preferable, but the Health Trainers could not
afford the time. During development the Health Trainers sat in front of the system
in order to test isolated interface controls or specific parts of the system only.
These were the parts of the system they asked to be changed in the previous cycle.
Design, implementation and evaluation of the system all happened on a laptop
which was taken to the Health Trainers' office. The laptop was connected to a
bigger computer screen so that the Health Trainers could see the application
clearly. After the meeting with the Health Trainers ended the laptop was carried
away.

A list of important system tasks for the Health Trainers to perform was prepared
before the evaluation meetings begun (Table 4.3). Each Health Trainer had to
perform the same tasks while being observed by the researcher. The specific tasks
were chosen by the Participatory Research Team and they represented the most

important functionality of the system. The Participatory Research Team decided that the list could not be longer as a result of time limitations.

Before the evaluation started the researcher would typically encourage the Health Trainers to take their time, read the instructions on the screen and if they faced any difficulties to use the Help system. When performing a task the Health Trainers were asked to speak aloud and describe what they were doing and thinking. When the Health Trainers faced difficulties they were asked to describe the type of problem they were facing. The Participatory Research Team also decided that if necessary the system could be improved further during the evaluation sessions. Therefore during evaluation the Health Trainers could give further input on improving the system where necessary.

The procedure for the evaluation decided by the Participatory Research Team was the following:

- During the evaluation meeting one Health Trainer sat at the machine on which the system was running.
- The researcher sat next to the Health Trainer so that he could observe how the he or she was using the system.
- The prepared tasks were then read one after another for the Health Trainer to perform.
- While performing the task the Health Trainer was asked to speak aloud of what she/he was doing.
- The researcher observed how the user performed the task while writing down notes.
- After each task the researcher took time to complete his notes and then proceeded to the next task.

Table 4.3 - Tasks that were performed by each Health Trainer for the purpose of system use evaluation and to gather data for answering research question two.

Task to be performed	Observations and notes written down at the time of the evaluation
Please try to find the page with the title, 'Healthy eating.'	*The researcher's observations for each task were written in this column as presented in the tables that follow.*
Do a search for the word 'test' and go to one page that has the word on it.	
Go back to the 'home page'	
Please try to 'log in' using the following, User-name: *admin* Password: *admin*	
Please try to change the following page 'test page 1.' 1. Please try to add and delete some text. Add *'This page was made in order to test the system.'* 2. Try to create a link to the site www.nhs.uk	
Please try to make a new page with the title *'Living healthy lives'* • Write the following on it: *'One way to keep healthy is by exercising.'* • Try to add an image	
Please try to delete the page 'test page 1.'	
Now please try to undelete 'test page 1.'	
Please try to register a new user. User-name: *Mary* Password: *Mary* e-mail: *mary@server.com* Security question: *What is your favourite colour?* Security answer: *red*	

The evaluation revealed minor changes or new requirements that did not surface during the design and development iteration cycles, especially in the Help system. These were implemented into the system when all the evaluation sessions finished. Finally, after the evaluation and after the minor changes were implemented, the system was deployed online.

4.7.1 Evaluation Observations

This section describes the researcher's observations during system use evaluation, supported with exemplifying verbatim written down notes. The complete set of notes written while observing the Health Trainers are presented in Appendix 4.

Bonnie, one of the two younger Health Trainers, was the first individual who was observed while using the system for the purpose of system use evaluation. Bonnie managed to complete all the tasks of the list (Table 4.3) without many difficulties. However, during the link creation task Bonnie reported that she forgot how to do it, and therefore used the video Help tutorial on link creation. The researcher's observation notes for the link creation task are presented in Table 4.4. After viewing the Help tutorial Bonnie managed to create the link. (Parts of the notes in the tables that follow are *italicised* in order to draw attention to observations that support the researcher's comments).

Table 4.4 - The researcher's verbatim notes written down when Bonnie performed the link creation task.

Task to be performed	Researchers verbatim notes as written down during evaluation observations
• Try to create a link to the site www.nhs.uk	Creating a link: *she first thought about it for ten to fifteen seconds* then she clicked on the appropriate link creation button. She typed the www.nhs.uk address in the appropriate place and clicked the OK button. Then she saved the page and *stayed there thinking for while staring at the screen.* I asked her if she would like to tell me if she is having trouble or what she is thinking about. She replied "It's not what I want to do." Then *she reported that she forgot how to do it and that she forgot the steps, and that she is going to watch the video.* She clicked on the appropriate Help link on the right side of the page to watch the video tutorial for creating a link to another website. While watching the video tutorial she kept pausing at each step (shown in the video) and was going to the system to

	perform the step she just watched. *After watching the video she managed to create the link* by writing down the sentence 'click here to go to the NHS website' and then making that sentence into a link.

While observing Bonnie as she watched the Help video on link creation the researcher noticed that she kept pausing the tutorial quite often and during each pause she tried to go to the system and perform the instructions of the part of the video she had just watched. This observation led the researcher to wonder whether the video tutorial was still too long even though the effort was to make it as short as possible. In a system requirement during system development the Health Trainers had asked for the Help videos to be short, as they suggested if the videos were long they would not be able to remember them. After the evaluation with Bonnie ended she was asked by the researcher to comment on the video tutorial for link creation. She suggested that it was rather long and that it should be broken down into smaller clips.

The next Health Trainer to take part in the evaluation was Brenda. This happened during our next meeting. Brenda had to do the same tasks which Bonnie and all other Health Trainers did. The only task that Brenda had difficulties performing was to add an image to a page. The researcher's observation notes for this task are presented in Table 4.5. While trying to add the image Brenda initially forgot to click on the 'Browse Server' button in order to see the list of images and stated that she forgot what to do next. Then she decided to watch the appropriate video tutorial in the Help system and finally managed to add the image. While watching the video tutorial Brenda used the same technique as Bonnie. She paused the video at specific moments and immediately went to the system in order to perform what she just watched. Brenda finally managed to complete the image insertion and all the other tasks of the evaluation.

Table 4.5- The researcher's verbatim notes written down when Brenda tried to add an image to a page.

Task to be performed	Researchers verbatim notes as written down during evaluation observations
Try to add an image	Adding an image: When trying to add the image Brenda clicked on the appropriate button. The proper dialogue box appeared. Brenda looked at it for about fifteen-twenty seconds and then *she reported that she forgot what to do next and that she was going to watch the appropriate video in the Help system.* Cancelled the dialogue box and clicked on link/button for proper Help video. While watching the video she paused it twice and went to the system to perform the step she just watched. *By doing the steps shown in the video she managed to add the image.*

The next evaluation session happened at our next meeting during which Roy and Tanya were observed. Tanya sat at the computer first and Roy followed her after a short break. Tanya had more difficulties using the system compared to the two younger Health Trainers Bonnie and Brenda. Before starting Tanya reported that she felt anxious about it. In order to calm her down the researcher reminded her that the evaluation was not a test. The researcher also emphasized the advice which he was giving to everyone. The advice was to take their time, read the instructions on the screen and to view the video tutorials of the Help system if necessary. Tanya had some difficulties starting from the second task, how to do a search for a word. In order to perform the 'search' task Tanya had to first carefully read the screen instructions and watch the appropriate video of the Help system (Table 4.6).

Table 4.6 – The researcher's verbatim notes written down when Tanya tried to perform the search task for system use evaluation.

Task to be performed	Researchers verbatim notes as written down during evaluation observations
Do a search for the word 'test' and go to one page that has the word on it.	*She started by reading the screen. She saw the video Help 'click here to learn how to do a search' and clicked on it. She watched the video.* Then she went to the search textbox typed in the word 'test' and clicked the appropriate button. After the results of the search were returned *she spent some time looking at them thinking.* Then she clicked on one of the titles to go to one of the pages.

Tanya had to carefully read the information on the screen first in order to perform a number of other tasks as well. Those tasks were, to log into the system, to create a link and to create a new page. She also used the Help system another two times, for creating a link and to add an image to a page. The two younger Health Trainers did not have to read the instructions on the screen or use the Help system as many times as Tanya did. Tanya also paused more times in order to think what she had to do taking longer compared to the younger Health Trainers. Abstracts from the researcher's verbatim notes for the tasks with which Tanya was challenged are presented in Table 4.7.

Table 4.7 – The tasks during system use evaluation with which Tanya was challenged.

Task to be performed	Abstracts from the researchers verbatim notes
Please try to 'log in' using the following, User-name: *admin* Password: *admin*	*Spend time carefully reading the screen first.* She found the button/link for log in and clicked it. She typed the user-name and password and clicked the correct button to log in.
Please try to change the following page 'test page 1.' • Please try to add and delete some text. Add 'This page was made in order to test the system.' • Try to create a link to the site www.nhs.uk	*Thought about it for a while,* then clicked on the menu 'List all pages,' *read the screen* and clicked on the title to go to 'test page 1.' Spend five-ten seconds looking at the page then she clicked on the appropriate button to put it in edit mode... Creating a link: *She thought about it for*

	a while, and then started reading the screen. She clicked on the Help button 'How to make a link to another website.' She watched the video to the point which shows the appropriate button to click and paused it. She came back to the editor and clicked on the link creation button (without typing something first). The dialogue box appeared. She read the dialogue box*, took some time to think* and then typed www.nhs.uk at the proper place and clicked OK…
Please try to make a new page with the title 'Living healthy lives' • Write the following on it: 'One way to keep healthy is by exercising.' • Try to add an image	*She took some time to read the screen first trying to decide which button/menu to click.* She found the appropriate menu and clicked it to get to the new page creation form… Adding an image: *She first clicked the wrong button, realised it and cancelled the dialogue box.* She then thought for about twenty seconds, moved her mouse over various buttons and clicked on the correct button. *She stared at the dialogue box that appeared [insert image dialogue box] and then reported that she will use the Help and cancelled the dialogue box. She watched the Help video* until the point it shows what to do when the insert image dialogue box appears and then came back to the editor forgetting to pause the video… On the new dialogue she *clicked the OK button and added the image.*
Please try to register a new user. User-name: Mary Password: Mary e-mail: mary@server.com Security question: What is your favourite colour? Security answer: red	Clicked on the Administration menu, then clicked on appropriate command, *spend some time to read the instructions* in the right margin, filled in the form appropriately and created the user.

Roy had slightly fewer and similar challenges to the ones that Tanya had, but more compared to Bonnie and Brenda, the two younger Health Trainers. Before starting, like Tanya, he also reported that he was worried and the researcher had to

calm him by repeating the same advice that was given to Tanya. In order to perform the tasks of the evaluation Roy had to use the Help system two times, one time for creating a link and another for adding an image to a page. He also had to carefully read the instructions on the screen in order to perform the following tasks: performing a search, creating a new page, and for deleting and un-deleting a page. Roy managed to delete a page by reading the instructions on the screen and then when he was asked to undelete it he spent some time thinking aloud of how to do it. He then remembered that it had to be done by using the Trash Bin but he could not remember where it was so he started clicking around to find it. When he found the Trash Bin he managed to undelete the page. Abstracts from the researcher's verbatim notes for the tasks with which Roy was challenged are presented in Table 4.8.

Table 4.8 - Tasks during system use evaluation with which Roy was challenged.

Task to be performed	Abstracts from the researchers verbatim notes
Do a search for the word 'test' and go to one page that has the word on it.	He thought a little bit then typed the word 'test' into the appropriate search textbox at the top of the screen and then clicked on the 'click to search' button. *When the search results appeared he read the instructions at top of screen* and then clicked on the title of one of the pages to go to the page.
• Try to create a link to the site www.nhs.uk	Creating a link: *Roy immediately said, "I think I am going to use the Help for this one." He clicked the appropriate video link on the right margin of the page…*
Please try to make a new page with the title 'Living healthy lives' • Write the following on it: 'One way to keep healthy is by exercising.' • Try to add an image	*He took time to read the screen first.* Then he clicked on the appropriate menu command which showed the new page creation form. *He read the information at the top of the form* then he typed the title into the proper place and *after some thinking* pressed the button to create the new page. After the page was created he typed the text on it.

	Adding an image: *Immediately reported that he is going to use the Help for this as well. He clicked the proper link to view the Help video on image insertion…*
Please try to delete the page 'test page 1.'	Mentioned, "I have to find the page first." Clicked on 'list all pages,' found the page, clicked on its title, went to the page. *There he stared at the screen for fifteen-twenty seconds,* and then he clicked on the appropriate button for deletion. *At the confirmation page that appeared he read the screen and then confirmed deletion.*
Now please try to undelete 'test page 1.'	*He spent some time thinking, and then he mentioned the Trash Bin. He clicked around trying to find the Trash Bin. He clicked several menu commands reading the screens that appeared.* When he found the Trash Bin under the Administration menu he clicked on it. *He read the instructions on the Trash Bin page,* found 'test page 1' and clicked the Restore button next to it.

4.7.2 Evaluation Conclusions

Brenda and Bonnie the two younger Health Trainers, performed with confidence most of the tasks posed to them during the evaluation. They were challenged with only two procedures. Bonnie faced some difficulties when she tried to create a link to another website, while Brenda was challenged when trying to add an image. In both situations the difficulties were overcome by using the Help system.

Roy and Tanya the two more mature Health Trainers faced more challenges compared to the younger ones but in the end they all managed to overcome their difficulties by using the Help system and by reading the instructions on the various screens. Thus the mature Health Trainers also managed to complete all the tasks posed to them during system use evaluation. The fact that all the Health Trainers finally managed to complete all the tasks posed to them suggests that their involvement developed an accessible and usable system.

As it will be discussed in Section 4.8, the system did have certain limitations mainly due to restrictions in resources. These limitations may have been a reason for some of the challenges that the Health Trainers faced during system use evaluation but as shown they were all challenges that were overcome with the use of the Help system. More findings and conclusions from the analysis of the data collected during system use evaluation, for answering research question two, are presented in Section 5.3.

It is worth stating that the system was evaluated by observing the Health Trainers who took part in its development. In the future in order to confirm usability and accessibility further the evaluation should also be conducted with a group of users with learning difficulties who were not involved in its development.

4.8 System Limitations

System limitations exist as a consequence of the limited resources of only one developer and the constraints of a PhD study. The fact that the Health Trainers had certain needs, like for example a need for additional time during their participation and the participatory methodologies used, also affected the development time demands. The system limitations were discussed with the Health Trainers who agreed that they did not affect system usability to such a degree that would render the system unusable. Ways to circumvent some of the problems caused by these limitations were also discussed.

Regarding system design and development the method which would offer complete flexibility would be to develop the whole system from the ground up (from scratch). This however is seldom done even within big commercial projects where a big number of developers are employed, as time and cost demands would be prohibitive. Indeed one of the most fundamental principles of software engineering is component based development which "encourages the use of existing software components" (Pressman 2001)p. 734). Like in other engineering

disciplines, a product is build by putting together a number of existing components. For these reasons the researcher decided to use an open source product which already offered the basic functionality along with the capability to modify it according to the needs of the study.

Using an open source system offered both advantages and disadvantages which had to be carefully weighted. The major advantage was that the study immediately had a basic working prototype which could be customised and this could save a considerable amount of development time. The major disadvantage was that the developer was not familiar with the code, as it was written by someone else, and this sometimes made it very difficult to adapt something to the needs of the Health Trainers. Often, the time taken to understand how another developer had programmed a specific function in order to change it, took much longer than it would take to develop it from scratch. This sometimes defeated the time saving advantages offered by using an open source system. After weighing these factors the researcher decided that using an open source system had more advantages than disadvantages and adopted the approach.

Due to the above stated challenges the system had the following limitations. One requirement that the Health Trainers asked was that there should be Help in the right column of each page. Although context related Help was implemented for most pages, some pages were left without a context related Help system. After discussing it within the Participatory Research Team, it was decided that the pages left without context related Help were the ones considered not to benefit much from it, and therefore it did not affect usability. For example, on certain pages the instructions on the actual page itself were so clear and simple that it would actually make the page seem more complicated if Help was added to its right margin; in general though the system could probably benefit from improvements in the Help system even though the Health Trainers did not specifically request it.

Recently many sites on the Web offer two specific accessibility features. These are three dedicated and conspicuous buttons for changing the font size and a feature for changing the combination of text and background colours, offering for

example, combinations of high contrast which may be helpful to people with dyslexia. As the developed system was designed to be accessible to people with learning difficulties it should probably offer these two common accessibility features. Unfortunately, this proved very difficult and time consuming to implement as it required changes on the whole user interface of the open source wiki. After discussing this issue within the Participatory Research Team, it was decided that the text size problem could be overcome because the content on the Health Trainers' wiki would be prepared by them and they knew that they had to use large fonts. The text and background colour combinations feature has not been addressed and remains a limitation of the system, probably to be addressed at a later stage.

Chapter Five: Findings

5.1 Introduction

This chapter presents the findings from the analysis of the data gathered during fourteen Participatory Action Research Meetings, listed in Table 3.6. The data collection and analysis methodologies used are described in Section 3.7. The findings validation methodology and procedure used are described in Section 3.7.2.1. All the findings presented in the section were validated by the Health Trainers.

The chapter begins with the categories and themes identified during the process of data analysis for research question one. Each category is listed along with the relevant themes that fall under it. Specific Health Trainers' suggestions, the researcher's own observations and any other written data are presented to demonstrate the themes and concepts. Subsequently the discussion turns to the findings for the other two research questions of the study, using a similar style of presentation.

5.2 Could the Health Trainers be Involved?

The data obtained from the Participatory Action Research Meetings identified three categories and twelve themes when analysed to answer the first research question. These categories and their relevant themes are shown in Table 5.1. This section examines each of the categories and their themes and includes selected data abstracts in order to support the demonstrated findings.

Table 5.1 – All the categories and themes identified during the data analysis to answer research question one.

Categories	Themes
Direct evidence of involvement	• Acted proactively
Involvement challenges and preferences	• Preference for simplicity • Preference for consistency • Preference for common vocabulary • Preference for non-technical terminology • Preference for shorter working periods • Managing disagreement • Learning challenges
Factors affecting involvement	• Computing skills • Appreciation for study objectives • Interest and excitement • Collaboration affected by tolerance

5.2.1 Direct Evidence of Involvement

Regarding research question one, the first category identified during data analysis was 'Direct evidence of involvement.' The one theme determined under this category is presented in Table 5.2.

Table 5.2 - The first category and related theme identified for research question one.

Category	Themes
Direct evidence of involvement	• Acted proactively

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During their involvement it was evident that the Health Trainers could discuss and elaborate on the subject of system design following the conversation. They successfully managed to communicate their queries so that the researcher could support them where necessary. The Health Trainers offered valuable input and asked for appropriate system requirements. As the system use evaluation showed (Section 4.7), the Health Trainers' input and requirements, helped make the developed wiki system usable and accessible. All recorded system requirements listed in Appendix 3 are examples that show that the Health Trainers could offer appropriate input for developing an accessible system. Furthermore most requirements demanded by the Health Trainers are corroborated by the literature as discussed in Chapter Six.

5.2.1.1 Acted Proactively

During software involvement the Health Trainers would often take a more proactive role suggesting changes themselves without waiting to react to the researcher's requests. In the discussion abstract below, while they were shown how to place an image on a page, Bonnie noticed the captions on the image placement controls and found them inappropriate so she proactively suggested the following:

> Bonnie: "Could we change 'Auto' and 'In-line' to something else?"
>
> Researcher: "Of course, tell me. Let's go back; here we have 'Right,' 'Left,' 'Auto' and 'In-line.'"
>
> Bonnie: "'Auto' means in the middle?"
>
> Researcher: "'Auto' means the program decides automatically, but it is not very good [it does not work properly]."
>
> All: "Take it out."
>
> Researcher: "Yeah, probably we should take it out."
>
> All: "Yes."

Without the researcher having to request it the Health Trainers suggested changes for the 'in-line control caption as well:

> Bonnie: "What is 'In-line' again?"
>
> Researcher: "'In-line' means..."
>
> Brenda: "Like in the middle."
>
> Bonnie: "Underneath the words?"
>
> Researcher: "Yes, like as you are typing words and then you put the picture in the same line with the words. If I type this and this and then I want to put a picture here I would put it in line so that it is after the words, like in the same line here."
>
> Tanya: "Where the pictures are now is that in line?"
>
> Researcher: "No, this is not in line, this is on the right."
>
> Tanya: "Well, that's confusing then."
>
> Roy: "Probably we should just leave 'Left' and 'Right.'"
>
> All: "Yes."

5.2.2 Involvement Challenges and Preferences

The Participatory Research Team was challenged during the development of the software system. The Health Trainers were challenged in the ways described below. The Participatory Research Team managed to overcome all challenges and the Health Trainers managed to provide input and guidance in order to build an accessible software system (usability conclusions can be found in Section 4.7.2). The data analysis revealed the following themes which relate to challenges and preferences that the Health Trainers faced during software development.

Table 5.3 - The second category and related themes identified for research question one.

Category	Themes
Involvement challenges and preferences	- Preference for simplicity - Preference for consistency - Preference for common vocabulary - Preference for non-technical terminology - Preference for shorter working periods - Managing disagreement - Learning challenges

5.2.2.1 Preference for Simplicity

The Health Trainers found complexity challenging and they showed a preference for simplicity. They did not appreciate complicated topics and in the case of software systems, complicated user interfaces. The first time that this became apparent was during system analysis and initial requirements gathering when Roy and Brenda sat at the computer to try to edit an article in the Simple English version of Wikipedia, the well known online encyclopaedia. In editing mode Wikipedia used a user interface, which was not What You See Is What You Get (WYSIWYG is described with more detail in Chapter Four, Section 4.5.1). When Wikipedia users tried to format a section of text in the editor, instead of seeing the edit results immediately the text remained the same and some cryptic tags appeared at the beginning and the end of the highlighted section. The formatting and edits applied appeared only if the user previewed or saved the article. Table 5.4 shows how a page looked in the Simple English version of Wikipedia's edit mode and what the Health Trainers of the study saw when they tried to edit the article.

Table 5.4 - What the users saw when they tried to edit an article in the Simple English version of Wikipedia. In edit mode the text contained a number of cryptic formatting tags.
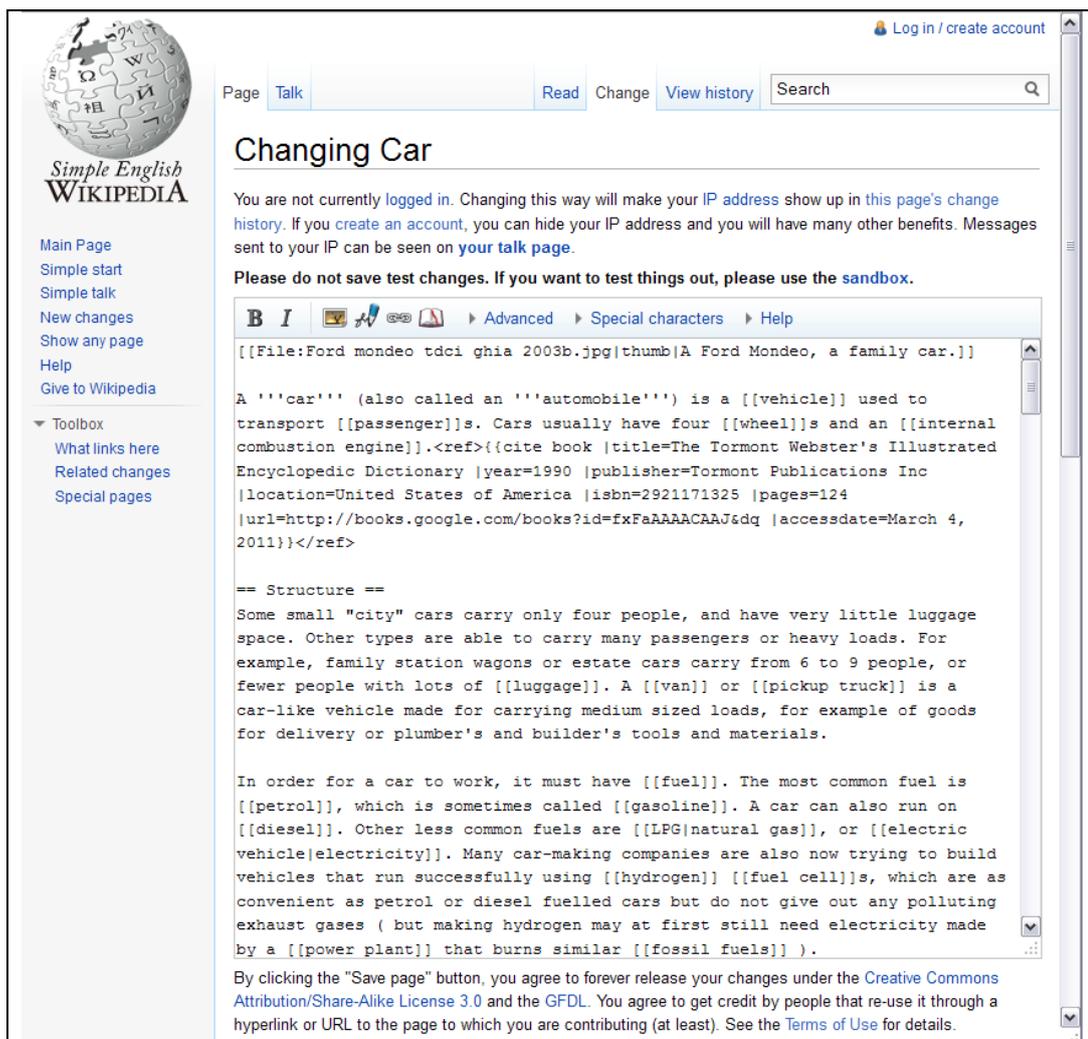
First the researcher showed everyone how to find an article in Wikipedia, go to it and then put it in edit mode. Then Brenda sat in front of Wikipedia to use it. Brenda found an article and while reading it the researcher pointed out a sentence and asked her to try to make that specific sentence 'bold.' Brenda then put the article in edit mode by clicking on the appropriate button. Below is the conversation that followed:

> Brenda: "This is difficult, eh… how do you?" (Long pause)
>
> Researcher: "Why is it difficult, can you describe the difficulty for us Brenda?"

Brenda: "What are all these? Where is the text? Is this the… it's difficult to find the text"

Researcher: "Why don't you try reading the article, you know try again, to find it."

Brenda: "I did but, it's full of… what are all these?" (Points at formatting tags)

Researcher: "Those are the formatting tags that I told you about."

Brenda: "Eh…, I think, I have not used anything like this before, I think it's… It is… its complicating"

Researcher: "Why is it complicated? What makes it complicated?"

Brenda: "It's a little confusing."

When Roy sat in front of Wikipedia he had a similar experience to Brenda and he stated, "…it is kind of complicated to do." When the two Health Trainers finished they were asked why they were challenged when trying to edit the article and they both reported that the reason was the fact that the wiki was confusing and complicated. The Health Trainers finally requested that the software system that would be developed for them should not be complicated and confusing in this way.

Another area where complexity posed challenges for the Health Trainers was the User Accounts system of the initial system prototype. The User Accounts system was used to add various types of user roles and assign permissions of what each role could do on the system. Initially it had three different roles, 'Guests,' 'Registered Users' and 'Administrators' as described below:

- Guests: Registering into the system was optional for Guests. If they did not register they could just view the different system pages. If they did register they could also change existing pages or add new ones.

- Registered Users had to be added by an Administrator and they could be assigned different permissions. For example one Registered User could be

assigned the permission to edit existent pages but not to add any new pages, while another Registered User could be allowed to add pages but was not allowed to edit the pages of others.

- Administrators could do everything on the website. They could add, change, delete and undelete pages. Administrators could also add new users and other Administrators.

During the system requirements gathering procedure, when the Health Trainers were shown how to use the User Accounts system in order to offer feedback for it, they had problems understanding it. As soon as the team's sixth meeting finished, the researcher wrote down the following in his observation notes (the researcher's observation notes are quoted verbatim in the thesis):

> A big part of today's meeting was spent to explain the User Accounts system to the Health Trainers. This system was already explained to the Health Trainers once during our previous meeting and they reported that they had difficulties understanding it, but we run out of time and decided to leave its explanation until today's meeting. Today after explaining it again I asked the Health Trainers if they understood it and if they would be able to use it and they said that they did not understand it. I then explained it a second time. The Health Trainers again reported that they had difficulties understanding it. After the third time I asked the participants what was the reason they believed they had difficulties understanding it. Tanya said that she found it to be "confusing and hard to remember." The other participants agreed with Tanya. For example, they said that they were confused of whom they should add and whom they should not, when one should become an Administrator or a Registered User and it was difficult for them to understand when to assign different permissions to different users. Roy also reported that he found it complicated. Finally the Health Trainers asked me if it was possible to make the User Accounts system simpler in order for them to be able to understand and remember it. Bonnie asked me if was possible to remove certain things like we did with the buttons that offered no useful functionality in the FCKeditor.

As the Health Trainers could not understand the Users Account system it was difficult for them to offer input and ideas on how to improve it. They realised however that their challenge was the fact that the system was complicated and

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asked if it was possible to simplify it in order for them to understand it. Before our next meeting the User Accounts system was simplified in the following ways.

The Guest user account role was removed from the system completely and only two roles were left, those of the Registered User and Administrator.

- The Registered User role was changed and instead of having a number of permissions from which an administrator could choose to assign to the role, it was decided that it should only have two fixed roles. Registered Users were allowed to add new pages and edit existing ones but they could not do anything else. With the simplification Registered Users could not delete pages and they could not add other users either. Registered Users could only be added to the system by an Administrator. They could not add themselves.

- Finally the role of the Administrator remained the same. An Administrator could do everything on the system. In order to simplify things further all the Health Trainers were registered as Administrators.

As there were only two roles left (Registered Users and Administrators) and all the Health Trainers became Administrators the only role they had to understand and remember was that of the Registered User. By simplifying the User Accounts system this way the Health Trainers finally reported that they could understand it.

Other recorded data that shows the Health Trainers' dislike for complexity and preference for simplicity were a number of requirements that they asked for the system under development. By requesting the changes shown in Table 5.5 the Health Trainers' aim was to create an uncluttered, simple system interface for both themselves and their clients most of whom were people with learning difficulties.

Table 5.5 – Noted down system requirements along with the researcher's verbatim notes, which show the Health Trainers' preference for simplicity (Comments in square brackets [ ] were added for clarification during the writing of the thesis).

Health Trainers' user requirements	The researcher's comments written down at time of meeting or immediately afterwards
The buttons for editing a page in the FCKeditor which will not be used by the Health Trainers must be removed. According to the Health Trainers the following buttons must be removed: 'Source', 'DocProps', 'Save', 'NewPage', 'Preview', 'Templates', 'PasteWord', 'SpellCheck', 'Find', 'Replace', 'SelectAll', 'RemoveFormat', 'Form', 'Checkbox', 'Radio', 'TextField', 'Textarea', 'Select', 'Button', 'ImageButton', 'HiddenField', 'StrikeThrough', 'Subscript', 'Superscript', 'Outdent', 'Indent', 'Blockquote', 'JustifyFull', 'Anchor', 'Flash', 'SpecialChar', 'PageBreak', 'Style', 'FitWindow', 'ShowBlocks'.	The Health Trainers reported that these buttons offered functionality that was redundant to them and that they should be removed in order to make the editing interface simpler and uncluttered. Roy: "I get confused when there are many buttons on the screen."
Dynamically hide 'click here to see this page as it was before' (found at the bottom of each page) from guest/visitors because they do not to use it. Only Registered Users and the Health Trainers (after they log-in) must be able to view this command because they are the only ones that use it.	The Health Trainers asked for this because as they said the less buttons there are on a screen the better, because it makes the interface look simpler and less confusing.
Dynamically hide the page creation menu command 'Add a New Page' from guests/ visitors because they do not to use it. Only Health Trainers and Registered Users (after they log-in) must be able see this menu because they are the only ones that use it.	The Health Trainers asked for this because as they said it would make the interface look simpler and uncluttered and this would make it less confusing and more accessible to their clients or other users with learning difficulties.
Dynamically hide the command 'Administration' from guests/visitors because they do not to use it. Only Health Trainers and Registered Users (after they log-in) must be able to see this menu command because they are the only ones that use it.	The Health Trainers asked for this because as they said it would make the interface look simpler and uncluttered and this would make it more accessible to their clients or other users with learning difficulties.

Guests/visitors who do not have to log-in must only see four menus 'go to home page,' 'list all pages,' 'websites' and 'your ideas.' The rest of the menus must become visible only when a user logs in because only logged in users use them.	The Health Trainers asked for this because as they supported the less buttons, commands and menus there are on a screen the better as this makes the interface look simpler and uncluttered and thus less confusing and more accessible to their clients or other users with learning difficulties.
The Web address must change from www.bit.uwe.ac.uk/???? to something simpler/shorter and easier to remember.	The Health Trainers supported that the Web address was long and complicated and that their clients would not be able to remember it therefore we had to find a shorter one and one which was easier to remember. [Unfortunately we were limited by the address names available on the Internet, many names we wanted to use were already taken.] [Requested and implemented after system went online. As already described in Section 4.3 the Web address cannot be disclosed in order to preserve the anonymity of the Health Trainers. The purpose of the question marks (????) in the Web address on the left is to hide the real address and therefore the names of the Health Trainers].

5.2.2.2 Preference for Consistency

During system design the Health Trainers were challenged by lack of consistency on the computer screen. Two of the Health Trainers expressed perplexity when the researcher showed to them one of the initial prototypes of the system in two different Web browsers. Being a Web application the wiki had to run through an Internet browser like Internet Explorer or Mozilla Firefox. Most Internet browsers have a row of menus and buttons (toolbars) at the top and a main window below the toolbars in which they load the Web pages/Web applications. The menus and toolbars of each browser look different even though they have similar functionality. For example, the menus may be in different order, the buttons may

use different icons and they may have different sizes in each browser. Until the sixth meeting with the Health Trainers the researcher always used to open the wiki under development in the Internet Explorer browser. The researcher approached the design this way because that was the browser which the Health Trainers used at work so they were familiar with it. During our sixth Participatory Action Research Meeting the researcher initially opened the wiki in Internet Explorer and showed it to the Health Trainers for about forty minutes. Then after a short break he decided to open the wiki in Mozilla Firefox as he wanted the Health Trainers to experience it in another browser. When the Health Trainers saw the wiki running in Firefox instead of Internet Explorer, the following conversation took place:

> Roy: "Sotiris, can I ask you, something changed there, why does it look different?"
>
> Tanya: "Yeah"
>
> Researcher: "Eh, what do you mean, what looks different?"
>
> Roy: "On the screen, it is not the same… like it was before."
>
> Tanya: (Pointing at the browser buttons) "Like the buttons of the website, at the top changed."
>
> Researcher: "Oh, I'm sorry, oh, ok, eh, I opened it in a different browser. Remember when I told you that our system is a website and runs in another application, an Internet browser, like Internet Explorer the software you use to get on the Internet?"
>
> (Long pause - The Health Trainers do not reply).
>
> Researcher: "Ok, eh do you understand where the wiki, our system ends and the Internet browser starts?"
>
> Roy and Tanya: "No."
>
> Brenda: "I think so… like I know that ours is a website."
>
> Researcher: "Aha, do you guys want me to explain again what we said last time, like how our system is a website that runs in an Internet browser?"
>
> Tanya: "Yes, please."
>
> Brenda: "Ok."

The Health Trainers were then shown and it was explained for a second time by the researcher, that the wiki under development was a Web application and that it could run in a number of different Internet browsers.

> Researcher: "Now going back to Roy's and Tanya's question, why did the looks of our wiki our system change, it is because I opened it in a different Internet browser, another one of those programs that we use to get on the Internet. Our wiki is a website so we can open it in different Internet programs. Here, let me open our wiki both in Internet Explorer and Firefox (pause). You see this is our wiki in Internet Explorer and this is again our wiki in Firefox, another Internet program."
>
> Roy: "Oh, I didn't know that you can do that."
>
> Researcher: "Does it make sense now?"
>
> Roy and Tanya (together): "Yeah."

At least two of the Health Trainers Roy and Tanya were confused by the fact that the wiki was first opened in Internet Explorer and then in Mozilla Firefox. The Health Trainers were used to seeing the wiki run in Internet Explorer and the inconsistency created when it was opened in another Web browser (Mozilla Firefox) confused them. Tanya and Roy expressed this confusion and their challenge was overcome when the researcher explained why this happened. Later Tanya asked to find a way to make the separation between the system under development and the Internet browser more apparent. The Health Trainers went on and gave suggestions for this which were recorded in the following system requirement:

Table 5.6 – The system requirement to make the separation between the wiki under development and the Internet browser more apparent.

Health Trainers' user requirements	Researcher's comments written down at time of meeting or immediately afterwards
The rectangle that logically encloses the wiki must move down and the margin left between the top of that rectangle and the Web browser buttons must become wider in order to make the	Two Health Trainers reported that they could not understand where the browser ends and where the wiki starts. Tanya asked to make this separation more obvious.

separation between the wiki and the browser window more apparent.	

The Health Trainers also felt that their clients would be challenged by an inconsistent User Interface. This is apparent from another system requirement that they asked as recorded in Table 5.7.

Table 5.7 - System change requested by the Health Trainers which suggests their preference for consistency.

Health Trainers' user requirements	The researcher's comments written down at time of meeting or immediately afterwards
The wiki must always present the Home Page when started.	The first prototype presents a random page every time it starts. The Health Trainers support that if the system remains as is now, presenting a page at random [non-consistency], this would confuse their clients who have learning difficulties. Therefore the wiki must change so that it presents the same page when it starts for consistency.

5.2.2.3 Preference for Common Vocabulary

During their involvement in software development the Health Trainers were challenged by uncommon words and continually showed a preference for a more basic ('non-academic' according to their phraseology) vocabulary. During a tutorial in our second Participatory Action Research Meeting for example, the Health Trainers asked the researcher to use as simple a language as possible. The below is from the researcher's journal notes for that meeting:

> The Health Trainers asked me to teach slowly and *to explain all the concepts in as simple a language as possible.* They said that this was necessary in order for all of them to understand and they also told me that they would like all tutorials to be taught this way.

The challenge of the Health Trainers with uncommon words was overcome, because when an uncommon word was encountered they asked for its definition/meaning. After repeating a definition several times, the Health Trainers usually memorised it and thus they asked for fewer word explanations during later meetings. Below some conversation excerpts are presented as examples. The whole list of words and terms which the Health Trainers found challenging during our Participatory Action Research Meetings is presented in Table 5.8.

During the Participatory Action Research Meeting in which the researcher presented the first prototype of the system, Roy noticed the 'Navigation' menu and commented:

Roy: "Navigation is...?"

Researcher: "Yes."

Roy: "Navigation is…?"

Tanya: "Does that mean menu?"

Researcher: "Navigation means 'where to go.' Do you think it is correct or should we change it?"

Tanya: "Yeah, to put 'where to go.'"

Roy: "Where to go."

Researcher: "'Where to go,' great."

[In the final prototype the 'Navigation' menu was actually taken out completely].

The very first prototype of the wiki was programmed in such a way so that when it started it would load a page at random. The researcher asked the Health Trainers to comment on it but the two mature ones, Tanya and Roy were not sure what the word 'random' meant. The two younger Health Trainers seemed to have some concept about the meaning of the word:

Tanya (looking at Roy): "Do you know what 'random' means?"

Roy: "No."

Researcher: "'Random' means…"

Bonnie: "Any page."

Tanya: "How would you explain it?"

Brenda: "Like someone, like you pick something up at totally random. If you know what I mean."

Roy: "Without thinking?"

Tanya: "To pick out something…"

Bonnie: "To pick out any page."

Researcher: "Let's say we want to have a draw…"

Tanya: "To pick out something…"

Bonnie: "Any page…"

Researcher: "Yes, without thinking. Let's say us five we want to have a draw of who is going to win one of those [I point to a box]. We write our names on five little papers and we put them in and then you say 'pick up one out of it at random,' without thinking, without wanting Brenda to win it, you know just anybody."

The first column in Table 5.8 lists all the words with which the Health Trainers were challenged during the Participatory Action Research Meetings. The second column of the table presents alternative words or phrases used with which the Health Trainers felt more comfortable. The words presented in the table are not computer terms; they are words that are used in everyday life. However, as the subject of the inquiry relates to software development, most of these words were used within a computing context.

Table 5.8 - Words which the Health Trainers found challenging and the more common alternatives used.

Challenging word	Substitute word/phrase used	Clarification notes
Create	Make	Because I was so used to using this word I kept forgetting and continued using it with the Health Trainers even after they told me that they did not understand it. Fortunately for me after explaining its meaning a few times they learned it and told me that it was OK to use it.
Navigation	Where to go	Website navigation.
Random	Any, without thinking	Used within a computing context. The initial prototype of the system when started presented one of the pages of the wiki at random.
Content	Information	Web content or the content that the system under development would contain. In this context 'information' was a suitable substitute.
Categories	Groups	No comments
Preview	View before you save	Preview was used within the context of the software application. In the first wiki prototype users had to click a 'Preview' button to see their work before they decided to save it or not.
Edit	Change, add something else	Used within the context of the software application under development.
Previous	Before	No comments

5.2.2.4 Preference for Non-Technical Terminology

During involvement in the software development all the Health Trainers were also challenged with a number of uncommon technical terms and asked for them to be explained. The following dialogue abstract is an example:

Bonnie: "What is 'In-line' again?"

Researcher: "'In-line' means..."

Brenda: "Like in the middle."

Bonnie: "Underneath the words?"

Researcher: "Yes, like as you are typing words and then you put the picture in the same line with the words. If I type this and this and then I want to put a picture here I would put it in line so that it is after the words, like in the same line here."

Table 5.9 presents all the uncommon technical terms with which the Health Trainers were challenged.

Table 5.9 – The uncommon technical terms which the Health Trainers found challenging.

Challenging technical term	Substitute phrase / explanation	Clarification notes
Administrator	Someone who can do anything on the system	Used within the context of the system under development.
Internal link	Link to another page	This is computer terminology which should not have been used. I tried to avoid using it during subsequent meetings.
External link	Link to another website	This is computer terminology which should not have been used. I tried to avoid using it during subsequent meetings.
In-line	Showed them on the computer what it means	This was used as a computing terminology.

During system design the Health Trainers suggested that the system under development should not contain any technical terminology as most users with learning difficulties would not be familiar with it. Thus any used technical terminology would make the system inaccessible to most people with learning difficulties. The Health Trainers therefore requested a number of relevant recorded system requirements presented in the table below:

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Table 5.10 – System requirements which show that the Health Trainers did not want the developed system to contain any technical terminology.

Health Trainers' user requirements	Researcher's comments written down at time of meeting or immediately afterwards
In the FCKeditor, Format drop down list, H1 must become 'Heading 1,' H2 'Heading 2' etc.	The Health Trainers supported that they prefer common vocabulary and no technical jargon. H1, H2 etc sounded like technical jargon to them.
The word 'wiki' must be taken out where it occurs.	The Health Trainers reported that users of the system with learning difficulties will not know what a wiki is and leaving it in would make the system harder to use.
Menu: The 'Index' menu must become 'list all pages.'	The Health Trainers supported that the captions of controls should not be a single keyword. Instead they should describe in full what a control does. They also supported that 'index' is not a common word and users with learning difficulties might not know what it means.
The terms 'internal' and 'external link' in the Help system are technical and they must be replaced by the simpler terms 'link to another page' and 'link to another website'	The Health Trainers supported that computer or any other technical terminology should be removed from the system because both they and their clients are not familiar with it and makes the system more difficult to understand and use. Internal and external links sounded more like technical jargon to them and asked to be replaced with something more common.

Roy and Tanya, the mature Health Trainers, were also challenged by a number of common computer terms and requested a definition. Bonnie and Brenda reported that they were familiar with those common terms and did not require an explanation. The common computer terms with which the two mature Health Trainers were challenged are presented in Table 5.11.

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Table 5.11 - The common computer terms with which Roy and Tanya were challenged.

Common computer term	Substitute phrase / explanation	Clarification notes
Cursor	Mouse	Computer screen cursor, computer mouse.
Scroll	(Showed the action of scrolling on computer screen)	Scroll the page of a software system. This word was explained by showing the action of scrolling on the computer screen.
Highlight	Select	Used within the computing context, for example highlight some text in Word. The Health Trainers learned this word and started using it later.
Homepage	First page	First page seen when you go to a website. They learned this word and used it at later meetings.
Upload (to the Web)	(Showed them the action on the computer)	Showed them on the computer how to do it.
Download	(Showed them the action on the computer)	Showed them on the computer how to do it.
Attachment	Add on	Used within a computing context.

Section 3.5.2 describes that the sample of the present study could logically be divided into two groups of Health Trainers. In the one group were Roy and Tanya, the two mature Health Trainers, who belonged to a generation of people less exposed to technology developments and who had less developed computing skills. In the other group were Bonnie and Brenda, the two younger Health Trainers, whose generation was exposed more to technology developments and thus had better computing skills. The two younger Health Trainers had computer training for several years at secondary school but this was not available to the two mature Health Trainers. Also during the course of the study the younger Health Trainers owned personal computers while the two mature Health Trainers did not (some time towards the final stages of the study Roy acquired a personal laptop).

As the younger Health Trainers were familiar with the above common computer terms while the mature Health Trainers were not, the researcher concluded that the reason may have been the difference in computing skills. The younger Health Trainers were familiar with the terms because they had better computing skills and the mature Health Trainers were not because of less developed computing

skills. At the end of a Participatory Action Research cycle, the researcher brought up the following subject for discussion within the Participatory Research Team:

> Researcher: "There is something else I marked down to discuss with you today, eh, I noticed that… eh, ok, this is how we are going to do this, basically I want us to discuss why different people know, or do not know some computer words, and what they do, because I noticed a difference… ok let me ask you and you tell me please if that is ok, for example I wrote down that in the our previous meetings Roy and Tanya asked me what 'scrolling' was and also what an 'attachment' was, but Bonnie and Brenda knew, what those words meant, could we discuss that? Is that ok?"
>
> (Pause, silence)
>
> Researcher: "Do you want me to repeat the words?"
>
> Tanya: "Yes, please."
>
> Researcher: "Scrolling and attachment, I marked down that Bonnie and Brenda knew their meaning, what scrolling is, what it does, but you Roy asked me what scrolling meant and Tanya asked me what an attachment was, why do you think that is so, can we discuss this?"
>
> Tanya: "You mean why did I, and Roy did not know scrolling, what it is, the two words, but Bonnie and Brenda did know?"
>
> Researcher: "Yes."
>
> Tanya: "Well, Brenda and Bonnie took many computer classes, they know computers I think, but like, my computer classes were cancelled… and, and I do not know, or use a computer as much..."
>
> All: "Yeah."
>
> Bonnie: "Yeah, like I know how to use my computer."
>
> Researcher: "So you mean, because you two guys [pointing to Brenda and Bonnie] know about computers, you have good computer skills, and you use a computer more, and more often you also know more computer words and what they do, is that what you mean?"
>
> Bonnie: "Yes, I think so."
>
> All: "Yeah, aha."

The Health Trainers confirmed that there was a direct association between computing skills and knowledge of computer terms and what those terms meant. The two younger Health Trainers, who had more computer classes, had better computing skills and more experience with computers also knew more computer terms and what those terms meant. Finally, the Health Trainers managed to overcome all the challenges with the various technical terms by asking for definitions and explanations.

5.2.2.5 Preference for Shorter Working Periods

During involvement the Health Trainers were challenged to stay concentrated during long meeting sessions. In the first two meetings of the study the Participatory Research Team arranged to have a break about every hour but the team did not have a detailed discussion on the subject. During our third Participatory Action Research Meeting the Health Trainers twice asked for a short break before our usual hourly break.

> Brenda: "Sotiris, can we take a break?"
>
> Researcher: "We'll have a main break in about… twenty minutes, eh, do you need to go to the toilet maybe, Brenda?"
>
> Brenda: "No."
>
> Tanya: "Actually we also need a break, if it's ok."

After the Participatory Research Team came back from the second short break that the Health Trainers asked, the subject of session length and how often the Health Trainers would like a break was brought up by the researcher for discussion. [1] During the discussion the Health Trainers suggested that they would

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[1] Within one meeting the Participatory Research Team had several sessions separated by breaks. The number of sessions depended on each session's length and how long the meeting was. The length of each meeting depended on factors such as how much time the participants could afford.

like a break more often instead of every hour. During the same discussion Roy also mentioned:

> Roy: "People with learning difficulties cannot stay concentrated for too long Sotiris."
>
> Researcher: "Is that so?"
>
> All: "Yes, aha"

From then onwards and for the rest of the study the Participatory Research Team decided to have breaks approximately every forty minutes. The more often breaks made a single Participatory Action Research Meeting last longer, and over the whole length of the study the Participatory Research Team had to organise more meetings.

5.2.2.6 Managing Disagreement

Sometimes there was disagreement between the Health Trainers regarding specific software requirements and features that the system should have. This created a challenge because the Participatory Research Team had to decide which opinion to adopt. A short discussion would take place until agreement was reached. Agreement was achieved in all occasions.

One example of disagreement was when Tanya alone suggested that people with learning difficulties do not understand upper case writing and therefore everything should be in lower case, but the rest of the Health Trainers disagreed as shown in the dialogue excerpt below:

> Tanya: "Also, I have heard that people with learning difficulties don't understand words with capital letters. Have you heard that before?"
>
> All: "No."
>
> Tanya: "Because on here there is a poster, it is your poster Brenda, isn't it? And I noticed that the title is not in capitals, so that must be for a reason, yeah?"

Brenda: "It don't have to be for a reason, perhaps they just want it like lower case."

Tanya: "I think the reason is that is the way they understand."

Researcher: "This is up to you to decide, if you think you don't need to capitalise some words then you can use all lowercase, I mean this program [the developed system] can do both, lower and upper."

Roy: "I don't think it matters."

The researcher suggested that it was up to the Health Trainers to decide if they wanted to use lower or upper case letters as the system could do both. Roy ended the conversation by saying that what is used does not really matter. Tanya decided not to insist on the exclusive use of only upper case fonts. Finally, the Participatory Research Team concluded that this was not a problem as the system supported both upper and lower case text and the Health Trainers could later decide on which to use.

> **Reflexive Note:** Friedman and Bryen (2007) compiled a list of top Web access design recommendations for users with 'cognitive disabilities' based on frequency cited by existing Web design guidelines. Recommendation number eighteen on that list actually states "Use Lower case, no ALL CAPS" (p. 208). What Tanya suggested probably coincides with this guideline but as I was not familiar with the recommendation during that period I did not state it. In retrospect I realised that during the meeting I should probably have explored further why Tanya suggested that only lower case fonts should be used.

In another case the Participatory Research Team was discussing the creation of a menu which when clicked should present a page which contained important Web links to websites for people with learning difficulties. Bonnie recommended the menu caption 'useful websites,' but Tanya suggested the addition of the words '…for people with learning difficulties' to the caption (i.e 'useful websites for people with learning difficulties'). Bonnie disagreed with this recommendation supporting that as the whole site was for people with learning difficulties there was no need to point this out in the menu caption as well:

Bonnie: "Can you put on top 'useful websites?'"

Researcher: "I can make another link here. Should I make another menu here saying 'useful websites?'"

Bonnie: "Yes."

Researcher: "Sure."

Tanya: "Could it be like, 'Useful websites for people with learning difficulties?' So that people with learning difficulties can identify that is for them, to have a look at. The learning difficulties give a clue that oh, this is..."

Researcher: "Sure."

Bonnie: "It is a website for people with learning difficulties."

Tanya: "Yes, but could it be texted in, 'for people with learning difficulties?'"

Roy: "They might think other health trainers if it is..."

Tanya: "I mean for them, to be interesting for them."

Researcher: "Basically, what Bonnie said, from what I understand, is that this site is for people with learning difficulties, so everybody who will come to the site…"

Bonnie: "Yeah, they should know if it says 'Useful websites.'"

Tanya: "For me with a learning difficulty, that's good for you, but for me with a learning difficulty it has to say, this website is for people with learning difficulties, so that then I know it is about interesting things for people with learning difficulties."

For the above disagreement the Participatory Research Team finally reached the conclusion that there was only room for a single word to be used on the interface of the wiki under development. Therefore the caption finally used, due to space limitations, was the single word 'Websites.' As there were no space limitations for tooltips though, the Participatory Research Team also agreed that, the tooltip which appears when users take their mouse over the 'Websites' caption to say, 'Click here to see useful websites for people with learning difficulties.'

One reason the Health Trainers sometimes had difficulties agreeing was due to variation in their computing skills. For example, when discussing about the interface control with which the users would be able to upload files on the system, Roy and Tanya, the two mature Health Trainers, were not familiar with what uploading does and suggested that this term should not appear on the control's interface. Bonnie however, one of the two younger Health Trainers who had better computing skills, did not seem to mind if the term 'upload' was used on the system's interface control.

> Researcher: "...but let's say you guys want to use a new picture, you first come down here and you say 'Upload', you see?"
>
> Roy: "Upload...?"
>
> Researcher: "Is that good or, how should I change it? 'Upload, means load up on the Internet."
>
> Tanya: "What is another word for upload?"
>
> Roy: "Put pictures?"
>
> Researcher: "The problem is this is not only for pictures; it is for other things like, in the future you might add sound as well."
>
> Bonnie: "Upload is ok actually."
>
> Researcher: "Upload is ok? Tanya, do you understand upload?"
>
> Tanya and Roy together: "No."
>
> Roy: "I have never seen that word."

After the researcher explained the term upload and showed an example of uploading to the Health Trainers on the computer, Tanya and Roy decided that they could remember it so the word was left in the system. Uploading was something that only the Health Trainers would be performing on the system. The rest of the wiki users, like the clients of the Health Trainers, would not have to upload, so leaving the term in the system would not affect its accessibility.

5.2.2.7 Learning Challenges

One important challenge that the Health Trainers faced while being involved in software design and development related to learning and retaining new knowledge on the topic of the study. For example, the Health Trainers asked for a tutorial on Web 2.0 technologies to be repeated twice during two different meetings. They also asked for the tutorial on how to use the wiki system under development to be repeated at three different meetings. During these tutorials they also asked for the explanation of some concepts to be repeated sometimes more than twice. All learning challenges were overcome by allowing for additional time in order to explain things slowly, in simple language and sometimes repeating explanations until the Health Trainers understood them. This process made teaching the Health Trainers slower. In the long run the Health Trainers' involvement took longer, but their learning challenges did not render their engagement impossible.

As already described in Chapter Four, Section 4.5.1 during our second Participatory Action Research Meeting, the Participatory Research Team spent approximately two hours on a tutorial in which the researcher showed to the Health Trainers three Web 2.0 technologies, wikis, blogs and social networking. In the observation notes for that meeting the researcher noted down the following:

> The Health Trainers asked me to teach slowly and to explain all the concepts in as simple a language as possible. They said that this was necessary in order for all of them to understand and they also told me that they would like all tutorials to be taught this way…
>
> During the tutorial I kept asking them if they could follow [the material taught] and if they understood what was taught. For example every time I finished explaining a new concept I always asked them if they had understood it. If they did not understand it, they had no problem saying so. If there was something which they did not understand I repeated it until they confirmed that they had understood it. This process of trying to make sure that they understood everything forced me [within the same session] to explain many concepts two and even three times each. At the end of the tutorial there were more questions from the Health Trainers which were answered.
>
> … At the end of this meeting I felt confident that the Health

Trainers understood what Web 2.0 technologies are and how they are used. I asked them about this and they answered positively.

Two months later during the third Participatory Action Research Meeting the Participatory Research Team spent part of the time talking about technologies that could support their work. During that conversation the Health Trainers asked the researcher to repeat the Web 2.0 tutorial presented in our previous meeting. This surprised the researcher and in his observation notes for that third meeting he highlighted the following:

> The Health Trainers mentioned that they liked one of the systems that I had shown them during the [Web 2.0] tutorial in our previous meeting but they said that they had forgotten what it was called and how it works. Therefore they asked me to repeat the Web 2.0 tutorial again. I was surprised of the request because the previous meeting happened only two months ago and back then when I asked them, they reported that they had understood everything I showed them very well.

During the Participatory Research Team's initial meetings the Health Trainers determined that an accessible wiki software system should be developed which could be used to support their work. The researcher prepared an initial prototype of such a wiki which was presented to the Health Trainers in our fifth Participatory Action Research Meeting. Most time during that fifth meeting was spent on a tutorial in which the researcher showed the Health Trainers how to use the new system. It was a step-by-step tutorial which covered the whole functionality of the system. In his observation notes for that meeting the researcher wrote the following:

> Like in the case of previous tutorials this was also taught at a slow pace and in common language like the Health Trainers had asked me before and all the concepts were explained clearly. At the end of each section I used to ask the Health Trainers if they understood it and if they reported that they did not I would then repeat the explanation in order to clear any confusion. By using this teaching method many concepts were explained twice and some of them even three times. I wanted to make sure that the Health Trainers learned to use the new system because this is necessary for the procedure we will use from now on in order to gather system requirements.

[The procedure which the Participatory Research Team was planning to use is described in Section 6.8.1. This procedure was later abandoned because it did not meet the needs of the Health Trainers, as described in the section. The procedure that was finally used is described in Section 4.4.2.]

Three months later during our sixth meeting, the researcher presented to the Health Trainers a second prototype of the system. Some of the observation notes the researcher wrote down for that meeting were the following:

The intention today was to start using the procedure for gathering system requirements. The procedure required that one-by-one the Health Trainers sit in front of the second prototype of the wiki (which included all their requirements from our previous meeting) and use it while I was observing them. If they faced difficulties while using the system they were expected to tell me how to change the system in order to make it accessible to their needs…

This procedure required that the Health Trainers knew how to use the wiki. We already had a tutorial on how to use the system in our previous meeting and I thought that the Health Trainers would know how to do that today. When I described the procedure Roy and Tanya [the two mature Health Trainers] told me that they forgot how to use the system and asked me if it was possible to show them again one more time. I then asked Brenda and Bonnie [the two younger Health Trainers] if they also needed to see the tutorial on system use again. Brenda replied "I think it would be better if we do it again," and Bonnie agreed.

Approximately two weeks later during our seventh meeting when the third system prototype was presented to the Health Trainers, Roy and Tanya the two more mature Health Trainers asked for the tutorial on system use to be repeated for a third time. The researcher wrote down the following in his observation notes for that meeting:

…when I asked which Health Trainer would like to sit in front of the computer to use the system while I would be observing, the participants were looking at each other and could not decide who would go first. Then Tanya asked me if it was possible to quickly show them system use one more time. I then asked the rest of the Health Trainers if they would like to see the tutorial on system use one more time. Roy said that he would, while Bonnie and Brenda [the two younger Health Trainers] reported that they did not need to.

During that meeting the researcher asked Tanya and Roy to explain why they felt that they needed to see the tutorial for a third time and Tanya replied as follows:

> Tanya: "Because I do not use computers much, and I easily forget how to do something on the computer."

The tutorial was finally repeated for a third time. Another note that the researcher wrote down in his observation journal for that meeting was:

> … After today's meeting I realised that usually at the beginning of each of our meetings I have to repeat what I taught them [the Health Trainers] in the previous session (or sessions).

The data observed above when brought together suggests that the Health Trainers of the study while being involved in software development faced certain challenges relating to speed of learning and retaining new knowledge on the subject of computing. The learning challenges were overcome however, because the Health Trainers did not hesitate to ask for appropriate support. By teaching slowly, clearly and repeating explanations all the above stated learning challenges were overcome. As a result of the Health Trainers asking to be taught slowly and requesting repeat explanations, their involvement in software design required additional time.

5.2.3 Factors Affecting Involvement

Regarding research question one, the third category identified during data analysis was 'Factors affecting involvement.' The themes determined under this category are presented in Table 5.12.

Table 5.12 - The third category and related themes identified for research question one.

Category	Themes
Factors affecting involvement	• Computing skills • Appreciation for study objectives • Interest and excitement • Collaboration affected by tolerance

5.2.3.1 Computing Skills

As already discussed in Section 3.5.2 and Section 5.2.2.4 the sample of the study could logically be divided into two groups of Health Trainers. In the one group were Roy and Tanya, the two mature Health Trainers who had less developed general computing skills (as defined in Section 3.5.2). In the other group were Bonnie and Brenda, the two younger Health Trainers who had better computing skills. As a result of this obvious division it was easy to observe that the two younger Health Trainers with better general computing skills could get involved in the software development part of the study, easier and with less effort compared to the mature Health Trainers. For example, it was obvious that the mature Health Trainers had to ask many computer related questions in order to follow the discussion and manage to get involved while the younger Health Trainers did not. In the example discourse presented below, Roy asked what 'scrolling' was, while Tanya asked if a user needed to use the right or left mouse button. Throughout the course of the software development, Brenda and Bonnie the younger Health Trainers, never asked to be explained 'scrolling' and they always knew when to click the left or right mouse buttons:

Researcher: "…you didn't have to scroll down all the time, but now because I made it big, you have to scroll."

Roy: "Scroll...?"

Researcher: "Scroll means, do this, you see, scrolling down."

Tanya: "Is that on the left side or the right when you scroll down?"

Researcher: "Everything is with the left button, no right button."

The below example shows how Bonnie one of the younger Health Trainers knew what an attachment was:

> Researcher: "I click this link I want to go to the example page when I click on that, I click 'Example page' and then here I have to type the text, and here I'm going to say 'example page,' I press 'Ok,' 'Save' and here it is 'example page.'
>
> Bonnie: "So, it is like an attachment."
>
> Researcher: "Yes, if you click on it you are going to go to that attachment, ok?"
>
> Bonnie: "Ok."

While the conversation above shows that Bonnie knew what an attachment was, Tanya one of the mature Health Trainers, did not know and had to ask:

> Researcher: "So, now let's say you want to add a new page, you want to put one of your brochures, one of your information, this is the very first page that everybody will see but then you will want to create, let's say you want to put information like one of your brochures on the website, like this one for example."
>
> Tanya: "Is that called an attachment?"
>
> Researcher: "No, this is going to be a new page…"

The fact that the mature Health Trainers had less developed computing skills compared to the younger Health Trainers does not mean that they did not participate in the software development part of the study. By asking appropriate questions the mature Health Trainers managed to get involved and contributed to the process. Computing skills was a factor that affected how easy or how difficult it was for the different Health Trainers to participate in software development rather than if they succeeded or not.

5.2.3.2 Appreciation for Study Objectives

As already shown in Chapters Two and Three, the Health Trainers of the study came from a marginalised group of people whose opinion is typically not valued by the software development community and by society in general. By asking the Health Trainers to participate in the study they were given the opportunity for their opinions, ideas, knowledge and experience to be heard, valued and implemented into a specific software system. In our first meeting, and several other times, it was explained to the Health Trainers that the aims of the study were to find out how they could be involved in software development and that this would help towards making Information Technology (IT) more accessible to the community of people with learning difficulties. The Health Trainers showed their appreciation both for the fact that the study was giving them the opportunity to be heard, but also for the fact that this would help them and their community. They thanked the researcher about these aims several times and reported that the objectives of the study were motivating them. The following quotation is from our second meeting:

> Researcher: "Like I explained one of the goals of our research is for your voice, your ideas to be heard in the software industry, because software developers, software programmers, the people who make software, do not take advice, they do not listen to the needs of people with learning difficulties when they make software…"
>
> Roy: "When you say software you mean like the internet?"
>
> Researcher: "Yes everything we use on the computer, the programs on the computer, when we use a computer we use software."
>
> Roy: "Hm ok"
>
> Researcher: "…so computer programmers, they do not involve people with learning difficulties in the design of programs, of software, and this is one reason that programs are not accessible to you guys, so if we show that people with learning difficulties can get involved in software design then maybe programmers will be convinced and they will start listening to your advice, and your ideas and software will become more accessible to people with learning difficulties."

Tanya: "So you are saying that this will help, make our voice to be heard and so many computer (pause) …or we'll be able to use computers better."

Researcher: "Yes, computer software will become easier to use to, for people with learning difficulties."

Tanya: "Yes thank you, actually it would be nice to do that, isn't it?"

All: "Yeah"

Roy: "That is nice of you Sotiris."

Researcher: "What's that?"

Roy: "We appreciate you trying to do that."

Researcher: "Yeah? …because I'm involving you or because we'll help people with learning difficulties?"

Roy & Tanya: "Both."

At the end of a Participatory Action Research cycle during findings evaluation the researcher mentioned that one of the themes was 'appreciation for study objectives.' The researcher described the theme to the Health Trainers and asked them to comment on it. After the Health Trainers confirmed that they agreed with the finding, the researcher added the following comment:

Researcher: "What does this make you feel?"

Brenda: "What do you mean?"

Researcher: "The fact that you appreciate the goals of the study, that this study will help people with learning difficulties, that it gives you the chance to give your input and ideas, you just said that you appreciate this right? Does this appreciation make you feel anything?"

Tanya: "Yeah, no seriously personally it makes me feel, eh how can I say this…"

Brenda: "I think it makes us feel like we want to work for this, you know."

Tanya: "Yeah, you are right Brenda, it makes me, makes us, want to

work for this."

Researcher: "Work towards this you mean? For the goals of the study?"

All: "Yes, aha."

The appreciation that the Health Trainers felt motivated them to work towards something that would help both them and their community.

5.2.3.3 Interest and Excitement

Another reason for the Health Trainers' involvement success was interest and excitement about the study. During the course of the study all four Health Trainers stated several times about how excited they were. The excitement of the Health Trainers was obvious from the very first meeting when the research was explained to them and the consent forms handed out. This excitement was recorded in the researcher's observation notes for that meeting as follows:

> They [Health Trainers] seemed very enthusiastic about the project [the study]. Even though I told them that they could take the consent forms home first and think if they would like to participate, or maybe talk to their carers about it and then decide, six out of seven Health Trainers [2] signed the consent forms immediately and handed them to me. I asked them, "Why don't you take them home to discuss them with your parents or a carer?" and "Are you sure you do not want to think about this more?" Brenda replied, "No we want to sign them before you change your mind about this!" The rest of the participants laughed and agreed with Brenda's statement. I explained to them that I am committed to this project and I will not change my mind.

> I translated their willingness to immediately sign the consent forms and Brenda's statement ["No we want to sign them before you change your mind about this!"] as excitement about the project and that they definitely wanted the project to happen. This sounded very pleasant to me and for a moment I thought that maybe I translated it

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[2] As explained in Section 3.5, initially seven Health Trainers showed interest to participate. Six of them signed the consent forms immediately while the seventh Health Trainer took the form home to discuss it with her carers and then decided not to participate. Later two of the Health Trainers withdrew leaving only four participants.

this way because I wanted things to be this way (wishful thinking), because I wanted to hear that. In order to confirm that my translation of their actions and Brenda's statement was correct I reacted spontaneously saying, "I understand this as excitement about the project, that you want the project to happen, and you are sure that you want to take part in it, is that correct?" Pleasantly the Health Trainers once again confirmed this was so. I then asked them why they were so excited about it [the study] and they reported that the reason for their excitement was the fact that the project [study] involved computing something they enjoyed. Some of them also said that they saw this as an opportunity to improve their computer skills.

The researcher's journal entry notes for our fifth Participatory Action Research Meeting highlight the following:

During this whole meeting, like in most other meetings, all the Health Trainers seemed to be very interested and excited about the project. For example they all were very eager to contribute with ideas on how to change the wiki in order to make it easier to use and accessible. In the cases where they did not understand something about the system they did not show indifference. Instead they asked questions in order to understand and then tried to contribute with ideas on how to improve it [the system] and make it accessible. This was especially true of Roy and Tanya whose computer skills are less developed compared to Brenda and Bonnie.

During our twelfth Participatory Action Research Meeting, after the developed system became available online and the whole study almost finished, the researcher asked the Health Trainers if they would like to talk about their whole experience of involvement in the study.

Researcher: "Can we talk about, what was this study like for you? I mean, lets talk about your whole experience with our research, our project, you know like your whole involvement, how did you experience it, how did you experience the whole study? (pause) Do you understand what I mean?"…

Some of the Health Trainers' comments from the conversation, which relate to interest and excitement, were the following:

Roy: "Personally, to me, it was very interesting, and I enjoyed it (pause) because, I learned, many, new things, I learned new things.

All: "Hm, yes." (nod in agreement)

…

Researcher: "I get the message that all of you enjoyed it, right? And found it interesting, even though it took a lot of time, like it was time consuming and demanding at times, am I correct?"

All: "Yes."

Researcher: "Can I ask you guys how did the interest that you mention, affect you? Did it affect you at all, in any way? Do you understand what I mean?"

Brenda: "Yes, because it made me want to come to the meeting, to our meetings."

Interest and excitement was a factor that positively affected the involvement of the Health Trainers giving them an incentive to attend the study's meetings.

5.2.3.4 Collaboration Affected by Tolerance

Another constructive characteristic observed about the Health Trainers, was the fact that they were generally tolerant in their interactions either with the researcher or their colleagues. For example, they were generally calm and were ready to quietly sit and listen what the members of the Participatory Research Team had to say. This, like the other characteristics observed in the previous sections, positively affected the team's involvement in the software development. Their tolerance and patience facilitated the co-operation of the team.

During a findings evaluation session the researcher stated to the Health Trainers the present theme. After explaining the theme the Health Trainers were asked to comment on it. Their comments were the following:

Tanya: "Yeah, we are patient."

Roy: "Hmm." (Agreeing)

Researcher: "You are more patient than other people, at least when I worked with you that's what I noticed. Do you want to talk about it more, why do you think you are patient?"

Tanya: "Because I think we don't mind, eh… how can I say it, hmm…, personally myself, it takes me time to learn things…"

Brenda: "Yeah."

Tanya: "…and I don't get impatient about that, I just want to learn it, and I know if I try to think quick then I make mistakes…"

Roy: "Yeah."

Tanya: "…so I try to take my time and I hope that I eventually understand in the end, yeah."

Researcher: "So because you do that you learn to be patient?"

Tanya: "Yeah."

Researcher: (Looking at the rest of the Health Trainers) "Do you guys agree?"

All: "Yeah."

5.3 Could the Health Trainers Use the System?

The data to answer research question two was gathered during system use evaluation as described in Section 4.7. System use evaluation was undertaken in order to find out if the developed system was usable and accessible. The data gathered for research question two aimed at discovering any other themes than usability, which emerged during the use of the system by the Health Trainers.

System use evaluation was conducted by observing the Health Trainers while using the system one after another. Each Health Trainer had to execute the same tasks while being observed by the researcher. The specific tasks were chosen by the Participatory Research Team because they represented the most important functionality of the system (the tasks are listed in Table 4.3). The Health Trainers were asked to speak aloud and report what they were doing or thinking. The

researcher kept observation notes about how each user performed and what they reported. All system use evaluation observation notes are presented in Appendix 4. The data obtained from system use evaluation identified one category and two themes when analysed in order to answer research question two, as presented in Table 5.13.

Table 5.13 – The one category and two themes identified during data analysis for research question two.

Category	Themes
Use of the system	- Pre-existing computing skills affected use - Preference for information in small units

This section examines each of the identified themes and includes selected data abstracts in order to support the findings.

5.3.1 Pre-existing Computing skills Affected Use

There was a difference between the system use abilities of Brenda and Bonnie, the two younger Health Trainers who joined the study with very good general computing skills, and Roy and Tanya, the two more mature Health Trainers who started with less developed computing skills. During system use evaluation Brenda and Bonnie worked faster, with more confidence and had fewer difficulties using the system, compared to Roy and Tanya.

For example, when Bonnie and Brenda were asked to do a search for the word 'test,' both immediately typed 'test' in the proper textbox and clicked the correct button performing the task without delay and without taking time to think or read screen instructions. For the same task Tanya had to first read the instructions on the screen and then use the Help facility. Roy took time to think and had to read the instructions on the screen at one of the steps in order to perform the task. Thus the mature Health Trainers worked more slowly and with less confidence.

Table 5.14 – Researcher's verbatim notes on how each of the four Health Trainers performed the search task. *Italics* are used to emphasize and draw attention to phrases that support the findings.

Task to be performed: Do a search for the word 'test' and go to one page that has the word on it.	Researcher's verbatim notes written down during system use evaluation observations.
Bonnie	*Without delay* she typed the word 'test' into the appropriate search textbox and then clicked on the 'click to search' button. When the search results appeared she clicked on the title of one of the pages to go to the page.
Brenda	She typed the word 'test' into the appropriate search textbox *without any delay* and then clicked on the 'click to search' button *without delay*. When the search results appeared she *immediately* clicked on the appropriate title of one of the pages to go to the page.
Tanya	She started by *reading the screen. She saw the video Help 'click here to learn how to do a search' and clicked on it. She watched the video.* Then she went to the search textbox typed in the word 'test' and clicked the appropriate button. After the results of the search were returned *she spent some time looking at them thinking.* Then she clicked on one of the titles to go to one of the pages.
Roy	*He thought a little bit* then typed the word 'test' into the appropriate search textbox at the top of the screen and then clicked on the 'click to search' button. When the search results appeared *he read the instructions at the top of screen* and then clicked on the title of one of the pages to go to the page.

Roy and Tanya also had to carefully read the instructions on the screen and do some thinking before managing to execute another two tasks, edit an existing page, and add a new page to the wiki. Bonnie and Brenda worked with more confidence while performing the same tasks. Thus, the two mature Health Trainers worked slower and with less confidence as compared to the younger Health Trainers who performed the same two tasks immediately, without reading instructions.

Table 5.15 – Researcher's verbatim notes on how each of the four Health Trainers performed the task of creating a new page in the system.

Task to be performed: Please try to make a new page with the title 'Living healthy lives.' Write the following on it: 'One way to keep healthy is by exercising.'	Researcher's verbatim notes written down during system use evaluation observations.
Bonnie	She *immediately* clicked on the appropriate menu for creating a new page. When the form for adding a new page appeared she typed the title I told her in the proper textbox and clicked the appropriate button. Then she typed the text on it.
Brenda	She looked at the screen for a few seconds, clicked on the appropriate menu to get to the new page form. Then she added the title to the form, and clicked the proper button to create a new page. She typed the text on it.
Tanya	*She took some time to read the screen first* trying to decide which button/menu to click. She found the appropriate menu and clicked it to get to the new page creation form. *She read the instructions at the top of the form* that appeared and then she typed the title into the proper place. Then *she read the instructions again* and pressed the button to create the new page…
Roy	*He took time to read the screen first.* Then he clicked on the appropriate menu command which showed the new page creation form. *He read the information at the top of the form* then he typed the title into the proper place and *after some thinking* pressed the button to create the new page…

Users usually retreat to the Help system of a software application when they have difficulties performing a task or procedure. During the whole system use evaluation and in order to manage to complete all the tasks, the two younger

Health Trainers, Bonnie and Brenda, retreated to the use of the Help system only one time each. Tanya though used the Help system three times, while Roy used it two times. The fact that the younger Health Trainers used the Help system fewer times compared to their mature counterparts, suggests that the two younger Health Trainers had fewer difficulties using the wiki application developed. Table 5.16 presents all the tasks for which the Health Trainers retreated to using the Help system.

Table 5.16 - All the tasks for which the Health Trainers retreated to using the Help during system use evaluation.

Health Trainers' name	Task performed	Abstracts from the researcher's verbatim notes written down during system use evaluation observations
Bonnie	Try to create a link to the site www.nhs.uk	…Then she reported that she forgot how to do it and that she forgot the steps, and *that she is going to watch the video. She clicked on the appropriate Help link on the right side of the page to watch the video tutorial for creating a link to another website…*
Brenda	Try to add an image	…Brenda looked at it for about fifteen-twenty seconds and then she reported that she forgot what to do next and that *she was going to watch the appropriate video in the Help system. Cancelled the dialogue box and clicked on link/button for the proper Help video...*
Tanya	Do a search for the word 'test' and go to one page that has the word on it.	She started by reading the screen. *She saw the video Help 'click here to learn how to do a search' and clicked on it. She watched the video…*
Tanya	Try to create a link to the site www.nhs.uk	*...She clicked on the Help button 'How to make a link to another website.' She watched the video…*
Tanya	Try to add an image	…and *then reported that she will use the Help* and cancelled the dialogue box. *She watched the Help video…*
Roy	Try to create a link to the site	Roy immediately said, "*I think I*

| | www.nhs.uk | *am going to use the Help for this one." He clicked the appropriate video link on the right margin of the page. While watching the video…* |
| Roy | Try to add an image | *Immediately reported that he is going to use the Help for this as well. He clicked the proper link to view the Help video on image insertion…* |

5.3.2 Preference for Information in Small Units

A final theme that emerged for research question two was, 'preference for information in small units.' During system design, before system use evaluation, the developer tried to make the video tutorials of the wiki's Help system short because the Health Trainers requested it (Table 5.17 presents the corresponding system requirement).

Table 5.17 – The written down system requirement with which the Health Trainers asked for short video tutorials, along with the researcher's verbatim notes.

Health Trainers' user requirement	Researcher's comments written down at time of meeting or immediately afterwards
The videos of the Help system must be in the form of short tutorials.	The Health Trainers asked for short video tutorials because as they supported people with learning difficulties including themselves and their clients *cannot stay concentrated for long periods of time*. Because of this they would not be able to absorb the information in long tutorials and they also *would not remember them*.

During system use evaluation while observing Bonnie, Brenda and Tanya as they watched the video tutorials of the Help system, the researcher noticed that they kept pausing the tutorial quite often and during each pause they tried to go to the application to perform the instructions of the video they had just watched (Table 5.18). This observation led the researcher to suspect that some video tutorials

were still too long even though he tried to make them short like the Health Trainers requested. From the way some Health Trainers used the video Help during system use evaluation, it was obvious that the videos were not made short enough.

Table 5.18 – The three Health Trainers shown in the first column of the table kept pausing certain video tutorials of the Help system in order to break the presented information to smaller units.

Health Trainer's name	Task performed	Abstracts from the researcher's notes as written down during system use evaluation observations
Bonnie	Try to create a link to the site www.nhs.uk	…She clicked on the appropriate Help link on the right side of the page to watch the video tutorial for creating a link to another website. *While watching the video tutorial she kept pausing at each step (shown in the video) and was going to the system to perform the step she just watched*…
Brenda	Try to add an image [to the wiki page]	…she was going to watch the appropriate video in the Help system. Cancelled the dialogue box *and clicked on link/button for proper Help video. While watching the video she paused it twice and went to the system to perform the step she just watched*...
Tanya	Try to create a link to the site www.nhs.uk	She clicked on the Help button 'How to make a link to another website.' *She watched the video to the point which shows the appropriate button to click and paused it. She came back to the editor and clicked on the link creation button… She then went back to see the rest of video help tutorial.* After watching the rest of the video she came back to the system and saved the page.

The first Health Trainer who performed the system use evaluation was Bonnie. When Bonnie finished her evaluation session, she was asked to comment on the length of the Help video tutorial for link creation. Bonnie suggested that she would prefer it to be shorter. Later in another meeting when all the Health

Trainers had finished the system use evaluation, they were shown the video tutorial on link creation once again and asked for their opinion about its length. Like Bonnie they all suggested that the video was still too long and that it should be broken down further. The Health Trainers also suggested that the reason they preferred short video clips was because they would not be able to remember long ones as they could not stay concentrated for long periods of time. Thus, they preferred the information contained in the Help system to be offered in small units.

As discussed in Section 4.4.1 Evolutionary Prototyping, the software development methodology used in the study, considers that a system prototype is never final. A system can continue to be improved even after it is used in production (Figure 4.3). Therefore the accessibility barriers discovered by the Health Trainers during system use evaluation were fixed in the next Evolutionary Prototyping cycle.

Despite the various challenges faced by the Health Trainers during system use evaluation they all managed to overcome them either by using the Help system or by reading the instructions on the various screens. As a result, they all managed to complete every one of the tasks posed to them. This suggests that the developed system was usable and accessible. Other than the fact that the developed system was usable, the data gathered during system use evaluation also revealed two themes. The first theme suggests that the pre-existing computing skills of the Health Trainers affected how they used the system. The younger Health Trainers with better pre-existing computing skills worked faster and with more confidence compared to their more mature colleagues. The second theme suggests that the Health Trainers preferred the information of the system's Help to be offered in short video clips because as they suggested it is easier for them to absorb and remember the information.

5.4 Use of the System over Time

The study's research question number three, aimed at exploring how the Health
Trainers used the system over a long period of time. Involvement over a longer
period would suggest that the system was useful to the Health Trainers and that it
benefited both them and their clients. The data for this question was gathered
during two Participatory Action Research Meetings. The first meeting took place
in April of 2010 approximately five months after the system became available
online and the Health Trainers started using it for their work needs. The second
such meeting took place in May of 2011, approximately one year later. The data
analysis revealed one category and two themes which affected use over a longer
period of time as shown in Table 5.19:

Table 5.19 – The category and themes identified for research question three.

Category	Themes
Use over time	- Clients' preferences - Quantity and stability of material used

5.4.1 Clients' Preferences

The months immediately following system completion all the Health Trainers
created several work related Web pages on the system and they then started
offering information to their clients either on the Internet or on paper. The
impression that the Health Trainers got from talking to their clients was that the
clients typically preferred the information on paper rather than on the Web. This
was as a result of the fact that their clients did not have easy access to the Internet.
Thus, system use over a long period of time was affected by their clients'
preference for paper rather than Web based information. As a result, the Health
Trainers more often provided the information on hard copies rather than as Web
pages, even though some information was available in both formats. The
conversation below is from the Participatory Research Team's April 2010
discussion on the present theme.

Researcher: "Can we discuss how useful the website is?"

Tanya: "We do find it useful... because we can put information on the Internet but… our clients, I don't think our clients do."

Researcher: "What do you mean Tanya? Please talk to me more about your clients."

Tanya: "Well because you know everybody that I told him, (pause) or her about it… I ask them if they prefer the information on paper or the Internet, and they usually say on paper, not many ask me to get it, the information on the Internet."

Roy: "Yes because we give them brochures, and we also talk to them, so they seem to like that."

Researcher (Looking at Brenda and Bonnie): "What about you guys, have you told your clients about the website?"

Brenda & Bonnie together: "Yes"

Bonnie: "They prefer paper, usually, not many of them can access the Internet."

The Health Trainers also reported that they mostly used the system for material which was not available to their clients as hard copies.

Researcher: "So when do you guys use the website?"

Roy: "When we don't have it, the material is not on paper."

Tanya: "Yeah, when we don't have it on paper."

5.4.2 Quantity and Stability of Material Used

Use of the system over a longer period of time was also affected by the quantity and stability of the material which the Health Trainers used to perform their work. The Health Trainers reported that they used the website mostly to offer the material which was not available to their clients on paper but that material was not much and it did not change very often.

Researcher: "So how often do you guys have new information to give to your clients? Like, how often do you have information which is not on your brochures, or how often do you change your brochures?"

Brenda: "Not often… Like I organized a 'women's group' and I put the days on the website."

Finally, the Participatory Research Team discussed system use by the Health Trainers' clients. The Health Trainers reported the following:

Researcher: "…do you guys know if any of your clients have looked at the website?"

Brenda: "Yeah, I know that some of my clients have."

Researcher: "What about the rest of you guys, any ideas if your clients have used it?"

Roy and Tanya: "Yes, they have."

5.5 Conclusions

The findings discussed in this chapter reveal that during software development the Health Trainers managed to communicate the challenges which they faced and certain needs they had. With easy to provide support from the researcher those needs were met and thus the Health Trainers managed to successfully engage in the process. As the needs requested by the Health Trainers were basic and could easily be provided by the researcher, and because they were indicated by the Health Trainers themselves, the researcher did not need specialised skills in order to support the Health Trainers engage in software development. With the exception of skills and knowledge of how to behave ethically towards people with disabilities, discussed in Section 6.7, the skills that the researcher already possessed in order to involve users from the general population were adequate to also manage to involve people with learning difficulties.

As the findings illustrate, some of the challenges that the Health Trainers faced are common to all users, including people who have no disabilities. Therefore, in

many situations, when engaged in software development the Health Trainers with learning difficulties did not act differently from general population users. To overcome some of the challenges, the Participatory Research Team sometimes had to work slowly. For example, the Health Trainers asked to be taught slowly and they asked for tutorials to be repeated several times until they understood them. Therefore second level analysis reveals that another overarching need that the Health Trainers had was that for additional time.

The analysis of the data also reveals a number of factors that affected the Health Trainers' involvement. Such factors were interest and excitement for the subject of the inquiry, appreciation for the study objectives and the Health Trainers' pre-existing computing skills. Most of these factors motivated involvement and made it either easier or harder but none of them affected the Health Trainers to such an extent as to fail engagement completely.

During system use evaluation all the Health Trainers managed to complete all the tasks posed to them. This suggests that the developed system was usable and accessible. System use was affected by a number of challenges and factors. For example, using the system was easier for the Health Trainers with better pre-existing computing skills. The Health Trainers were also challenged with long video tutorials and showed a preference for small information units.

Finally, another finding is that system use over a longer period of time was affected by factors other than the usability and accessibility of the system. The developed system was used in order to enhance the service which the Health Trainers provide to their clients. Two factors which affected system use over a long period of time were the preference of the Health Trainers' clients for paper rather than Web based information and the fact that the information used did not change very often.

Chapter Six: Discussion

6.1 Introduction

Chapter Two critically analyses the literature showing that there is lack of research which explores how people with learning difficulties can be involved in software development. The current study addressed this question by involving people with learning difficulties in the development of a Web 2.0 based application. An aim of the inquiry was to explore if the Health Trainers could overcome the challenges of software involvement and successfully manage to offer input and ideas in order to make the application more accessible to people with learning difficulties. Chapter Five presents the findings which are discussed in this chapter. The findings contend that people with learning difficulties can be involved in software development, like most other user groups, provided certain provisions are in place.

This chapter starts by presenting a summary of the latest knowledge on the phenomenon under investigation as presented in the existing literature. It continues by discussing the findings outlined in Chapter Five and then presents the contribution this work has made to the existing body of knowledge. Integral to this discussion is the recognition that firm conclusions are often elusive, therefore the limitations of the study are presented next along with suggestions for further research.

6.2 What We Already Know

During the last three decades Information Technology (IT) has become pervasive to the extent that it is almost impossible to socially function unless an individual has access to it. Unfortunately, IT is still largely inaccessible to most people with learning difficulties. A major reason for this is the fact that this community of users are seldom involved in the development process of software systems, in order to offer their input and ideas on how to make systems accessible to their

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needs. User-Centred and Participatory Design methodologies are considered by the software and engineering industries as the most acceptable method for the development of usable products. (Mao, Vredenburg et al. 2005, Lopresti, Mihailidis et al. 2004). Yet the opinion of people with learning difficulties on the accessibility of software systems is almost never sought after. Most software developers believe that people with learning difficulties are not capable of involvement in the design and development process. Moreover, software developers are uncertain of how to work with end-users who have learning difficulties and they express concerns about obtaining approval for inclusion from institutional review boards (McKenzie 2007, Grammenos, Savidis et al. 2009, Sullivan, McGrenere 2003, LoPresti, Bodine et al. 2008).

A small number of studies (presented in Chapter Two) have involved people with learning difficulties in software development but in all studies the emphasis was on the technology rather than the participation (Grammenos, Savidis et al. 2009, Dickinson, Gregor et al. 2003, Newell, Gregor 2000, Dawe 2007a, Aspinall 2008, Harrison, Stockton et al. 2008a). None of these studies presented a systematic account of the challenges that people with learning difficulties faced during their involvement or the factors that affected their participation like the current study does. The literature review conducted by this inquiry shows that there is lack of research which concentrates on the participation itself. Therefore the current study tries to answer the three research questions stated in Section 1.5. By answering these questions the study hopes to make a contribution towards convincing advocacy groups, software developers and researchers to work towards involving more people with learning difficulties in software development processes. Involvement of people with learning difficulties in software development should not happen only in a few research studies but it should become more widespread affecting the whole software industry. In order for people with learning difficulties to be included as equal members of society all IT must become accessible to them and not just a few specific applications. This would remove IT related environmental barriers to the inclusion of people with learning difficulties in the community. The sections that follow discuss the findings outlined in Chapter Five in relation to the research questions, the existing body of literature

and the position that people with learning difficulties can be involved, provided they are afforded with certain basic needs.

6.3 Could the Health Trainers be Involved?

As Section 5.2 describes, the analysis of the data for answering research question one revealed three categories and twelve themes (presented in Table 5.1). This section examines each of the categories and their corresponding themes. The section discusses each theme, in relation to the existing body of literature and the position that people with learning difficulties can be involved by overcoming challenges, provided certain provisions are in place. The analysis of the data reveals evidence that the participating Health Trainers could be involved in software development. The Health Trainers could discuss system design and communicate their thoughts, overcoming their challenges, successfully engaging in the development process. Furthermore, all the system requirements suggested by the Health Trainers are corroborated in the literature by principles of software design for people with learning difficulties. The requirements and corresponding supportive principles of design are listed in tabular form in Appendix 5. This serves as further evidence that the Health Trainers gave proper input and asked for appropriate system changes.

6.3.1 Acted Proactively

As defined in Section 2.8 participation is essentially judged by the extent to which people can exert influence and bring about change. The consumerist participation approach is concerned with improving the efficiency, effectiveness or economy of services and products. In the case of the current study, the Health Trainers provided input, consultation and system requirements to improve a software product and make it more usable and accessible. Therefore, users who participate in a product development process can offer input exerting their influence to change the product making it more effective (in the case of the current study more usable and accessible). Those who cannot or are unwilling to participate remain

passive and do not offer any input. In the latter case, the researcher or product developer may try to encourage them to participate with specific requests. Thus users act reactively waiting to respond to the researcher's requests.

During their involvement in software development the participating Health Trainers did not wait to respond to the researcher's requests in order to offer their input for changing the system. Instead, they acted proactively offering appropriate input at such a level that facilitated the software development process towards creating an accessible system. Ambler (2011) stated that, "Reactive stakeholders may be a sign that the stakeholder community has a poor relationship with the IT department" [online]. As during development the Health Trainers acted proactively it can be suggested that they formed a good relationship with the researcher and this is evidence that they can engage in software development.

6.3.2 Involvement Challenges and Preferences

While being involved in software development, the Health Trainers faced a number of participation challenges. Those challenges are discussed in the following sections.

6.3.2.1 Preference for Simplicity

One characteristic of the Health Trainers was that they found complexity challenging and showed a preference for simplicity. As described in Section 5.2.2.1, when Roy and Brenda tried to edit an article in Simple English Wikipedia they faced difficulties and they stated that the reason for that was the fact that the wiki editor was complicated and confusing. The two Health Trainers who used the wiki showed that they were conscious that complexity was the cause of their difficulties and as a result they asked for an appropriate system requirement to simplify the editor of the system that would be developed for their use.

Another area where complexity challenged the Health Trainers was the User Accounts system of the initial prototypes. This system was comprised of different roles (groups of users) and each role had specific permissions. Despite a number of repeated explanations, the Health Trainers found it difficult to understand and use. However, the Health Trainers again realised that the challenge was due to complexity and asked for appropriate simplification requirements.

The Health Trainers also asked for more appropriate system requirements in order to simplify other parts of the developed system. In relation to research question one, these recorded observations show consciousness of their challenges, ability to communicate them and ability to be involved in software development by asking for appropriate system requirements.

The fact that the complexity of IT systems poses challenges to people with learning difficulties is also supported by the relevant literature. For example, McKenzie (2007) observed, "Many authors have also focused on the complexity of existing resources for people with learning disabilities, given their cognitive limitations" (p. 19). Lewis (2007) contended that the complexity of most software systems is a major barrier to users with learning difficulties, "Technology offers substantial benefits to the many people with some form of cognitive disability. But the power of technology often comes in a package whose complexity is a barrier to many users, leading to calls for designs, and especially designs for user interfaces, that are 'simple'" (Lewis 2007)p. 351).

Dickinson, Gregor et al. (2003) observed that a classic problem with current systems is that there is too much evident functionality which makes the interface crowded, confusing and hard to remember, "The problem, in general, is not one of excess functionality per se, but of the excess interface complexity which is consequent on the additional functionality" (p. 63). Dickinson, Gregor et al. (2003) also suggested that ways should be found to choose only the core functionality and thus fight complexity.

Keates, Adams et al. (2007) stated that a central technological barrier to people with learning difficulties accessing IT is the complexity of software applications and contended that this is an area worth researching further: "In summary, the focus of research and development activities should be on: 1. reducing complexity-reducing clutter, use of chunking and consistency (thus increasing overall expectability)" (p. 338)

A number of guidelines for the design of software and Web applications for people with learning difficulties also state the need for user interface simplicity. Friedman and Bryen (2007) compiled two lists of top Web access design recommendations for users with 'cognitive disabilities' based on the frequency cited by the existing Web design guidelines and on guidelines that had achieved a high degree of agreement. Friedman and Bryen list twenty two existing Web design guidelines that are cited by Web accessibility experts, government and advocacy organizations with a frequency of more than 15%. According to the authors these were identified in an extensive literature review. Recommendation number seven on the list states: "Uncluttered, simple, screen layout" (Friedman, Bryen 2007b)p. 208).

Henry (2007) supported that the distinction between usability and accessibility is especially difficult to define when considering learning difficulties and that many of the guidelines aimed to improve accessibility are the same as general usability guidelines. Therefore people with learning difficulties are not the only IT users who are challenged by complexity and show a preference for simplicity. According to the literature, the simplification of a software system and its user interface make it more usable to any user. An effort for simplification is one of the most common principles for designing software systems for all users and not just a principle for designing systems for people with learning difficulties (Nielsen 1993, Dix, Finlay et al. 2004.). Norman (1998) summarised User-Centred Design using seven principles which he calls "Seven principles for transforming difficult tasks into simple ones;" (p. 188) principle number two "simplify the structure of tasks" states that tasks need to be simple in order to avoid complex problem solving and unnecessary memory load (Norman 1998, p. 188).

Dix, Finlay et al. (2004) stated, "Principle three is that the system be *simple* and intuitive to use, regardless of the knowledge, experience, language or level of concentration of the user" (p. 367).

The findings of the current study are consistent with the literature in the fact that the Health Trainers showed a preference for simplicity. The literature for the design of software for users with no disabilities supports avoidance of complexity and preference for simplicity in order for systems to be usable. Therefore simplicity or avoidance of complexity is not a unique necessity for people with learning difficulties but something appropriate for most other individuals. In the cases when they were challenged by complexity the Health Trainers were able to realise it, communicate it and ask for appropriate measures and system requirements in order for the developed system to become accessible. This suggests ability to exert influence and bring about change and thus the Health Trainers could be engaged in software development.

6.3.2.2 Preference for Consistency

As described in Section 5.2.2.2, during involvement in development, the Health Trainers were challenged by lack of consistency on the computer screen. Two of the Health Trainers stated confusion when an initial prototype of the system was opened in two different Web browsers. During one of our meetings the wiki was initially opened in Internet Explorer and shown to the Health Trainers for about 40 minutes. Then after a short break the researcher decided to open it in a different browser, Mozilla Firefox. When Roy and Tanya saw the wiki running in Firefox, they asked why the buttons of the application had changed, pointing at the Internet browser toolbar at the top. Roy and Tanya were confused by the fact that the researcher first opened the wiki in Internet Explorer and then in Mozilla Firefox. The Health Trainers were used to seeing the wiki run in Internet Explorer and the inconsistency created when opened in another Web browser was challenging to them. After spending time to explain and show to the Health Trainers that the wiki ran in an Internet Browser they stated that they understood why the appearance of

the application changed. They then went on to ask for a change which would make the separation of the system under development and the Internet Browser more apparent. The Health Trainers also asked for another appropriate system requirement relating to consistency when they noticed that the first prototype of the system presented a random page every time it started.

In relation to research question one, the Health Trainers managed to express their perplexity and they asked for appropriate requirements to lessen the chances of future users being confused by inconsistencies of the system. The Health Trainers' perplexity was cleared after the researcher spent time explaining that the system ran in an Internet browser. Explaining things slowly and clearly, was the only need which the Health Trainers had in order for them to understand, clear the confusion and manage to give appropriate input.

The above findings are consistent with the literature. Regarding consistency Thatcher (2006) stated, "Clear and consistent design and navigation: People with some kinds of cognitive disabilities have difficulty processing visual information. They may not be able to use a site if the navigation is not clearly distinguished and consistent throughout the site." (p. 6). Recommendation number three of the Friedman and Bryen's list supports: "Consistent navigation and design on every page" (Friedman, Bryen 2007a) p. 208). According to the list, recommendation three is cited in 60% of Web design guidelines for people with learning difficulties.

Striving for consistency, however, is not a guideline for the design of software and Web applications for people with learning difficulties only. An effort for consistency is a common design recommendation for all users.
Dix, Finlay et al. (2004) observed "Consistency – Likeness in input-output behaviour arising from similar situations or similar task objectives" is one of the principles which positively affect the usability and learnability of a software system (p. 261). Dix, Finlay et al. (2004) also stated that consistency is one of the principles espoused in Apple's Human Interface Guidelines, "Effective

applications are both consistent within themselves and consistent with one another" (p. 280).

Shneiderman and Plaisant (2005) listed 'strive for consistency' as the number one rule under the heading 'use the eight golden rules of interface design' and stated that consistency is a strong determinant of the success of user interfaces (p. 74). From these guidelines for the design of software for people without learning difficulties it is obvious that all software users are challenged by the inconsistencies of a system and its user interface. Therefore, people with learning difficulties are not unique in this respect and they are just like any other software user. During engagement in development the Health Trainers managed to express the confusion caused by inconsistencies and asked for appropriate requirements to rectify the situation. Therefore the findings of the present study are consistent with the literature and suggest that the Health Trainers could participate in software development.

6.3.2.3 Preference for Common Vocabulary and Non-Technical Terminology

During engagement in software development, the Health Trainers were challenged with uncommon vocabulary and terminology. Two of them were also challenged by common computing terminology. However, whenever the Health Trainers did not understand a word, phrase or term they asked for its meaning. The challenge was therefore easily overcome by explaining to the Health Trainers what the word or phrase meant or by using a more common alternative.

On the issue of vocabulary Thatcher (2006) supported the following, "Accessible websites can benefit people with low literacy levels and people who are not fluent in the language of the website. Specifically, many of the aspects of Web accessibility for people with cognitive disabilities help people who do not know the language well" (p. 10). Also, recommendation number two on Friedman and

Bryen's first list states, "Use clear and *simple* text" (Friedman, Bryen 2007b)p. 208).

Friedman and Bryen (2007) compiled a second list of additional Web design recommendations for people with learning difficulties. The recommendations of the second list are cited by less than 15% of the accessibility guidelines for people with learning difficulties found in the literature. Recommendation number fifty one from the second Friedmand and Bryen list states: "Provide definitions of terms and lingo. Some words have multiple meanings" (p. 209). On the same topic Savidis, Grammenos et al. (2007) observed the following: "Existing design guidelines for the specific target user group [people with learning difficulties], include… clear paratactic syntax, and avoidance of terminology or other understanding barriers" (p. 404).

Braddock, Rizzolo et al. (2004) studied the emerging technologies for people with learning difficulties and observed the following regarding the use of proper vocabulary: "…for information to be accessible to a person with an intellectual disability, it must… be presented in a vocabulary or reading level that approximates the level of the recipient" (p. 5). Shneiderman (2000) discussed the issue of Human-Computer Interaction for universal accessibility and stated "Cognitively impaired users with mild learning disabilities, dyslexia, poor memory, and other special needs could also be accommodated with modest design changes to improve layouts, *control vocabulary*, and limit short-term memory demands" (p. 8). Arnott, Alm et al. (1999) observed: "The variety of cognitive difficulties which users may present are wide-ranging. The types of user interface which will be needed could therefore also range widely. People with aphasia (e.g. after CVA) may be unable to use traditional language-based interfaces, and need to use a *limited user-defined vocabulary* augmented by personalised graphics and symbols" (p. 348). Finally, on the issue of vocabulary which should be used within a software system intended for all users Nielsen (1993) stated, "In addition to such general standards, a project can develop its own ad hoc standard with elements like a dictionary of the *appropriate terminology* to be used in all screen designs as well as in the other parts of the total interface" (p. 91).

The literature therefore seems to suggest that different groups of users seem to have specific vocabulary needs and this includes people with learning difficulties. The findings of the present study are consistent with the literature in the fact that the Health Trainers had specific vocabulary needs. Moreover, the Health Trainers managed to overcome any vocabulary challenges they faced during software involvement by asking for definitions and thus they successfully managed to engage.

6.3.2.4 Preference for Shorter Working Periods

During the third Participatory Action Research Meeting the Health Trainers were challenged with session length and asked to have breaks more often. In a discussion that followed the Participatory Research Team decided to have breaks every about 40 minutes, than every hour as it was initially agreed. The Health Trainers associated their request for more often breaks, with inability to stay concentrated for long periods of time. On this issue Dickinson, Gregor et al. (2003) stated that while working on the design of Piloot, a communication software system developed with the involvement and for the use of people with learning difficulties "Working speed was often slow, *and concentration short*" (p. 62). Thus the findings of the study are consistent with the literature.

Even though until our third meeting the Health Trainers did not directly ask for the subject of break frequency to be discussed, they requested to have breaks more often than those planned. This prompted the researcher to suggest a discussion of the subject. Thus, the challenge was overcome enabling the Health Trainers to continue engagement in the process. By having more breaks the Participatory Research Team had to either make meetings longer or to add additional meetings. These changes made the overall length of the Health Trainers' involvement take longer.

6.3.2.5 Managing Disagreement

Sometimes there was disagreement between the Health Trainers regarding specific software requirements and features that the system should have. In order to overcome this challenge the Participatory Research Team had a discussion until a decision was reached. In all cases an agreement was reached and thus the Health Trainers overcame the particular challenge, managing to engage in the process of software development.

Disagreement is not unique to people with learning difficulties and it is rather a universal characteristic expected whenever human beings try to make decisions on a number of questions or issues like the characteristics and features that a software system should have. Waller, Black et al. (2009) stated disagreement among researchers, for example, "When a difference of opinion arose between the researchers, a short discussion took place. These disagreements occurred infrequently and a consensus was reached in all instances" (p. 12). If individuals did not have different opinions and all of them always agreed, then there would be no need for user involvement in software development. Software developers would adopt their ideas knowing that everybody would agree with them.

6.3.2.6 Learning Challenges

An important challenge that the Health Trainers of the study faced while being involved in software development, related to speed of learning. The Health Trainers asked for the delivery of tutorials at a slow clear pace and requested the use of simple language. A Web 2.0 tutorial was delivered this way once but then after two months this was repeated as the Health Trainers had forgotten the content. The Health Trainers also asked for a tutorial on how to use the system under development to be repeated three times. During these tutorials they also asked for the explanation of several concepts to be repeated sometimes more than twice. On the topic of learning, McKenzie (2007) stated, "Many, however, share some particular cognitive difficulties that can make learning about and accessing IT more difficult. Examples include generalising information (Ferretti, Cavalier

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1991), *learning and retaining new information* (Tully, Cahill 1984) and difficulty with language skills (Clements 1987)" (p. 18).

Dickinson, Gregor et al. (2003), who involved people with learning difficulties in the design of software systems observed, "During pilots the users often learned quickly, but did not retain what they had learned, meaning that the next week they started from the beginning again" (p. 62). The findings of the study are consistent with Dickinson's observation that the users "did not retain what they had learned" but are inconsistent with the position that "the users often learned quickly." The current study suggests that the people with learning difficulties who participated were not quick learners. The Health Trainers themselves stated that they were slow learners. For example, they asked for tutorials to be taught at a slow pace, suggesting that this was necessary to facilitate their understanding. When talking about patience and tolerance Tanya also observed "…personally myself, it takes me time to learn things" (Section 5.2.3.4). These comments by the Health Trainers of the study challenge the Dickinson, Gregor et al. findings. However, Dickinson, Gregor et al. (2003) did not mention the severity of learning difficulty of their participant group. Instead they stated that, "During the development of Piloot the users involved varied in terms of the severity of their impairments" (p. 62). Therefore, the difference in learning speed between the sample of the current study and the one in the Dickinson study may be due to differences in learning difficulty severity.

The learning challenges faced by the Health Trainers of the study did not stop them from engaging in software development though. All learning challenges were overcome as the Health Trainers were conscious of them and they asked for appropriate support. The learning needs and challenges of the Health Trainers slowed down the team's speed though and this is corroborated by Dickinson, Gregor et al. (2003) who observed, "*Working speed was often slow*, and concentration short" (p. 62).

The findings of the study agree with another quote from Dickinson, Gregor et al. (2003), "Often these users had experienced failures and were worried about

getting things 'right,' and this inhibited them from just going ahead and doing things" (p. 62). When two of the Health Trainers were asked to explain why they needed to see a tutorial on system use for the third time they stated:

> Tanya: "Because I do not use computers much, and I easily forget how to do something on the computer."
>
> Researcher: [to both Tanya and Roy] "Is it because you forget or because you don't feel confident that you can do it?"
>
> Roy: "A little bit of both."

Despite their learning challenges the Health Trainers managed to engage in software development as the Participatory Research Team allowed additional time for slow and clear explanation. Many other challenges that the Health Trainers faced required additional time in order to be overcome. Therefore, second level analysis suggests that additional time was another need that the Health Trainers had in order to engage. This need for additional time when working with people with learning difficulties is corroborated by the literature. In her online text on accessibility Henry (2011) noted that more time may need to be scheduled for test sessions which engage people with 'cognitive disabilities.' This need for additional time and the speed with which the Participatory Research Team worked necessitated a change of the requirements gathering procedure used as described in Section 6.8.1.

6.3.3 Factors Affecting Involvement

The analysis of the data revealed several factors that affected the Health Trainers' involvement in software development as described in Section 5.2.3. The revealed factors made involvement either easier or more difficult but none of them affected the engagement of the Health Trainers to the extent that they could not engage.

One factor that affected the involvement of the Health Trainers was their general computing skills (as defined in Section 3.5.2). The two younger Health Trainers with better computing skills could get involved in the software design part of the

study, easier and with less effort than the mature Health Trainers whose computing skills were perceived to be less developed. Nasirin (2005) referred to users with good computing skills as talents adequate to enable interaction with the system under consideration. Nasirin (2005) also argued that untrained users would not be productive or motivated, as those who are trained. However, despite their less developed computing skills, the mature Health Trainers did manage to engage and contribute to the process by asking appropriate questions. Computing skills was a factor that affected how easy or how difficult it was for the different Health Trainers to participate in software development rather than whether they succeeded or not.

The Health Trainers of the study came from a marginalised group of people whose opinion is typically not valued either by society or the software development community. By asking them to participate they were given the opportunity for their opinions, knowledge and experience to be heard, valued and implemented into a software system. During the course of the study it was explained to the Health Trainers that one aim was to find out how people with learning difficulties could be involved in software development and that this would help towards making IT more accessible to their community. As shown in Section 5.2.3.2, the Health Trainers showed appreciation for this aim. The appreciation that the Health Trainers felt translated into motivation to work towards the goals of the study and this affected their involvement positively. On the subject of why people participate or volunteer Brodie, Cowling et al. (2009) stated that respondents to a United Kingdom (UK) national survey identified a variety of pragmatic, egotistic and altruistic reasons. The most common motive was "to improve things and help people" followed by "…an affiliation with the cause" (p. 27). Brodie, Cowling et al. (2009) also stated that, "…some commentators stress how individuals want to have a voice, and by participating through these direct political channels they are given the opportunity to 'have their say'" (p. 27).

As shown in Section 5.2.3.3, the Health Trainers were excited about the study for other reasons as well and this also affected their involvement positively. They stated, for example, that they were motivated because the study involved

computing, something they enjoyed. On this Johnson and Hegarty (2003) observed, "Nevertheless, many teenagers and adults with mild to moderate learning disability find computers interesting…" (p. 479). On the relationship between user participation motivation and enjoyment Clement and Van den Besselaar (1993) advised that the project should be fun and interesting (p. 35). The Health Trainers also stated that participation was an opportunity to learn more about and improve their computer skills and this excited and motivated them. On this later motivating factor Brodie, Cowling et al. (2009) stated that people also participate in order to learn and experience new things and to develop life skills for work advancement (p. 28).

Another constructive characteristic that affected the Health Trainers' involvement was the fact that they were generally tolerant in their interactions as described in Section 5.2.3.4. For example they were generally calm and were ready to quietly sit and listen to what the different members of the Participatory Research Team had to say. This affected the co-operation of the group positively. When asked about this characteristic, the Health Trainers stated that it is the experiences they have as a result of their learning difficulties that make them more tolerant and patient. If this is indeed the case and the experiences they have as a result of their learning difficulties make them more tolerant, then this could even be an advantage that this community of people may have when involved in software development.

6.4 Could the Health Trainers Use the System?

The system use evaluation described in Section 4.7, aimed at finding out if the developed system was usable and accessible. The results of the evaluation suggest that the system was indeed usable. The data to answer research question two, was gathered during the system use evaluation. Research question two aimed at exploring any factors and challenges that the Health Trainers faced while using the system developed with their involvement. The following sections discuss the findings for research question two (described in Section 5.3).

6.4.1 Pre-existing Computing skills Affected Use

As discussed in Section 6.3.3, the analysis of the data to answer research question one, suggest that the Health Trainers' involvement in design was affected by their general computing skills (defined in Chapter Three, Section 3.5.2). The younger Health Trainers with better computing skills could engage more easily compared to the mature Health Trainers with less developed computing skills. During system use evaluation, computing skills was also a factor which affected the use of the system by the Health Trainers.

Section 5.3.1 describes that there was a difference between the system use abilities of Brenda and Bonnie, the two younger Health Trainers who came into the study with good computing skills and Roy and Tanya, the two more mature Health Trainers who started with less developed computing skills. During system use evaluation Brenda and Bonnie worked faster, with more confidence and had fewer difficulties using the system compared to Roy and Tanya.

As described in Section 5.2.2.7, during design the Health Trainers did not have the confidence to sit at a computer and use the whole functionality of the system under development and instead asked for a system use tutorial to be repeated three times. When system development finished and the Health Trainers had to use it for the evaluation, they all did sit in front of the computer and used the whole functionality of the system, successfully completing all the tasks posed to them. This shows that there was confidence gained from developing the system together. Despite the confidence gain though, there was still a difference in how the younger and mature Health Trainers performed during the system use evaluation. As the findings suggest, pre-existing general computing skills still affected system use even though the Health Trainers were involved in the development of the system they were tested on. Therefore, pre-existing general computing skills proved to be an important factor both during engagement in design, but also during the use of the software system.

6.4.2 Preference for Information in Small Units

Section 5.3.2 describes that during system use evaluation the Health Trainers showed a preference for information in small units. This finding emerged during system use, because certain videos of the Help system were not made short enough during design. In system use evaluation, three of the Health Trainers kept pausing specific Help video clips and immediately went to the system's editor to perform the part of the task they had just watched in the video. Later, when the Health Trainers were asked to comment about the length of the video clips in the Help system, they stated that they were still long and should be broken down further. The Health Trainers also stated that the reason they preferred shorter video clips was because they could not stay concentrated for long periods of time and that they would not be able to remember them. The Health Trainers stated something similar during system design, when they asked for more breaks and shorter participatory sessions (Section 5.2.2.5).

The Health Trainers' preference for shorter video clips, because as they suggested they would not be able to remember long ones, is consistent with the literature. Recommendation number forty-two on Friedman and Bryen's second list of guidelines states, "Reduce short-term memory load" (Friedman, Bryen 2007b)p. 209). The Health Trainers' suggestion that another reason they preferred short video clips was because they could not stay concentrated for long periods of time, is also consistent with the literature. Dickinson, Gregor et al. (2003) stated that while working on the design of Piloot, "Working speed was often slow, *and concentration short*" (p. 62).

Concluding, the Health Trainers managed to overcome all the challenges they faced during system evaluation completing all the tasks posed to them. This suggests that the developed system was usable and accessible. Therefore, the Health Trainers gave appropriate input and asked for appropriate system requirements. It is also important to mention that the Health Trainers who took

part in the system use evaluation were the same people who helped design it. To confirm usability and accessibility further, the system should be evaluated with a group of users who were not involved in its design. This should be part of a future research study.

6.5 Use of the System Over Time

The aim of research question three was to explore how much the Health Trainers used the system over a long period of time. Use over a longer period would show how useful the system was to the Health Trainers and their clients. It could also reveal factors that may affect the use of similar systems over a longer period of time.
The findings from answering research questions one and two, suggest that the involvement of people with learning difficulties was indeed possible and that such involvement did create a usable and accessible system. The findings for question three, which are described in Section 5.4, suggest that factors other than accessibility, also affected how the system was used in the long run.

The findings suggest that certain unique characteristics of the Health Trainers' profession limited system use over time. A factor which affected system use over a long period of time was the preference of the Health Trainers' clients for paper rather than Web based information, as a result of the fact that most clients did not have access to the Internet. This finding is consistent with the literature. McKenzie (2007) maintained that the proportions of people with learning difficulties who have access to the Internet and IT in general are lower compared to the rest of the population. McKenzie (2007) also supported that there are more factors other than the accessibility of software systems, which also affect the adoption of IT by the learning difficulties community. "The main barriers to use identified were: lack of funds; lack of training; complexity of the device; and lack of information about the potential benefits" (p. 19). The Health Trainers also stated that in the long run, they used the system to offer material which they did not have on paper, as a result of their clients' preferences, but this material was limited and did not change very often, thus limiting system use.

6.6 Contribution to Knowledge

Chapter Two demonstrates that there is a lack of research which concentrates on the participation of people with learning difficulties, to study how they can be involved in the software development process and how software developers can approach this field. The current study presents findings suggesting that a specific group of Health Trainers with learning difficulties were involved in software development, and illustrates how that was done. Therefore, the researcher contends that the findings of the study represent an original contribution to the existing body of knowledge.

The findings present a number of challenges impacting the Health Trainers' involvement and how those challenges were dealt with. The Health Trainers managed to overcome all the challenges they faced with support from the researcher. The Health Trainers offered appropriate input and a considerable number of system requirements, which as the system use evaluation showed, contributed towards creating a usable and accessible system. The Health Trainers could use the developed software and the findings suggest a number of factors affecting system use. Finally, the findings suggest that the use of the system over the long run was affected by factors other than the system's accessibility and usability. All these point towards the Health Trainers' ability to be engaged in software development and how that was done.

6.6.1 Ability to Overcome Involvement Challenges

The study findings present evidence suggesting that the Health Trainers managed to engage in software development by overcoming all the challenges they faced. In most cases the challenges were easily overcome by satisfying certain easy to provide specific needs that the Health Trainers had. The Health Trainers pointed out the following software development involvement needs:

- To be taught and explained things slowly, using common and clear language
- To have repeated explanations in order to understand the material under investigation
- To have breaks more often as a result of short attention span
- To have unknown vocabulary and terminology explained to them

In order to meet some of these needs the Participatory Research Team was required to work slowly and therefore there is also an overarching need for additional time.

The needs were indicated by the Health Trainers themselves and could easily be met. Therefore, it can also be suggested that the developer did not need any special skills in order to support the Health Trainers' involvement. The only additional specialised skill that the researcher acquired during the course of the study was knowledge of how to conduct the research and involve the Health Trainers in an ethical manner (discussed in Section 6.7). This finding suggests that software developers should not be concerned about acquiring special skills to involve people with mild learning difficulties in software development. A number of the challenges that the Health Trainers faced during engagement in software development also challenge most other users, including users who have no disabilities. Therefore in many respects the Health Trainers are not different from most users. Moreover, Section 5.2.1.1 presents evidence which suggests that during software involvement the Health Trainers acted proactively suggesting changes to the system without waiting to react to the researcher's requests.

6.6.2 Factors Affecting Involvement

The study findings also suggest that the engagement of the Health Trainers in software development was affected by the following factors:

- The Health Trainers with better general computing skills could engage more easily and with less effort compared to Health Trainers with less developed computing skills.
- Appreciation for the aims of the study motivated the Health Trainers to work towards its goals and this affected their involvement positively.
- The fact that the topic of the study was interesting and enjoyable motivated and excited the Health Trainers.
- Prospects for personal benefit also excited and motivated the Health Trainers.
- Tolerance and patience towards other members of the Participatory Research Team facilitated co-operation.

Pre-existing computing skills proved important both during engagement in software design and also during the use of the system. The two younger Health Trainers with better computing skills could engage during design more easily and with less effort compared to the mature Health Trainers whose skills were not as good.

The appreciation that the Health Trainers felt as their ideas and opinions were valued, and because the research would help and promote the rights of their community, translated into motivation to work towards the goals of the study. The fact that the study involved computing, something they all enjoyed and would help improve their computing skills, also motivated them to engage.

The Health Trainers stated that their learning difficulties make them tolerant and patient towards others. The tolerance that characterised the Health Trainers was another constructive characteristic that affected their involvement by facilitating the co-operation of the Participatory Research Team. All these factors should be considered by software developers when involving people with learning difficulties in software development.

6.6.3 Use of the System

During system use evaluation the four Health Trainers managed to complete all the evaluation tasks. This demonstrates that the system requirements suggested by the Health Trainers and the input they provided contributed towards creating a usable and accessible system customised to their needs. Moreover, the use of the system was affected by the computing skills of the Health Trainers. The two younger Health Trainers with better computing skills worked faster, with more confidence and had fewer difficulties using the system, compared to the mature Health Trainers whose skills were less developed. During system use evaluation the Health Trainers also showed a preference for small information units.

6.6.4 Use Over Time

System use over a longer period of time was affected by factors other than its usability and accessibility. A factor which affected system use in the long run was the preference of the Health Trainers' clients for paper rather than Web based information. This preference was as a result of the fact that most client users did not have easy access to the Internet. The Health Trainers also reported that they used the system in order to post on the Web the work material which was not available on hard copies. That material was not much though and it did not change very often and this limited the use of the system over time.

6.6.5 Empowered Sample

As previously stated in Section 3.5 one reason this research is original is because it explores the involvement of people with learning difficulties in software development within the context of an empowered and innovative project such as that of the 'Bristol Health Trainers with Learning Disabilities.' As the Health Trainers themselves reported, their participation was affected because they were used to working together as a team. As a result of their training to become Health Trainers they knew how to offer accessible information. The Participatory Action

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Research Meetings were happening at the Health Trainers' work office and therefore it was easy for them to attend. This was a venue where the Health Trainers gathered together for work three days per week and therefore the Participatory Research Team did not have to make special travel or meeting arrangements. They also stated that to be a Health Trainer must have helped their involvement in the research.

The fact that the Health Trainers had an income allowed them to live independently and empowered them to make decisions on their own. They did not depend on family members or carers to make decisions for them. As described in Section 5.2.3.3 this fact became obvious from one of the very first meetings held with the Health Trainers. During the meeting the researcher asked the Health Trainers to take the research information sheet and consent forms home and discuss their participation with their parents or carers. However, six out of seven Health Trainers immediately decided to sign the participation consent forms without consulting their carers. This example suggests that the Health Trainers were already an empowered group and this fact affected their research participation. On these issues the Health Trainers stated the following:

> …
>
> Researcher: "Now let's turn this around, do you feel that the fact that you are Health Trainers (pause), eh, do you believe that this fact affected the way we worked together? Or how did it affect our project?"
>
> (silence)
>
> Researcher: "I understand that this is a rather difficult question, I am sorry, but actually I may have asked you something similar in the past. Ok, do you understand me, or would you want me to repeat the question again and explain it further?"
>
> Tanya: "Yes, please."
>
> Researcher: "Ok basically you are the only Health Trainers with learning difficulties in the country, in the UK, right? So I would like us to talk about, if this fact affected eh like our project, our research together and in what ways? You know, I don't want us to talk only about the system we developed though, the technology. Please talk

to me about anything, like maybe it affected the way we worked together. Eh, imagine for example that you guys are not Health Trainers, do you believe that our work together, our project together, would be different if you were not Health Trainers, lets say?"

(pause, thinking)

Bonnie: "Yes."

Researcher: "In what way?"

Bonnie: "Like, we work together as a team, and so that maybe has helped, I believe it may have helped us for what we do together."

Researcher: "Very good, Bonnie, thank you, would anybody else like to expand more on this?"

Tanya: "Even though sometimes we have our, disagreements, I would say."

All: "Yes." (Laughing)

Roy: "To be a Health Trainer must have probably helped Sotiris."

All: "Yes."

Researcher: "So, Roy you say being a Health Trainer helped, right?"

Roy: "Yes."

Researcher: "So when you say helped, what exactly do you mean? Can you expand on it please?"

Roy: "Like we have been trained to know what our clients need, like the material or information for example."

Researcher: "To make it accessible you mean, or the information itself?"

Roy: "Both."

Researcher: "Great, what else?"

Tanya: "Personally, if we were not Health Trainers and did not meet here, I would probably not be able to attend, you know. Because it is very easy for me to attend the meetings if they happen during work, but if I had to travel for it, maybe I would not be able to afford it."

Researcher: "So you mean, the fact that we use this office but also

the fact that probably being employed as a Health Trainer makes you able to afford it? Financially I mean?"

Tanya: "Yes, that too, but also the fact that I travel here for work and I don't have to travel to attend our meetings. Like in the past, I had to travel to attend some meetings and I had to pay myself. But I was not employed back then, now that I have an income, maybe it would be different."

For the present study power was shared with the Health Trainers as much as was feasible and thus their role surpassed that of typical participants. The Health Trainers also consulted the team on many different issues such as, how to make the developed technology accessible, ensuring that the research was relevant and useful to their community, on the needs and preferences of their clients and the type of support they themselves needed in order to manage to engage in the process. The Health Trainers also took part in the analysis of the data and validated the findings and the results of the research. One reason they managed to do these things was because they were an empowered group due to their role as Health Trainers.

6.7 Limitations of the Study

A number of limitations affected the results of the current study. As stated in Sections 3.5 and 6.6.5 one reason the study is original is because it explored the involvement of people with learning difficulties within the context of an empowered group such as that of the Health Trainers. In this sense the identity of the Health Trainers and the fact that they worked together and knew each other acted as strength for the study.

Conversely, during the period that the study happened the Health Trainers were also co-operating as a result of their work (outside of the study). In commercial situations when final users are involved in software design they typically do not know each other and do not have a working relationship outside the product design. In this sense, the fact that the Health Trainers knew each other and were

co-operating outside the study is a weakness as this is not typical in commercial situations. Therefore the fact that the involved people with learning difficulties were Health Trainers, knew each other and were working together outside the study in some ways was a strength while in others a weakness for the study.

The current study was a small scale PhD inquiry with limited resources and as a result it was affected in several ways. Financial resources were restricted and therefore a number of activities that would have been beneficial could not be afforded. The researcher acted as the only software developer and this affected how much computer programming could be done. As a result the developed system had certain limitations as described in Section 4.8. To compound the system limitations discussed in Section 4.8, certain software components which would enhance the system further could not be purchased as they were unaffordable.

As described in Section 3.6 the study explored the possibility of acquiring ethical approval from the Department of Health and also applied and was granted ethical approval from the Faculty of Health and Social Care Ethics Sub-Committee at the University of the West of England. As a result of these proceedings it was essential for the researcher to become familiar with appropriate ethical conduct for working with people with learning difficulties. This may be a limitation of the study as in a commercial setting software developers do not typically possess this type of knowledge.

LoPresti, Bodine et al. (2008) asserted that informal discussion with interested software developers suggests that many of them do not include people with learning difficulties in their test panels as they are concerned about how to obtain approval for inclusion from institutional review boards. Lewis (2005) stated that researchers have similar concerns to those of software developers but suggested that this is a soluble problem:

> "The biggest reason for our ignorance is there have been so few studies of people with cognitive disabilities in usability tests. Discussion of this omission suggests that an important reason for it

is uncertainty about how to obtain human subjects review approval for working with such participants. This appears to be a soluble problem, in that appropriate protocol treatments could be developed and shared among research groups" (p. 4).

Finally, as the Health Trainers were not paid for their time and the ownership of the research was not theirs (explained in Section 3.4.6) they were willing to offer a limited amount of time for the needs of the study. This limited the level of Participatory Action Research achieved.

6.7.1 Level of Participatory Action Research Achieved

The aim from the start was to encourage the Health Trainers' involvement in every aspect of the study so as to engage them as co-researchers according to the Participatory Action Research approach. While trying to fully adopt Participatory Action Research the study faced a number of difficulties and challenges, mainly because it had to follow specific PhD procedures and as a result of financial and time limitations (explained in Section 3.4.6). The present section attempts to demonstrate the level of Participatory Action Research that was achieved during the course of the inquiry. The section lists the basic characteristics of Participatory Action Research as presented in the literature and discusses to what level each was adopted. During certain stages of the research a specific degree of participation was expected from the Health Trainers which was not achieved. Those stages are discussed as well.

Hagey (1997) presented the following seven characteristics so that researchers can evaluate their projects regarding participatory research. The present section starts by discussing Hagey's characteristics in relation to the study (Hagey 1997)p. 1):

1. The 'problem' originates within the community or workplace itself.
2. The research goal is to fundamentally improve the lives of those involved, through structural transformation.

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3. The people in the community or workplace are involved in controlling the entire research process.
4. The focus of Participatory Action Research is on oppressed groups whose issues include inaccessibility, colonisation, marginalisation, exploitation, racism, sexism, cultural disaffection, etc.
5. Participatory research plays a role in enabling by strengthening people's awareness of their own abilities.
6. The people themselves are researchers, as are those involved who have specialised research training.
7. The researchers with specialised training may be outsiders to the community, but are committed learners in a process that leads to militancy (fighting for change) rather than detachment.

As explained in Section 3.4.6 this inquiry deviated from the first Hagey characteristic because of PhD procedures that had to be followed. The research was not initiated by the Health Trainers but by the researcher and the supervisory team who set the research agenda. The research questions were also formed by the researcher and supervision team rather than the Health Trainers as the questions were part of the research proposal which was submitted before developing the Participatory Action Research methodology. As a result the Health Trainers did not own the research completely. The responsibility of study success or failure belonged to the researcher and the supervision team rather than the Health Trainers. The Health Trainers did not initiate the research in order to start a solution process. Instead they were asked if they would like to take part in a specific research study which in the end would probably help them and their community. All these factors affected the Health Trainers' involvement. If the study was initiated by the Health Trainers, they completely owned the research and the responsibility of its success, they would get involved differently (Williams, England 2005).

The same bureaucratic factors that affected the attainment of Hagey's characteristic number one, also affected characteristics three and six which were partly fulfilled. Characteristic number three, states that the community participants

should be controlling the entire research process. Although the Health Trainers were involved in the research process it can not be claimed that they controlled it. That type of control was mostly in the hands of the researcher and the supervision team. In relation to Hagey's characteristic number six, "The people themselves are researchers," the Health Trainers did participate in the research even though not to the anticipated extent. For example, the Participatory Research Team analysed part of the data and the Health Trainers participated in the findings validation.

The study fulfilled the rest of Hagey's and a number of other basic characteristics mentioned in the literature. Hagey's characteristic number two states that, the research goal of Participatory Action Research studies is to fundamentally improve the lives of those involved. The research aim of the current study was to show how people with learning difficulties can be involved in software development. If this could be shown, it was hoped that it would make a contribution towards convincing activists as well as the practitioner and researcher communities to pay more attention to the needs of people with learning difficulties regarding the accessibility of software. In turn this had the potential to create more accessible software which would contribute towards an inclusive environment and benefit both the Health Trainers and their community. The study suggests that people with learning difficulties can be involved in software development and presents the type of support they need. For the needs of the study a usable software system was developed which the Health Trainers use to enhance the service they provide. This can also be suggested as an improvement for the participants' lives.

Hagey's characteristics number four and five were also attained. The focus of the study was indeed on an oppressed group who were facing inaccessibility, marginalisation and discrimination by the people involved in research and software development. Therefore, characteristic four was accomplished. For the fulfilment of characteristic number five, the Health Trainers did gain an awareness of their own abilities through their involvement and their familiarity with the results of the study which suggest that people with learning difficulties can be involved in software development if appropriate support is provided.

Finally, Hagey's characteristic number seven was also accomplished. Even though the researcher was an outsider and unfamiliar with the problems and barriers that people with learning difficulties face in their everyday lives, during the inquiry he was indeed a committed learner. The whole experience of working with the Health Trainers made him aware of the discrimination and other social barriers that people with learning difficulties face. This experience turned him into an activist supporting the rights of this community of people, especially in relation to technology.

Section 3.4.3, presents a number of other attributes of Participatory Action Research, additional to Hagey's. One basic attribute is that the family of Participatory Action Research methodologies are characterised by a cyclical inquiry process. The participants are facilitated through cycles of planning, action and reflection (O'Brien 1998, Lewin 1951, Reason, Bradbury 2001, Stringer 1996). During the whole course of the study, five such Participatory Action Research cycles were performed. At the end of each cycle the completed research was reviewed and the findings evaluated. It was then decided how to improve the research in the next cycle. The reviewing and any decisions were decided by the Participatory Research Team.

Another characteristic of Participatory Action Research is that it incorporates the knowledge and expertise of the individuals experiencing the research problem, as they are seen as experts in the field (Reason, Bradbury 2001, Macauley, Commanda et al. 1999). The involved Health Trainers used computers at work and had a firsthand experience of the accessibility issues that people with learning difficulties face. As software users they acted as experts directing the software design in order to develop an accessible system.

Participatory Action Research relates to the creation of new knowledge, "Participatory Action Research attempts to negotiate a balance between developing valid generalisable knowledge and benefiting the community that is being researched (Macauley, Commanda et al. 1999, p.774)." The study generated

new knowledge as discussed in this and the next Chapters, thus fulfilling another basic characteristic of Participatory Action Research.

Participatory Action Research is characterised as being flexible in contrast to the rigid and linear design of most conventional research methodologies (Cornwall, Jewkes 1995). One reason Participatory Action Research was chosen as the appropriate methodology for the current study was because this flexibility offered advantages when working with people who had specific needs such as people with learning difficulties. For example, the gathered data quantity was very large. As a result, the Health Trainers reported that they could not get involved in analysing all of it because of a limited amount of time they could afford for the needs of the study. The Participatory Research Team therefore decided that the Health Trainers would only be involved in analysing part of the data. The rest of the analysis was completed by the researcher as described in Section 3.7.2. This type of flexibility is acceptable within Participatory Action Research. Cornwall and Jewkes (1995) asserted that Participatory Action Research allows flexibility to the degree of participation. There are different levels of participation, from shallow to deep, and that the participation degree is not fixed. "In practice, movement from one mode to another may take place at different stages of the research and for different purposes" (Cornwall, Jewkes 1995, p. 1669).

Despite the various challenges and difficulties, a good level of Participatory Action Research was achieved by the study. Out of eleven basic Participatory Action Research characteristics presented in this section, seven were fulfilled while four were only partly fulfilled. The fact that Participatory Action Research was partly implemented does not affect the findings. The aim of the inquiry was to try to explore how people with learning difficulties could participate in software development and the challenges a software developer would face during such involvement. In a practitioner setting the participants will not be involved in both research and in software development at the same time, like they did in the current study. Typically, when final users are involved in development by the software industry the data gathered is for the production of usable technology rather than for answering research questions. Even though the Health Trainers did not fully

participate during certain stages of the research, they participated wholly during the software development sessions. Thus the findings of the study are not affected. The process of trying to adopt Participatory Action Research within the framework of a PhD study, the difficulties and challenges faced, and the choices made to overcome them, were a major learning experience for the researcher and the Health Trainers. This knowledge can and will be used in future research projects in order to avoid similar difficulties when applying Participatory Action Research.

6.7.2 The Position of the Health Trainers in Relation to the Research

Williams and England (2005) asserted that there are a range of ways in which people with learning difficulties can be involved in research "…the field of inclusive research with people with learning difficulties is very varied and rich, and there are probably as many different ways of working together as there are researchers and projects" (p. 38). For example, in the 'Plain Facts' model an individual with learning difficulties can be employed as part of a team, in order to make information about the research accessible to other people with learning difficulties. This person's job typically involves checking text and images, commenting on them, preparing copies for publication and helping to produce tapes (Williams, England 2005). Richardson (2000) described a process in which the participants with learning difficulties were involved in checking analysis and meanings with the supporting researcher, while Ward and Simons (1998) reviewed the different methods of involvement.

The term 'inclusive research' was coined by Walmsley and Johnson (2001, 2003) to cover the wide range of modes of involvement of people with learning difficulties in research studies. This term is indeed descriptive of the background and philosophy for this type of research involvement. 'Inclusive research' is also a term which avoids the assumptions implicit in other terms such as 'emancipatory research.' For example, there are debates over whether 'emancipatory research' is

possible when people with learning difficulties are in control because of their need for support. Supported by researchers who have no disabilities is often seen as mitigating true 'emancipatory research.' "The question is, can people with learning difficulties both have support and remain in control?" (Williams, England 2005, p. 31). Mouse England, a person with learning difficulties and a member of the Bristol Self-Advocacy Research Group, has the following view on this issue (Williams, England 2005, p. 31):

> "We need support to do it, but we can take the challenge. Support is important. I like to have back-up, because if we are stuck we should always have someone there to help us. Everyone's different, it's according to what you need. When we get support, does this mean we are not taking the lead? I think we are taking the lead for ourselves when we do research. We can get support and take the lead. People may think we don't understand and we haven't got the guts to do it, but we say: 'Hang on. We need your support. We'll take the lead, and perhaps you can learn it from us.'"

People with learning difficulties, however, are rarely fully in control of every aspect of research that they get involved and which concerns their lives. Most research studies in the field of Learning Difficulty are typically started by non-disabled researchers, who have involved people with learning difficulties in their work as *co-presenters*, *co-researchers* or *as consultants* (Tarleton, Williams et al. 2004).

> "If we are concerned to include people with learning difficulties as researchers, it would make good sense to include them in the debates about the research process. In general, it is probably fair to say that the non-disabled researcher's perspective still dominates those debates…" (Williams, England 2005, p. 38)

In the current study the Health Trainers acted as consultants on many different issues such as:

- The type of software system to enhance the service they provided
- How to make the developed technology accessible
- Ensuring that the research was relevant and useful to them and their community
- The type of support they needed in order to manage to engage in the process
- Factors which affected their involvement
- The needs and preferences of their clients

Tarleton, Williams et al. (2004, p. 78) contended:

> "In the final analysis, it must be acknowledged that the involvement of people with learning difficulties as consultants to research is never going to result in full engagement with the research questions and issues. Such a process takes time and energy, and will require the research to be set up in a different way."

In the current study, the Health Trainers also took part in the analysis of the data and validated the findings of the research. After the research questions were decided by the researcher and supervision team (for reasons explained in Sections 3.4.6 and 6.7.1), the Health Trainers were also involved in most decisions regarding the research, taken within the Participatory Action Research Meetings. Therefore, the power was more evenly shared with the Health Trainers who acted beyond typical research consultants or typical participants.

Tarleton, Williams et al. (2004) asserted that inclusive research depends on the researchers' identity as people with learning difficulties. People with learning difficulties get involved in research exactly because they have a learning difficulty. "If they did not, then they would not be there" (p. 83). One of the skills people with learning difficulties bring to research is that they understand how it

feels to face cognitive limitations. Thus inclusive research should not be conceived as an academy which will produce people with learning difficulties with advanced cognitive or research skills. It is enough for people with learning difficulties to have an understanding of who they are and why they are doing the research. Researchers with learning difficulties can turn to supporters for help with many of the technical tasks of research and this does not mean that they lose control over the process. The priority should be to involve people with learning difficulties in the process (Smyth, Williamson 2004, p. 212).

Finally, the findings of the current study suggest that during software development an empowered group of users such as that of the Health Trainers managed to communicate the challenges which they faced and certain needs they had. Thus they successfully engaged in the process and the software developer did not need any specialised skills to support the Health Trainers. The skills which the software developer already possessed to involve users from the general population were adequate to also manage to involve an empowered group of users such as that of the Health Trainers with learning difficulties.

Section 2.9 describes the Dundee University's 'Straight-Talking User Group.' This is a user centre within the School of Computing which offers a place where adults with complex disabilities can meet and work with researchers to explore and develop technology. The disabled members of the user centre develop their computer skills and also provide feedback for accessibility research. The centre provides researchers with access to disabled expert and empowered users such as the Health Trainers (Prior 2011, Waller, Prior et al. 2011). Software developers and the software development community in general should approach and seek to co-operate with this or other similar centres which also employ activists that are already established in the field and are involved in issues of accessibility.

6.7.3 Video and Role-Play as a Research and Development Resource

Forum theatre was developed in Brazil in the 1970s by Augusto Boal (Boal 2008). It is described in a book with the title 'Theatre of the Oppressed,' and Boal originally intended forum theatre to be used by oppressed and marginalised groups. Forum theatre is intended as a resource for these groups, allowing them to express their views and exert pressure for political change. Forum theatre typically consists of a short drama performance designed to ignite conversation and feedback from the audience. The play usually includes a controversial point at which the performance stops to encourage the audience to participate and discuss it (Boal 2008). Since its beginning in the 1970s, forum theatre has been adapted for various other purposes, including software development requirements gathering (Newell, Carmichael et al. 2006, Newell, Morgan et al. 2006, Carmichael, Newell et al. 2005).

For software development, forum theatre is particularly appropriate when the technology does not yet exist as it allows the audience/participants to imagine how a system could be used (Rice, Newell et al. 2007, Carmichael, Rice et al. 2008). Developers with experience in using forum theatre for system requirements gathering believe that it presents certain advantages. For example, it can facilitate the discussion of sensitive issues with potential users and it can cover several potential uses of a system in a plot (Carmichael, Newell et al. 2005). For people with disabilities forum theatre could be useful in order to help them visualise a situation and to make them feel more comfortable to share their views (Newell, Morgan et al. 2006). Role-play and forum theatre can also be used for teaching research skills to people with learning difficulties (Marriott, Williams 2011).

Prior (2011) described how role-play and forum theatre techniques were used at Dundee University's Straight-Talking Centre (please see Section 2.9) to help prepare with the challenges created when disabled participants were involved in student technology projects. Centre staff took the role of the actor, playing various different characters. Some portrayed students as being nervous about working with people with Severe Speech and Physical Impairments (SSPI) while others

acted as students who were domineering and did not take the time needed to allow centre members to speak or express their views. One centre member would play the part of the evaluator while others were watching, providing suggestions on how they could deal with the student. By using role-play, participants were able to discuss challenging topics in a non-threatening environment. As the 'students' they were discussing were seen as fictional, the participants did not feel uncomfortable talking about them (Prior 2011, p. 340).

> "…video and role play can be useful ways of teaching people with learning disabilities about interviewing techniques. Some people find it very helpful to watch them selves on video, and participating in role-plays can also assist with exploring how it feels to be the person being interviewed. This can help the person that will be conducting the interviews develop a sense of empathy with the research participant, which may improve their interview skills" (Marriott, Williams 2011, p. 170).

Forum theatre can also be video recorded in order to be presented to the participants later or several times if necessary. Prior (2011) described the use of video recorded forum theatre with participants with SSPI. The aim was requirements gathering on the types of information these particular participants would want stored on a Communication Hospital and Multimedia Patient Information Organisational Network (CHAMPION) system. The information that would be held on the system was about the problems which adults with SSPI faced when they were admitted to hospital. The motivation for using video recorded forum theatre was to understand the way participants would want to share information with medical professionals. Following the formation of the video, a meeting was held with three participants with SSPI. First the video was shown on a large television screen and paused at the tension point. The participants with SSPI were able to follow the scenarios on the video. A short discussion was then held on what the participants had seen and they were invited to share their thoughts and provide feedback. The three participants identified four

important requirements which related to information that should be held on the CHAMPION system.

Another way that video could be used during software development, particularly when involving people with disabilities, would be for capturing interactions between the participants and a system. Moffatt, McGrenere et al. (2004) described how video recordings were used to capture interactions between the participants and an Enhanced with Sound and Images Planner (ESI Planner) system developed with the involvement of users with aphasia (please see Section 2.9). The recordings included unsuccessful screen taps that could not be captured in an event log and verbal interactions between the participants and the researcher. The video was used for user interface evaluation regarding the participants' experience using the daily planner and their user interface preferences. Marriott and Williams (2011) also reported using video to record people with learning difficulties while working with their personal assistants.

> "Video has many advantages, whatever analytic method is planned, since it is a naturally accessible format. People with learning disabilities can return to video data easily, while paper records of interviews, or even audio data, are much more dense and difficult. Some projects have included researchers with higher support needs by using pictorial and video methods, alongside drama and role play" (Marriott, Williams 2011, p. 171).

The present study did not use forum theatre mainly because the researcher did not have any relevant experiences with role-play. This is a limitation of the study but as discussed earlier, forum theatre is particularly appropriate when the technology does not yet exist because it allows the participants to imagine how a system could be used (Rice, Newell et al. 2007, Carmichael, Rice et al. 2008). In the case of the current study the Participatory Research Team was working with an open source system which was functional for typical users and was adapted to the needs of people with learning difficulties. As the original basic system was functional, the Health Trainers could see how it worked and they did not need to imagine it.

Forum theatre can also facilitate the discussion of sensitive issues with the participants (Carmichael, Newell et al. 2005). The researcher, from the beginning of the study, felt that there was a good rapport with the Health Trainers. The researcher did not feel that the Health Trainers were particularly uncomfortable in disclosing information or discussing their disabilities and the challenges they caused them. This was maybe due to the fact that the Health Trainers were an empowered group. As a result of this fact, the researcher did not have to seek alternative methods in order to elicit the feelings or any system requirements from the Health Trainers.

In addition, this study did not use video. As already discussed video has many advantages because it is a naturally accessible format (Marriott, Williams 2011). It does however require additional resources, such as special equipment, training and time. Considering the additional required resources, the Participatory Research Team decided that the study would not particularly benefit from the use of video. There was no specific need for video despite its advantages.

6.8 Future Work

The current study into the involvement of users with learning difficulties in software development has made distinct contributions to the existing body of knowledge. In addition to addressing the stated aims of the thesis, opportunities for further research have been identified. The thesis indicated a number of limitations which affected the results of the study. This was a small scale exploratory inquiry whose aim was deep understanding rather than statistical inference. One key area of further research would be for the inquiry to be repeated with a more representative sample. This would have the potential to enable the generalisation of the findings to a wider portion of the learning difficulties population.

Another identified area for future investigation relates to the evaluation of the developed system. The accessibility and usability evaluation of the system described in Section 4.7 was conducted by observing the same users that were involved in its development. In the future in order to confirm usability and accessibility further it should also be conducted with a group of users who were not involved in the system's development.

In Section 6.3.3, a number of factors are presented which affected the Health Trainers' involvement in software design. Even though there is research which explores the motives and factors that affect the involvement of people with learning difficulties in various other types of investigations, there is a lack of research which explores the motives and factors affecting their involvement in software development projects. Therefore this issue should also be explored further.

A number of important challenges that the Health Trainers faced during their involvement were learning challenges. The Health Trainers were especially challenged with learning speed and retaining what they learned. They therefore asked to be taught slowly and have repeated explanations (described in Section 5.2.2.7). The literature lists 'learnability' as a major attribute that affects the usability of any system. Both Nielsen (1993) and Dix (2004) listed learnability as the number one attribute which affects usability. Learnability is defined as "the ease with which new users can begin effective interaction and achieve maximal performance" (Dix, Finlay et al. 2004.)p. 260). As learning presents challenges to people with learning difficulties, increasing the learnability of a system should theoretically at least increase its accessibility. Nielsen (1993) observed that certain systems ("walk-up-and-use systems" p.28), such as museum information systems which are intended to be used only once, essentially have zero learning time allowing users to be successful from their very first attempt at using them. Alternatively, one common theme in the relevant literature is the fact that complexity in IT systems poses challenges to people with learning difficulties, and therefore software system should be simplified in order to become accessible (discussed in Section 6.3.2.1). Furthermore, simplicity and learnability are inter-

related. Nielsen (1993) supported, "User interfaces should be simplified as much as possible, since every additional feature or item of information on a screen is *one more thing to learn*, one more thing to possibly misunderstand and one more thing to search through when looking for the thing you want" (p. 115). Therefore, the study suggests that the inter-related attributes of learnability and simplicity and how they affect the accessibility of a system for people with learning difficulties should be explored further.

6.8.1 Requirements Gathering Procedure Change

The lack of confidence of the Health Trainers to use the whole functionality of the system after a single system use tutorial and the limited amount of time available to the study, forced the Participatory Research Team to adapt the intended requirements gathering procedure (discussed in Section 5.2.2.7). The original procedure intended to be used was the following:

- One after another the four Health Trainers would be asked to sit at the computer which was running the wiki and try to perform a set of pre-determined tasks covering the whole system functionality.

- During use the Health Trainer would be asked to speak aloud, verbalising both her thoughts and what she was doing, especially when she faced difficulties.

- The Health Trainer would be encouraged to suggest system changes which would make the task she was performing and the user interface easier and accessible.

- The researcher would sit next to the user and would mark down observations notes and any system requirements asked by the Health Trainers.

- At the end of a user's session the researcher would confirm his notes with the Health Trainer involved.

This speak aloud protocol procedure is commonly used when involving final users in system use evaluation and in iterative development processes to gather user feedback for the improvement of a system (Dix, Finlay et al. 2004.).

The above procedure was finally abandoned and was instead adapted as described in Section 4.4.2. The procedure used was in the form of a tutorial during which the Health Trainers were interrupting the researcher in order to provide input and suggest changes. From time to time the Health Trainers would sit at the computer to perform specific isolated tasks. This type of methodology suited the needs of the Health Trainers as during design they did not have the confidence to use the whole system functionality and repeatedly asked to be shown a tutorial on system use. As the Health Trainers did not have the confidence to use the system after one tutorial and the study not could afford the time for both additional tutorials and requirements gathering sessions, the Participatory Research Team decided to combine the tutorials with system requirements gathering.

The need to adapt design and development methodologies for Health Trainers with learning difficulties was suggested by Newell, Carmichael et al. (2002). Newell, Carmichael et al. (2002) described research and approaches which were successfully used to develop interfaces for people with various types of 'cognitive impairment,' "Much of the methodology used in these developments, however, had to be developed *ab initio*. Traditional User-Centred Design does not have the flexibility for these user groups" (Newell, Carmichael et al. 2002)p. 476). Newell, Carmichael et al. suggested that a new design approach, based on the already accepted User-Centred Design, should be developed specifically for developing software for people with learning difficulties (Newell, Carmichael et al. 2002)p. 478). Dickinson, Gregor et al. (2003) observed that from their research in developing software systems for people with learning difficulties, "…it may be possible to distil a methodology for the design of appropriate systems" (Dickinson, Gregor et al. 2003)p. 61).

The adapted requirements gathering procedure used in the study was deemed by the Participatory Research Team as the most appropriate for the needs of the inquiry. The fact that the procedure had to be adapted is presented to support the claim that development methodologies need to be adapted for working with people with learning difficulties. Therefore the study suggests further

investigation into adapting or creating new software development procedures and methodologies appropriate for people with learning difficulties.

Chapter Seven: Conclusions and Recommendations

7.1 Introduction

This research explored how a group of Health Trainers with learning difficulties could be involved in software development. It looked into the factors that affected the Health Trainers' involvement, the challenges they faced and how they were overcome. It also considered how the field was approached by the developer, the issues faced, and how those were overcome. It explored if the Health Trainers could use the system which was developed with their participation and looked into themes that emerged during use. Finally, the study explored how the developed system was used over a longer period of time and which factors affected its use. This study concentrated on answering three research questions as stated in Section 1.5.

7.2 Objectives of the Study

All three research questions posed by this inquiry were answered. For research question one this thesis presents evidence confirming that the Health Trainers managed to participate in the software development process. A number of themes presented in Section 5.2 suggest evidence of the Health Trainers' involvement. The study also reveals a number of challenges which the Participatory Research Team managed to overcome facilitating participation. The challenges were overcome because particular Health Trainer needs were identified and addressed. The developer did not need any specialised skills to support the Health Trainers' involvement as the needs were indicated by the Health Trainers and could easily be met. The findings also suggest a number of factors which affected the Health Trainers' engagement.

During system use evaluation all the Health Trainers managed to complete the whole list of computer tasks posed to them. They were therefore able to use the system. The evaluation suggests that the system developed with the Health Trainers' involvement and input was accessible, usable and customized to their particular needs. The analysis of the data also revealed two themes for system use. System use was affected by the pre-existing computing skills of the Health Trainers and they showed a preference for information to be offered in small units. Finally, Section 5.4 illustrates that the system was used in order to help the Health Trainers in their duties. Thus, research question two was also answered.

Section 5.4, also presents the findings for research question three which suggest that the use of the system over a long period of time was affected by factors other than its accessibility and usability. One such factor was the preference of the Health Trainers' clients for paper rather than Web based information. The reason that some clients had such a preference was a result of the fact that they did not have easy access to the Internet. The quantity and stability of the material used by the Health Trainers to perform their work was another factor that affected system use over the long run.

7.3 Social Applications and Recommendations

As McKenzie (2007) asserted, people with learning difficulties are still viewed as part of a stigmatised group and this affects others' expectations of their abilities and their self-efficacy. This research suggests that with support mechanisms in place the Health Trainers with learning difficulties could be involved in software development and that they could use a system developed with their input. Acknowledging the potential of engaging people with learning difficulties in software development is part of a wider societal change that recognises their value and worth and aids the development of equality. Although it has to be acknowledged that some initiatives and legislative frameworks supporting inclusivity have been developed (Section 2.6.2), the required attitudinal and perception changes are as important. These attitudinal changes must come from

re-education about people with learning difficulties and their abilities. The current study recommends that one way to change the perception of future software developers for people with learning difficulties would be to introduce an accessibility module into computing or other relevant design and engineering academic curriculums.

According to Katsanos, Tselios et al. (2012) many websites remain inaccessible to people with disabilities, despite the availability of relevant guidelines and tools and this is mainly due to lack of appropriate training of Web designers. Such a module should teach accessibility both from a technical perspective and also re-educate on the subject of disability theory by using the tenets and principles of the social model of disability. The material of the module should also be compiled with the involvement and input of people with disabilities. This type of interdisciplinary module would promote learning about how to design accessible technology and at the same time teach accessibility theory encouraging attitudinal change towards the disabled community. Similar modules on how to involve people with disabilities in software development could also be introduced. Such modules should include training on the ethics of involving people with disabilities. According to LoPresti, Bodine et al. (2008) many software developers do not include people with learning difficulties in their test panels because they are concerned about how to obtain approval for inclusion from institutional review boards.

As described in Sections 4.4.3 the software community puts special emphasis on the use of User-Centred Design and other participatory development methodologies which involve the final users in the process. Participatory methodologies are interdisciplinary as they deal with both technology and the participation of users. The inclusion of users in the software development process requires familiarity with concepts from the social sciences, such as how to act ethically or how to hand power over to the participants. Software developers however are not trained in these issues and they face challenges when they try to use participatory methodologies. The current study therefore recommends the introduction of relevant social science concepts within the computing curriculum.

Outlining the requirements of the system developed for the Health Trainers, it can be observed that the most important changes requested were simplifications and user interface changes in order to increase learnability. The system changes that the Health Trainers requested to make the original open source wiki accessible were not drastic in extent. This is consistent with the literature. For example, Fryia, Wachowiak-Smolikova et al. (2009) who researched the accessibility of a Web based e-learning system for individuals with learning difficulties asserted that "…relatively small changes to existing technologies, rather than substantially new ideas, were needed to create accessible Web-based systems" (p. 155). Therefore, in most cases commercial software firms would not have to dedicate considerable resources in order to make their existent systems accessible to people with learning difficulties. This is an argument that policy makers and advocacy groups could make to support the position that the software industry should include people with learning difficulties in their user panels.

Adopting the above recommendations would put disability on the political agenda and promote attitudinal change. Inclusive and accessible environments are central tenets of the arguments maintained by advocates of disability. The government has set itself a task of striving for a society where people with learning difficulties can participate as equal citizens. The current study claims that by embracing inclusive design principles and adopting the principles of the social model of disability can assist with the ambition of people with learning difficulties to obtain an equitable lifestyle, something which they aspire. Moreover, if software developers embrace inclusive design methods by involving people with learning difficulties, they will contribute to the formation of a fairer society.

The current study suggests that the stereotypical belief that end-users with learning difficulties may not be able to articulate what they want or need when they participate in software development is erroneous. The people with learning difficulties who participated in the current study could indeed articulate what they needed and they contributed to the process of creating an accessible software system. Moreover, the developer did not need special skills to engage with the

people with learning difficulties as they were able to indicate their own needs regarding their involvement. Therefore, concerns of how to work with users with learning difficulties cannot be substantiated and should be alleviated. The study has shown that the only additional skills which the developer needed were:

- To teach and explain things slowly, using common and clear language
- To be able to offer repeated explanations until the Health Trainers with learning difficulties understood what was taught
- To be able to offer breaks more often as a result of short attention span
- To explain unknown vocabulary and terminology
- To know how to behave and conduct the research in an ethical manner

These are skills that any professional who already involves users in research or the software development process should be able to offer without further training. Therefore researchers and software developers should stop being concerned about how to work with people with learning difficulties and should start involving them more utilising their feedback and input.

The Participatory Research Team had to change the system requirements procedure which intended to use in order to adapt it to the specific needs of the Health Trainers. As discussed in Section 6.8, the literature supports further research on how to adapt or create new procedures and methodologies appropriate for people with learning difficulties (Newell, Carmichael et al. 2002). The current study maintains this view and additionally recommends that any future methodologies developed specifically for people with learning difficulties should take into account their slow learning speed and the need for additional time that this community of users has when they participate in software development.

As shown in Chapter Six most system changes that the Health Trainers requested are also corroborated by principles of software design for people with no disabilities. Moreover, many types of challenges that the Health Trainers faced are not unique to people with learning difficulties. Therefore, any changes necessary to make a system accessible to people with learning difficulties will also benefit

most other users including those without disabilities. This position is further substantiated by the literature (Grammenos, Savidis et al. 2009, LoPresti, Bodine et al. 2008, Haberman, Jones et al. 2005, Liu, Hile et al. 2006). Harrison, Stockton et al. (2008) asserted, "However, developing an accessible VLE [Virtual Learning Environment] that can benefit learners with learning difficulties and/or disabilities may also benefit other users, as accessible software can often be the most usable software" (p. 1027). Liu, Hile et al. (2006) stated, "Although this paper focuses on a system for people with cognitive impairments, it is likely that a design that requires low cognitive overhead will also be attractive to many users without impairments" (p. 96).

7.4 Study Challenges and Implications

The author of this thesis acted both as a researcher and as a software developer in order to complete the study. During the course of the study he was challenged while performing the two roles, but he gained valuable learning and insights which have implications for future researchers and software developers who would like to involve people with learning difficulties in their projects.

The author's formal education and professional experience is in computing but the study was interdisciplinary requiring social science knowledge and skills as well. The interdisciplinary nature of the study created a number of challenges which future researchers who choose to explore a similar area will probably face.

The researcher was not familiar with social science philosophical positions or research methodologies and had to learn them along the way. While reading social science material it was more difficult to understand it, compared to reading material on computing. As a result more reading was necessary. He was also more challenged while trying to write the sections of the thesis which relate to the social sciences, compared to the sections which relate to computing.

A very important part of the author's education was mathematics and he spent most of his professional career writing computer code. Both mathematics and computer languages express ideas succinctly. Having to write a thesis not typically required by the natural and mathematical sciences was challenging. Gathering, analysing and presenting qualitative data, which is the form of data that the study used for the reasons described in Section 3.7.1, was also challenging.

Individuals trained in technology often find working with people in general challenging. This may be a reason why software developers do not like to involve end-users in software development processes and why they report that they do not know how to work with people with learning difficulties (Sullivan, McGrenere 2003, LoPresti, Bodine et al. 2008). This research study required engagement with people using a participatory methodology, and to compound that the Health Trainers were people with learning difficulties. The researcher felt that this would be even more challenging and at the beginning of the study he was feeling uneasy about it. This uneasiness was enhanced by lack of past similar experiences. However, as the findings suggest, working with Health Trainers with learning difficulties proved to be not as difficult as the researcher felt at the beginning and the researcher's nervousness disappeared after the first few meetings with the Health Trainers.

As the study used a Participatory Action Research methodology the Health Trainers were involved in the research part of the study as well as the software development part. The Health Trainers faced similar challenges both during their involvement in software development and during involvement in the research part of the study. For example, the Health Trainers asked for slow, clear and common language use. Although easy to do, it required conscious thought and reminders, which at times could be frustrating.

Other support that the Health Trainers requested was to have breaks more often as a result of short attention span. During tutorials the Health Trainers asked for repeated explanations, and on occasion asked for complete tutorials to be repeated

several times. Although this support was easy to provide it required additional time and this created frustration and anxiety and had time and financial limitations for the study. This type of frustration and anxiety will probably be felt by future developers and researchers who choose to involve groups similar to the one engaged in this inquiry. Prior preparation and planning for the additional time needed should help alleviate these issues.

Prior to the study, the researcher was not familiar with disability theory, the social barriers that disabled people face or the social model of disability. It is probable that most software designers will come from a similar position, with preconceptions about normality and wrong stereotypical beliefs about people with disabilities. Through engagement in the study, the researcher had to go through the process of re-education and attitudinal change which is recommended in Section 7.3. There is a tendency to unconsciously resist changing preconceptions and beliefs about people with disabilities mainly because they are very prevalent in society. Therefore attitudinal change is not easy and this is something that future researchers and software developers will also face if they involve people with disabilities. However, engagement with people with learning difficulties can change perceptions of disability and lead to adopting and supporting the tenets of the social model of disability and the rest of disability theory. For the researcher, this attitudinal change was one of the most important lessons learned from his PhD journey.

In comparison to previous experiences the researcher had, he feels that the overall experience with the Health Trainers was neither easier nor more difficult. It was just different. For example, working with the Health Trainers was more time consuming and frustrating at times, as the researcher had to repeat explanations and tutorials many times or be more considered in conversation. Conversely the Health Trainers were tolerant and co-operative. On a personal level the most important advantage of the experience with the Health Trainers was the fact that it was very educational. Working with a segregated group of individuals who face discrimination, and viewing the world through their eyes can indeed be life changing. The researcher feels that this experience changed him as a human

being. This is a benefit that future researchers and software developers who decide to involve people with learning difficulties in their projects can also have.

7.5 Conclusion

During the last few decades the government policy and focus in the United Kingdom (UK) regarding people with learning difficulties has been on enabling inclusion, ensuring rights, providing choice and developing advocacy. During the same decades Information Technology (IT) has become pervasive to such a degree that it is almost impossible for individuals to socially function successfully, unless they have access to it. Unfortunately, most IT remains inaccessible to people with learning difficulties. To achieve the goals of social inclusion for people with learning difficulties, IT must become universally accessible to them. A step towards fulfilling this goal would be if activist and advocacy organisations were convinced to promote the inclusion of people with learning difficulties in software development processes. The best way to make software systems usable and accessible is by including the end-users in the development process in order to offer their input and ideas. Software developers and researchers typically do not include people with learning difficulties in their projects though. A number of software developers and researchers believe that people with learning difficulties cannot be involved at all, while others report that they do not know how to work with this specific group of end-users. Activist and advocacy organisations should work towards influencing the research and software development communities to conduct more studies and include people with learning difficulties in software development processes more.

The current study illustrates how a group of Health Trainers with learning difficulties were involved in software development and that their involvement promoted the creation of an accessible system. Moreover, the study findings suggest that the researcher did not need any special skills in order to involve the Health Trainers as they themselves were indicating any special needs they had during the process. The study also illustrates how all the challenges which the

Health Trainers faced during their involvement could be overcome. Therefore, the findings of this inquiry support the aim of inclusivity and they can be used by policy makers and advocacy groups in order to exert further pressure on the wider research and practitioner communities toward fulfilling this aim.

I would like to close this thesis with a reflection on my PhD journey from the perspective of a software developer. I feel that it is important to highlight the challenges that software developers will face when involving users with learning difficulties in their projects. I started this journey into accessibility and the field of learning difficulties out of interest for Human-Computer Interaction (HCI). I believed that if I learned about accessibility I would be viewing HCI from another perspective and this would help me understand it better, and indeed this has been the case. The first important lesson I learned was that there is no 'typical' software system user. Instead there is a range of different users, from children, to older people and people with disabilities. As a software developer I have to design for all of them. From my academic training in computing and my ten year professional experience, I can argue that the concept of a heterogeneous range of users is not well understood in the computing community. Most software developers view themselves as typical and design for themselves. This is what they describe as the typical user. Trying to design accessible systems, usable to a range of users indeed requires a view from a different perspective and this is very helpful in understanding HCI better. In fact I would argue that textbooks on HCI should be re-written including the ideas of accessibility and heterogeneous users from the very first chapter to the last.

During the first stage of my journey the idea of involving Health Trainers with learning difficulties made me anxious as I did not have previous experiences with this specific community of users. My anxiety however disappeared early, during the very first meetings I had with the Health Trainers. As the findings suggest the Health Trainers supported me by showing their particular needs.

Another important challenge I faced during my journey was dealing with the interdisciplinary aspects of my study. Unfortunately, the classical computing

education I had did not prepare me for this. The choice to use social science methods was an unfamiliar approach to me. The study also required the design and development of an accessible software system for which I also did not have previous experience. However, during my journey I found out that all above mentioned challenges could be overcome.

For the design and development of the software system Evolutionary Prototyping, a User-Centred Design methodology was used. User-Centred Design is recognised by both the academic and practitioner communities as the best way to improve system usability (Mao, Vredenburg et al. 2005). Proof of this endorsement by the computing community is the fact that it has been standardised by the International Organization for Standardization (International Organization for Standardization (ISO) 2010, International Organization for Standardization (ISO) 1999). User-Centred Design places special emphasis on multi-disciplinary design teams and the involvement of the users in the software development process. Therefore software developers can use various social science methods in order to facilitate user involvement (described in Section 4.4.4). Yet my classical computing education did not prepare me in the use of social science methods and this was one reason I faced challenges during my PhD journey. The prevalence of User-Centred Design in the computing world, which requires the involvement of users should be supported through, education. A computing curriculum should include material on social science methods and not just technology.

User-Centred Design is a democratic process in which the users are empowered to advise on the design of the software system. Under User-Centred Design the software developer has to accept the users' recommendations and thus shares some power with the users. As a software developer however, I spent years of academic and professional training in the design of software and I therefore consider myself a specialist on this field. The fact that I consider myself to be a specialist on the subject of software design, made it very challenging for me to share my power with users during the study. This challenge was compounded by the fact that my academic and professional training did not prepare me to the democratic and ethical concepts of the sharing of power within the User-Centred

Design process. I believe that other software developers face similar challenges when they involve users. Earlier I argue that software developers also need to be designing accessible software for a group of heterogeneous rather than 'the typical' user. To do that they will also have to involve users with disabilities within User-Centre Design and this is even more challenging. Therefore, this is another reason why a computing curriculum must include teaching material from the social sciences.

In order to successfully involve people with learning difficulties, Evolutionary Prototyping alone was not adequate and had to be enhanced with concepts from Participatory Action Research a social science methodology (described in Section 4.4.3). The fact that software development methodologies have to be adapted accordingly in order to successfully involve people with disabilities was another major lesson I learned from my PhD journey.

In Participatory Action Research the role of the researcher is to support the participants in order to conduct their own investigation. The current study involved people with learning difficulties who had specific needs and was dealing with a technical subject. During the study I discovered that my role was very subtle and at times difficult. As a trained specialist I had to support the Health Trainers but at the same time I had to hand over to them as much power and research ownership as was possible. Therefore using a social science methodology in combination with Evolutionary Prototyping obliged me to work in a way which was different than if I had to use a software development methodology alone.

Conversely, Participatory Action Research requires that the participants take up a more active role, research ownership and thus more responsibilities regarding the study. These Participatory Action Research requirements empowered the Health Trainers who in turn helped me. I call this 'cyclic support' because I supported the Health Trainers and they in turn supported me by showing me, among other things, what type of support they needed. This is the reason that one of the study findings suggest that I (the software developer) did not need special skills in order to successfully involve the Health Trainers; because the elements from

Participatory Action Research which we included in Evolutionary Prototyping empowered the Health Trainers to help me overcome my own challenges. Another name for this type of support would be 'a virtues support circle.' This cyclic support which was the result of including elements from a social science into a software development methodology was one major reason that the involvement of the Health Trainers was successful. These facts suggest that there is a need to adapt software development methodologies in order to make them functional for people with learning difficulties. One way to do this would be to hand over part of the ownership of the software development process to the participating people with learning difficulties. This way the participants are empowered to become more actively involved, supporting the software developer and ensuring that the process succeeds. Within the software industry, this type of involvement with specific responsibilities placed on the participants with learning difficulties could also be financially rewarded. An income would in turn promote the independence and inclusion of the specific group of users into society.

Participatory design and research methodologies are not only about acquiring requirements for system development or advancing knowledge. They also present an ethical dimension for giving participants and users a voice in technology and/or research (Newell, Gregor 2000). People with learning difficulties are often marginalised in these processes and participatory methodologies promote mutually respectful relationships with stakeholders. This also leads to an immersion of the researcher or the software developer in the participants' world and allows for a more empathetic interpretation of their contributions (Porayska-Pomsta, Frauenberger et al. 2012, Porayska-Pomsta, Lemon 2012). As I describe in many parts of the present thesis, my immersion into the world of the Health Trainers, seeing things from their perspective was eye opening for me and one of the most important lessons I learned from my journey.

Before the study I did not know about the difficulties and discrimination that people with learning difficulties face. When the study started, I was probably a typical software developer with the wrong stereotypical beliefs about people with learning difficulties. Through the process of this exploration my ideas and beliefs

for people with learning difficulties changed completely, making me a strong supporter of their struggle for dignity, equality and inclusivity. For me this knowledge and change in attitude represents one of the most important benefits I had as a result of my journey. The encouragement and confidence to persist, felt when I read the story of Ed Roberts on a night when I was disappointed with the progress of my study, will remain with me forever. I am hoping that the study will affect other individuals in a similar manner. The biggest contribution that this work could offer to humanity would be to make a case towards convincing activist organisations to work in the direction of influencing the research and software communities to change their attitude towards people with learning difficulties. People with learning difficulties indeed deserve to be treated as equal members of society like all of us.

Appendices

Appendix 1 - Method Used to Find Material for the Critical Review of the Literature

This appendix describes the process used to choose appropriate material and conduct a thorough literature review. For the literature search the researcher used electronic article databases which specialise in the following subjects, Computer Science, Information Systems, Health and Social Care, Engineering, Design, Science and Sociology. A sample of the databases is presented in Table 1. The University of the West of England (UWE) library subscribed to the databases at the time of the literature search. The researcher also used the online library catalogue of UWE which searches for hard copy articles, books and other material kept at the library and Google Scholar which searches the World Wide Web for scholarly literature across an array of publishing formats and most disciplines.

Table 1 – Sample of the electronic databases used for the literature review search

- ACM Digital Library
- ANTE: Abstracts in New Technologies and Engineering
- Arts & Humanities Citation Index
- ASSIA (Applied Social Sciences Index and Abstracts) (via Proquest)
- Business Source Premier
- Cambridge Journals Online
- CINAHL Plus (Cumulative Index to Nursing and Allied Health Literature
- CiteSeerX (Research Index)

- Compendex
- EBSCO Host Electronic Journals Service
- EdITLib
- Emerald
- IBSS (International Bibliography of the Social Sciences) (via ProQuest)
- IEEE Xplore
- JSTOR
- Library, Information Science and Technology Abstracts LISTA
- MEDLINE
- PsycInfo (via Ebsco) Science and Technology Abstracts LISTA
- LISA: Library and Information Science Abstracts
- SAGE Journals Online
- Safari Books Online
- Science Citation Index
- ScienceDirect
- Social Care Online
- Social Sciences Citation Index
- Sociological Abstracts
- SpringerLink
- Zetoc

The researcher searched each individual article database separately using the 'advanced search' facility when it was available. Certain databases did not offer advanced search capabilities and therefore the available search facility was used. The general query used for the search was separated into two clauses. Clause 1 contained all the Learning Difficulty terms (Table 2) and clause 2 contained all the computing terms (Table 3) of the query. The two clauses were joined with the 'AND' logical operator as shown in the examples of Table 4. Each database's search engine was different therefore the query was adapted accordingly.

Table 2 – Clause 1: The different Learning Difficulty terms used during the literature search

- Learning disability
- Learning difficulty
- Mental handicap
- Mental retardation
- Mental sub-normality
- Mental deficiency
- Developmental disability
- Intellectual disability
- Cognitive disability
- Cognitive disorder
- Cognitive dysfunction
- Cognitive impairment

Table 3 - Clause 2: The different computing terms used during the literature search

Software

Software design
Software development
User centered (centred) design; User-centered (centred) design
UCD
Participatory design
Inclusive design
Accessibility
e-Inclusion (eInclusion)
e-Accessibility (eAccessibility)
User engagement
User involvement
User participation
Cognitive technologies
Cognitive systems
Web 2.0
Wiki
Social networking
Blogs
Rich Internet Applications

Table 4 – Three examples of the search query used to find relevant literature

Query example 1
"Learning disability" OR "Learning disabilities" OR "Learning difficulty" OR "Learning difficulties" OR "Mental retardation" OR "Developmental disability" OR "Developmental disabilities" OR "Intellectual disability" OR "Intellectual disabilities" OR "Intellectual difficulty" OR "Cognitive disability" OR "Cognitive disabilities" OR "Cognitive difficulty" OR "Cognitive impairment" OR "Cognitive impairments" OR "Mental handicap" OR "Mental retardation" OR "Mental subnormality" OR "Mental sub-normality" OR "Mental deficiency" OR "Mental deficiencies"   AND   "software development"

Query example 2
"Learning disability" OR "Learning disabilities" OR "Learning difficulty" OR "Learning difficulties" OR "Mental retardation" OR "Developmental disability" OR "Developmental disabilities" OR "Intellectual disability" OR "Intellectual disabilities" OR "Intellectual difficulty" OR "Cognitive disability" OR "Cognitive disabilities" OR "Cognitive difficulty" OR "Cognitive impairment" OR "Cognitive impairments" OR "Mental handicap" OR "Mental retardation" OR "Mental subnormality" OR "Mental sub-normality" OR "Mental deficiency" OR "Mental deficiencies"   AND   "participatory design"

Query example 3
"Learning disability" OR "Learning disabilities" OR "Learning difficulty" OR "Learning difficulties" OR "Mental retardation" OR "Developmental disability" OR "Developmental disabilities" OR "Intellectual disability" OR "Intellectual

disabilities" OR "Intellectual difficulty" OR "Cognitive disability" OR "Cognitive disabilities" OR "Cognitive difficulty" OR "Cognitive impairment" OR "Cognitive impairments" OR "Mental handicap" OR "Mental retardation" OR "Mental subnormality" OR "Mental sub-normality" OR "Mental deficiency" OR "Mental deficiencies" AND "User-centred design"
The query was repeated until all the computing terms of Table 3 were used in clause 2

The above query process returned a large number of articles and other material which was filtered down further using the following criteria. As described in Section 2.2 of the thesis a variety of terms and definitions for learning difficulties are used in different parts of the world. Therefore the literature material chosen was deemed appropriate by examining the given learning difficulties definition. In some parts of the world, like for example in the United States of America (USA), learning difficulties is used for a different group of disabilities compared to how the term is used in the United Kingdom (UK). The researcher was looking for studies that involved people with learning difficulties (PWLD) as defined by Department of Health in the UK. In some of the material found a definition for learning difficulties was not present. In those cases common sense was used to decide if the material was relevant. For example the researcher looked at the geographical region that the research took place or descriptions of the people with learning difficulties.

The search found many studies relating to software systems and people with learning difficulties. The aim of the study was to explore if and how people with learning difficulties could participate in software development and use though. Therefore the literature was filtered by including studies which engaged people with learning difficulties during any phase of the software development process. A number of found studies designed software systems based on principles of design only without involving people with learning difficulties. Studies which did not involve people with learning difficulties were not included in the list of studies which were critically reviewed in Section 2.9 of the thesis.

The search did not return any studies which explicitly engaged people with *mild* learning difficulties. Therefore the found literature was not filtered by the severity level of the Health Trainers' learning difficulty. Studies involving people with learning difficulties from any severity level were included.

The found material was also filtered by the language in which it was written and the date which the described research studies took place. The only two languages which the researcher understands are Greek and English. Therefore the material had to be written in one of those two languages. Finally, research studies which happened more than twenty years ago were deemed as obsolete and were not included in the final list.

The researcher studied all the material left after the filtering. While studying it he was marking down cited articles or other material which he decided were

important to the current study. The marked down material was later found and studied as well. Also while reading the material certain authors' names kept appearing repeatedly. The researcher decided on a list of authors whom he considered as important researchers on the topic of the study and therefore searched, found and studied as many of their articles as was possible.

Appendix 2 - Research design submitted to the National Research Ethics Service

Title: User Engagement in the Development of Web 2.0 Technologies for People with Learning Disabilities

Principal Research Questions:
(1) Can Health Trainers (HT) with Learning Disabilities (LD) be involved in the design and development of software in order to create a service customized to their needs and for their own use? (2) Can HT with LD use an integrated, Web 2.0 based, e-learning service to help them in their health trainer duties? (3) Can a service designed by HT with LD be used by other People with learning disabilities (PWLD)? (4) How do HT with LD engage with such a system over time?

Justification for the Research:
In recent years we have witnessed a growing interest in the latest generation of Web-based collaboration tools and services (a.k.a. Web 2.0 tools/services) such as wikis, blogs, social bookmarking and social networking. PWLD are excluded from using such technologies one major reason being that they were not designed with their needs in mind. The purpose of this research is to design a Web 2.0 e-learning software based service around the needs of HT with LD in order to enable them to use Web 2.0 technologies like the rest of us.

Sample:
The current study involves two cohorts of LD health trainers from the 'Bristol Health Trainers with Learning Disabilities' project, the only one in the UK. Optimum group size: 2 groups of 6 participants each

Inclusion Criteria:
Participants who have mild LD. Participants who do not have serious difficulties in communicating with others. Participants who have good computer skills, comparable to people with no disabilities. Participants who live and work in the Bristol area

Procedure:
This study will be devoted to the design and development of an e-learning Web 2.0 based software service for the needs of HT with LD. For the design and development of the service an iterative process will be used which will ensure it is customized for the needs of the LD HT. The iterations will be from design and development to evaluation/feedback from the LD users/participants. The feedback given by the users will then be applied to the design and coded into the system and then back to LD user evaluation and feedback again, and so on. This cycle

will continue until we have the proper Web 2.0 based service specifically customized for the LD HT.

In system design and development participants will be shown the functions of a basic Web 2.0 based e-learning service and asked what kind of enhancements and features they would like in order to become usable to them. The features and enhancements requested by the participants will then be coded into the system and presented to them during a second meeting. During this second meeting they will also be shown how to use the changed system. The participants will then be asked to use the system for a period until a next focus group meeting.

During this next focus group participants will be asked to evaluate each of the features requested in the first focus group meeting. This is after using the service for a certain period. If they still think that a feature is useable to them then the feature will stay in the system. If they want the feature changed/enhanced it will be changed. If they think that it is not useful, it will be taken out. They will also be asked if they came up with any new ideas about new features and enhancements they would like.

The changes and new features requested will then be coded into the system, presented to them and so on. This cycle will be repeated for about 5 times.

After development finishes completely the participants will be asked to use the final service for a period of a few months. The participants will then be asked questions of their experiences about using the service. Each one of them will also be asked to sit at a computer and start using the service. The researcher will then walk to each one of them individually and ask the participant to speak aloud and explain what he/she is doing and why.

When the service is developed it will have the capability to record who (codename), when and how much time a user spends on the system. This data will be stored in a password protected database and will be analysed to show system use over time. The participants will be informed that the system records the time they spend while using the service.

Appendix 3 – System Requirements

The system requirements requested by the Health Trainers and the notes which the developer was writing down either during the time of the meeting or immediately afterwards, presented verbatim. Comments in square brackets [ ] were added for clarification during the writing of the thesis.

Health Trainers' system requirement	Developer's verbatim comments written down at time of meeting or immediately afterwards

Initial requirements	
A common wiki where all the Health Trainers can co-operate in order to produce Web documents (Web pages) similar to the hard copy brochures they already prepare.	[Self explanatory]
Even though each of the Health Trainers will be preparing different Web pages which relate to the subject area each specialises they want to be able to edit all the pages of the wiki and not just the ones that each will be creating.	The Health Trainers ask to co-operate in the creation of all Web pages.
Clients/visitors must be able to create Web pages on subjects of their choice.	[This functionality was later changed so that only the users who have been registered in the system by the Health Trainers would be able to edit the site. This was done for security reasons as described in Chapter Four, Section 4.3.
The Health Trainers must be able to upload sound files for voice captioning of text, voiceover.	The Health Trainers said that they have appropriate digital equipment on which they can record their voices. They asked for the capability to upload sound files on the system. The sound files will contain their voices while reading a page so that a client/visitor with reading difficulties could hear instead of read a topic. They supported that many people with learning difficulties have reading difficulties.
The visitors/clients must be able to listen to the sound files uploaded (for voice captioning of text, voiceover).	[Self explanatory]
The editor of the wiki must be WYSIWYG (What You See Is What You Get) No text editing tags.	I asked two Health Trainers to try to edit an article in the Simple English Wikipedia but they could not do it. They pointed at the tags used by Wikipedia and reported that the user interface was confusing. Then they asked me for something like Word which does not have tags.
The gathered requirements on the first prototype were the following	Iteration One
System must allow and facilitate the content creators to use large fonts.	The Health Trainers reported that in their brochures they usually use a font bigger than point 14. They asked the same facility for the system because as they supported people with learning difficulties prefer bigger fonts and thus it will make the system more

	accessible to people with learning difficulties.
The text on the wiki interface and the Help system must be at least 14 points or bigger.	Roy: "A lot of people with learning difficulties like words written in font 20, because I was in a panic once and I said to my boss I got something in font 18 but she said that is ok as long as it not under 14."
The wiki must always present the Home Page when started.	The first prototype presents a random page every time it starts. The Health Trainers support that if the system remains as is now, presenting a page at random [non-consistency], this would confuse their clients who have learning difficulties. Therefore the wiki must change so that it presents the same page when it starts for consistency.
Menu: The 'create page' menu must become 'add a new page.'	Health Trainers report that they are not familiar with the word 'create' therefore in order for the system to be accessible to them the word must be replaced with a word they know like the word 'add.'
Menu: The tooltip of the 'create page' command must say 'click here to add a new page to this site.'	[The tooltip is the information that is revealed in a comic book type dialogue balloon (on a Windows PC the colour of the balloon is usually yellow) when the user moves the mouse cursor over the control. The tooltip usually describes what the control does].
The caption of the 'save' button must change to 'save this page on the Web.'	The Health Trainers support that control captions should not be a single word/keyword. Instead they should be descriptive, explain what the control does because this would make the system accessible to both them and their clients most of whom have learning difficulties.
The caption of the 'edit page' button must become 'click here to change this page.'	The Health Trainers report that they are not familiar with the word 'edit' and if the system is to be accessible to them and users with learning difficulties that word must be replaced with another more common word like 'change.'
The tooltip of the 'edit page' button must become 'click here to add or delete information on this page.'	[Self explanatory]
In the FCKeditor, Format drop down	The Health Trainers supported that

list, H1 must become 'Heading 1,' H2 'Heading 2' etc.	they prefer common vocabulary and no technical jargon. H1, H2 etc sounded like technical jargon to them.
The word 'wiki' must be taken out where it occurs.	The Health Trainers reported that users of the system with learning difficulties will not know what a wiki is and leaving it in would make the system harder to use.
Menu: The 'Index' menu must become 'list all pages.'	The Health Trainers supported that the captions of controls should not be a single keyword. Instead they should describe in full what a control does. They also supported that 'index' is not a common word and users with learning difficulties might not know what it means.
Menu: The tooltip of 'list all pages' menu must say 'click here to see a list of all pages.'	[Self explanatory]
Menu: The 'Home' menu must become 'Go to home page.'	The Health Trainers support that interface control captions should not be a single keyword but instead they should tell the users with learning difficulties what the control does in full. This would make the system more accessible to both them and their clients.
Menu: The tooltip of 'go to home page' must say 'click here to go to the homepage of the site.'	[Self explanatory]
The gathered requirements on the second prototype were the following	Iteration Two
Menu: A 'websites' menu command must be added which when clicked must display a page with links to important websites for people with learning difficulties.	We decided for a single keyword for this command because there was no room (real estate) on the user interface for a more descriptive command. We also said that the tooltip could be descriptive and hopefully this might lessen any difficulties caused by the single keyword.
On the 'websites' page the Heath Trainers must be able to add and delete links to important for people with learning difficulties Internet websites.	[Self explanatory]
The tooltip for the 'websites' menu command must say 'click here to see important websites for people with learning difficulties.'	Because the command is a single keyword, we chose a fully descriptive tooltip.
The users must be able to download	[A 'downloads' page was created in

files from the wiki.	order to satisfy this requirement. From the 'downloads' page users could download a number of different files.]
The visitors must be able to give feedback or their ideas regarding the site. Feedback examples could be how to make the website more accessible, suggestions on how to improved the site etc.	[The 'your ideas' menu command was added for this feature.]
Menu: A 'your ideas' menu command must be created. When the command is clicked it must take the visitor to a Web form which can used to email feedback to the Health Trainers.	[Self explanatory]
Menu: The tooltip of the 'your ideas' menu must say 'click here to e-mail us your ideas about this website.'	[Self explanatory]
There must be video Help for new visitors explaining what the website is about and how they can use it.	According to the Health Trainers video is preferable because many people with learning difficulties do like to read long pieces of text and some of them even have difficulties reading.
The log-in command (at top right of site) must become, 'To add or change pages you must be a Registered User or a Health Trainer. First Click here to login.'	The Health Trainers asked for Descriptive interface control captions. They supported that descriptive control captions would make the system easier to use for them and their clients.
The 'log-in' button caption must become 'click here to log in'	The Health Trainers report that descriptive interface control captions would make the system easer to use.
Increase the size of the blue header so that the 'Click here to login/logout' command fits and is visible even in cases where the user increases the size of the text using the Browser menus and commands.	[Self explanatory]
The command 'Click here to view previous versions of this page' must become 'Click here to see this page as it was before.'	The Health Trainers supported that wording the caption this way would make it easier to understand because the word 'previous' is not a common word and some people with learning difficulties may not know it.
The rectangle that logically encloses the wiki must move down and the margin left between the top of that rectangle and the Web browser buttons must become wider in order to make the separation between the wiki and the browser window more apparent.	Two Health Trainers reported that they could not understand where the browser ends and where the wiki starts. Tanya asked to make this separation more obvious.

The buttons for editing a page in the FCKeditor which will not be used by the Health Trainers must be removed. According to the Health Trainers the following buttons must be removed: 'Source', 'DocProps', 'Save', 'NewPage', 'Preview', 'Templates', 'PasteWord', 'SpellCheck', 'Find', 'Replace', 'SelectAll', 'RemoveFormat', 'Form','Checkbox', 'Radio', 'TextField', 'Textarea', 'Select', 'Button', 'ImageButton', 'HiddenField', 'StrikeThrough', 'Subscript', 'Superscript', 'Outdent', 'Indent', 'Blockquote', 'JustifyFull', 'Anchor', 'Flash', 'SpecialChar', 'PageBreak', 'Style', 'FitWindow', 'ShowBlocks'.	The Health Trainers reported that these buttons offered functionality that was redundant to them and that they should be removed in order to make the editing interface simpler and uncluttered. Roy: "I get confused when there are many buttons on the screen."
Simplify the User Accounts system.	The Health Trainers had difficulties understanding and remembering the User Accounts system because as they said they found it to be confusing and complicated. The Health Trainers asked me to simplify it in order to make it possible for them to understand it. Bonnie asked me if was possible to remove certain things like we did with the buttons that offered no useful functionality in the FCKeditor.
The gathered requirements on the third prototype were the following	**Iteration Three**
Dynamically hide 'click here to see this page as it was before' (found at the bottom of each page) from guest/visitors because they do not to use it. Only Registered Users and the Health Trainers (after they log-in) must be able to view this command because they are the only ones that use it.	The Health Trainers asked for this because as they said the less buttons there are on a screen the better, because it makes the interface look simpler and less confusing. Roy: "I get confused when there are many buttons on the screen." Brenda: "Can we have a few buttons for us and other buttons for visitors?"
Dynamically hide the page creation menu command 'Add a New Page' from guests/ visitors because they do not to use it. Only Health Trainers and Registered Users (after they log-in) must be able to see this menu because they are the only ones that use it.	The Health Trainers asked for this because as they said it would make the interface look simpler and uncluttered and this would make it less confusing and more accessible to their clients or other users with learning difficulties.

Dynamically hide the command 'Administration' from guests/visitors because they do not to use it. Only Health Trainers and Registered Users (after they log-in) must be able see this menu command because they are the only ones that use it.	The Health Trainers asked for this because as they said it would make the interface look simpler and uncluttered and this would make it more accessible to their clients or other users with learning difficulties.
Guests/visitors who do not have to log-in must only see four menus 'go to home page,' 'list all pages,' 'websites' and 'your ideas.' The rest of the menus must become visible only when a user logs in because only logged in users use them.	The Health Trainers asked for this because as they supported the less buttons, commands and menus there are on a screen the better as this makes the interface look simpler and uncluttered and thus less confusing and more accessible to their clients or other users with learning difficulties.
Conspicuous Print Button for guests/visitors. Although users can print a page using the Web browser's print command, when they do it through the browser all the menus, buttons and other interface controls show in the printout. The dedicated 'print' button must only print the content of a page without the interface controls showing in the printout.	The Health Trainers supported that one thing that many of their clients would be doing would be to print a subject therefore there should be a button specifically for that which is clearly visible. They said that this would make the website easier for the clients and other people with learning difficulties to use. They supported that most of their clients would most probably not know how to print using the Browser's print command.
The caption of the print button must be 'click here to print this page.'	[Self explanatory]
The tooltip of the 'click here to print this page' button must say, 'click here to open a new window from which you can print this page'	[Self explanatory]
The caption of the delete button must become 'click here to DELETE this page.'	[Self explanatory]
Health Trainers and Registered Users must also be able to upload an image from the Administration page.	At the moment the Health Trainers can only upload images and other files from the FCKeditor dialog box only, the dialog box they see when they try to add an image to a page. The Health Trainers said that if they could upload images from the Administration page as well would make the system easier for them to use.
The command used to upload an image	[Self explanatory]

from the Administration page must have the following caption, 'click here to upload a picture.'	
There should be Help videos on the topics of 'How to make a link' and 'How to add a picture.'	Bonnie and Tanya tried to perform these two functions and they kept forgetting the steps they had to do. The Health Trainers requested Help videos on these two subjects to watch in case they forget all the steps they have to perform.
Take the picture of the Health Trainers off the top horizontal margin so that it does not display at the top of all the pages/topics.	According to the Health Trainers displaying their picture at the top of all different topics may confuse visitors/clients with learning difficulties. The participants reported that their picture should be above the Home Page only because on that page their clients would be reading about them [the Health Trainers]. They also said that it was not appropriate for their clients to see their [Health Trainers'] picture when they read about 'healthy eating' for example. The 'healthy eating' topic should have another more appropriate image at the top rather than the Health Trainers' picture.
The editor size must be the same size as an A4 page so that the Health Trainers can fit the same amount of text on the screen as they would fit on an A4 piece of paper. This way what they see on the screen will print similarly on a hard copy page.	The Health Trainers asked if it was possible to make the editor like Word, where what you type on the screen prints the same way on paper.
Dynamically hide the 'View Changes' menu from the visitors because they do not use it. Only Registered Users and the Health Trainers must be able to see it after they log-in.	[Self explanatory]
There must be Help in the right column of each page.	[A context related Help system was implemented for most pages. A few pages do not have the Help feature in their right margin. Please see section 4.x System Limitations].
Specific subjects of the Help system (especially long subjects) must be offered as video rather than as text.	According to the Health Trainers people with learning difficulties do not like to read long pieces of text.
The video of the Help system must be in the form of short tutorials.	The Health Trainers asked for short video tutorials because as they supported people with learning

	difficulties including themselves and their clients cannot stay concentrated for long periods of time. Because of this they would not be able to absorb the information in long tutorials and they also would not remember them.
The text of the Help system must be short, simple and to the point, not long and boring.	The participants asked for short pieces of text, in simple/common language so that a user does not have to read through a lot of boring information in order to get to the important parts.
Add instructions in the Help system on how to force a new line. (Hold down the Shift key and then press the Enter key).	Forcing a new line was something that the Health Trainers kept forgetting how to do quite often (when they tried to test working in the editor). It is also an action that a user of the editor needs to do often. The Health Trainers asked me to add this to the Help system.
Some requirements were asked during system evaluation.	Evolutionary Prototyping iteration four.
The video tutorials of the Help system must be broken to smaller chunks.	While observing Bonnie, Brenda and Tanya watch the video tutorials of the Help system I noticed that they kept 'pausing' the tutorials quite often and during each pause they tried to go to the application and perform the instructions of the part of the video they had just watched. After this observation I asked Bonnie to comment on the length of video tutorial she had used. She supported that it was rather long and that it should be broken down into smaller clips. Later I consulted all the Health Trainers who confirmed that some video tutorials should be broken into even smaller video clips.
The Web address must change from www.bit.uwe.ac.uk/???? to something simpler/shorter and easier to remember.	The Health Trainers supported that the Web address was long and complicated and that their clients would not be able to remember it therefore we had to find a shorter one and one which was easier to remember. [Unfortunately we were limited by the address names available on the Internet, many names we wanted to use were already taken.] [Requested and implemented after system went online. As already

	described in Section 4.3 the Web address cannot be disclosed in order to preserve the anonymity of the participants. The purpose of the question marks (????) in the Web address on the left is to hide the real address and therefore the names of the participants].
The terms 'internal' and 'external link' in the Help system are technical and they must be replaced by the simpler terms 'link to another page' and 'link to another website'	The Health Trainers supported that computer or any other technical terminology should be removed from the system because both they and their clients are not familiar with it and makes the system more difficult to understand and use. Internal and external links sounded more like technical jargon to them and asked to be replaced with something more common.

Appendix 4 – System Use Evaluation Observations

The complete set of observations written down during system use evaluation:

Table 1 – How Bonnie performed each task

Task to be performed	My notes as written down during evaluation observations
Please try to find the page with the title, 'Healthy eating.'	She immediately clicked on the menu 'List all pages' and found the page. She then clicked on the title to go to the page.
Do a search for the word 'test' and go to one page that has the word on it.	Without delay she typed the word 'test' into the appropriate search text box and then clicked on the 'click to search' button. When the search results appeared she clicked on the title of one of the pages to go to the page.
Go back to the 'home page'	Was done with one click on the appropriate menu.
Please try to 'log in' using the following, User-name: *admin* Password: *admin*	She immediately clicked on the correct button/link in order to go to the login page. Then immediately she typed in the correct text boxes the user-name and password and clicked the appropriate button without delay.

Please try to change the following page 'test page 1.' • Please try to add and delete some text. Add *'This page was made in order to test the system.'* • Try to create a link to the site www.nhs.uk	Found the page by clicking on the menu 'List all pages' and clicked on the appropriate button to put it in edit mode with no thinking delays. She first typed the appropriate text and then even changed its colour. Then she deleted it without difficulties. Creating a link: she first thought about it for ten to fifteen seconds then she clicked on the appropriate link creation button. She typed the www.nhs.uk address in the appropriate place and clicked the OK button. Then she saved the page and stayed there thinking for while staring at the screen. I asked her if she would like to tell me if she is having trouble or what she is thinking about. She replied "It's not what I want to do." Then she reported that she forgot how to do it and that she forgot the steps, and that she is going to watch the video. She clicked on the appropriate Help link on the right side of the page to watch the video tutorial for creating a link to another website. While watching the video tutorial she kept pausing at each step (shown in the video) and was going to the system to perform the step she just watched. After watching the video she managed to create the link by writing down the sentence 'click here to go to the NHS website' and then making that sentence into a link.
Please try to make a new page with the title 'Living healthy lives' • Write the following on it: *'One way to keep healthy is by exercising.'* • Try to add an image	She immediately clicked on the appropriate menu for creating a new page. When the form for adding a new page appeared she typed the title I told her in the proper text box and clicked the appropriate button. Then she typed the text on it. Adding an image: Clicked on the appropriate button. The proper dialogue box appeared, looked at it for some time, when asked to report what she is doing she said I am reading it, then she

	clicked on the 'Browse Server' button in order to see the list of images on the server. She chose a picture. When the picture appeared into the dialogue box she moved the handles to view it, then she clicked the OK button [which adds the image on the screen].
Please try to delete the page 'test page 1.'	Thought about it first. Clicked on 'list all pages,' found the page, clicked on its title, went to the page and without delay she clicked on the appropriate button and confirmation to delete the page.
Now please try to undelete 'test page 1.'	Clicked on the 'Administration' menu, read the screen, clicked on link to view the trash bin. In the trash bin screen she reported that she was thinking and reading the screen. She found the title of 'test page 1' from the list, then she clicked the 'Restore' button next to it and undeleted the page.
Please try to register a new user. User-name: *Mary* Password: *Mary* e-mail: *mary@server.com* Security question: *What is your favourite colour?* Security answer: *red*	Without delay, clicked on the Administration menu, then clicked on appropriate command, filled in the form appropriately and created the user without any difficulties.

Table 2 – How Brenda performed each task

Task to be performed	My notes as written down during evaluation observations
Please try to find the page with the title, 'Healthy eating.'	She immediately clicked on the menu 'List all pages' and easily found the page. She then clicked on the title to go to the page.
Do a search for the word 'test' and go to one page that has the word on it.	She typed the word 'test' into the appropriate search text box without any delay and then clicked on the 'click to search' button without delay. When the search results appeared she immediately clicked on the appropriate title of one of the pages to go to the page.
Go back to the 'home page'	Was done by clicking on the appropriate menu command without delay.
Please try to 'log in' using the following,	She immediately clicked on the correct link in order to present the login page.

User-name: *admin* Password: *admin*	Then she immediately typed in the correct text boxes the user-name and the password and clicked the appropriate button without delay.
Please try to change the following page 'test page 1.' • Please try to add and delete some text. Add *'This page was made in order to test the system.'* • Try to create a link to the site www.nhs.uk	Found the page by clicking on the menu 'List all pages,' clicked on the title to go to the page and then clicked on the appropriate button to put it in edit mode with no thinking delays. She managed to add the sentence I asked her and then she deleted part of it without delay or difficulties. Brenda clicked on the link button (without typing a phrase to turn into a link first) and she stared at the dialogue box that appeared for a while. Then she cancelled the dialogue box and went back to the editor. She typed the phrase 'NHS website' then she highlighted it and clicked on the proper link button again. She looked at the dialogue box for a few seconds then she wrote the URL at the appropriate text box and clicked on the OK button which created the link and took her back to the editor.
Please try to make a new page with the title 'Living healthy lives' • Write the following on it: *'One way to keep healthy is by exercising.'* • Try to add an image	She looked at the screen for a few seconds, clicked on the appropriate menu to get to the new page form. Then she added the title to the form, and clicked the proper button to create a new page. She typed the text on it. Adding an image: When trying to add the image Brenda clicked on the appropriate button. The proper dialogue box appeared. Brenda looked at it for about fifteen-twenty seconds and then she reported that she forgot what to do next and that she was going to watch the appropriate video in the Help system. Cancelled the dialogue box and clicked on link/button for proper Help video. While watching the video she paused it twice and went to the system to perform the step she just watched. By doing the steps shown in the video

	she managed to add the image.
Please try to delete the page 'test page 1.'	Clicked on 'list all pages,' found the title of the page, clicked on it and went to the page. Then she immediately clicked the appropriate button at bottom of page for deletion. A confirmation screen appeared she confirmed deletion and deleted the page.
Now please try to undelete 'test page 1.'	Some thinking delay initially. Clicked on various menus first reported that she forgot where the trash bin was. Clicked on the 'Administration' menu, read the screen then clicked the proper link to view the Trash Bin. She read the instructions on top of trash bin page then she found the title of the page from the list and clicked the 'Restore' button next to it.
Please try to register a new user. User-name: *Mary* Password: *Mary* e-mail: *mary@server.com* Security question: *What is your favourite colour?* Security answer: *red*	Clicked on the Administration menu, then clicked on appropriate command, filled in the form appropriately and created the user without difficulties.

Table 3 – How Tanya performed each task

Task to be performed	My notes as written down during evaluation observations
Please try to find the page with the title, 'Healthy eating.'	She clicked on the menu 'List all pages' and found the page. Then she clicked on title to go to page.
Do a search for the word 'test' and go to one page that has the word on it.	She started by reading the screen. She saw the video Help 'click here to learn how to do a search' and clicked on it. She watched the video. Then she went to the search textbox typed in the word 'test' and clicked the appropriate button. After the results of the search were returned she spent some time looking at them thinking. Then she clicked on one of the titles to go to one of the pages.
Go back to the 'home page'	Was immediately done by clicking on the appropriate menu command.
Please try to 'log in' using the following, User-name: *admin* Password: *admin*	Spend time carefully reading the screen first. She found the button/link for log in and clicked it. She typed the user-name and password and clicked the

	correct button to log in.
Please try to change the following page 'test page 1.' • Please try to add and delete some text. Add *'This page was made in order to test the system.'* • Try to create a link to the site www.nhs.uk	Thought about it for a while, then clicked on the menu 'List all pages,' read the screen and clicked on the title to go to 'test page 1.' Spend five-ten seconds looking at the page then she clicked on the appropriate button to put it in edit mode. She added the sentence I asked her and then she deleted a part of it without difficulties. Creating a link: She thought about it for a while, and then started reading the screen. She clicked on the Help button 'How to make a link to another website.' She watched the video to the point which shows the appropriate button to click and paused it. She came back to the editor and clicked on the link creation button (without typing something first). The dialogue box appeared. She read the dialogue box, took some time to think and then typed www.nhs.uk at the proper place and clicked OK. She mentioned "too many steps to remember." She then went back to see the rest of video help tutorial. After watching the rest of the video she came back to the system and saved the page.
Please try to make a new page with the title 'Living healthy lives' • Write the following on it: *'One way to keep healthy is by exercising.'* • Try to add an image	She took some time to read the screen first trying to decide which button/menu to click. She found the appropriate menu and clicked it to get to the new page creation form. She read the instructions at the top of the form that appeared and then she typed the title into the proper place. Then she read the instructions again and pressed the button to create the new page. After the page was created she typed the text on it. Adding an image: She first clicked the wrong button, realised it and cancelled the dialogue box. She then thought for

	about twenty seconds, moved her mouse over various buttons and clicked on the correct button. She stared at the dialogue box that appeared [insert image dialogue box] and then reported that she will use the Help and cancelled the dialogue box. She watched the Help video until the point it shows what to do when the insert image dialogue box appears and then came back to the editor forgetting to pause the video. She clicked the correct button for inserting an image and then the correct button on the dialogue box (Browse Server). She got the list of images. She stared at it for a while and then she clicked to choose an image. On the new dialogue she clicked the OK button and added the image.
Please try to delete the page 'test page 1.'	Thought about it first. Clicked on 'list all pages,' found the page, clicked on its title, went to the page. There she stared at the screen for a while, and then she clicked on the appropriate button for deletion. At confirmation page she read the screen first and then confirmed to delete the page.
Now please try to undelete 'test page 1.'	She said "I know I have to find the Trash Bin." She clicked several menu commands reading the pages that appeared looking for the Trash Bin. Under the Administration menu she found the Trash Bin, read the screen and clicked the proper link to view the Trash Bin. Read the instructions on the Trash Bin, found the title of the page from the list and clicked the 'Restore' button next to it.
Please try to register a new user. User-name: *Mary* Password: *Mary* e-mail: *mary@server.com* Security question: *What is your favourite colour?* Security answer: *red*	Clicked on the Administration menu, then clicked on appropriate command, spend some time to read the instructions in the right margin, filled in the form appropriately and created the user.

Table 4 – How Roy performed each task

Task to be performed	My notes as written down during

	evaluation observations
Please try to find the page with the title, 'Healthy eating.'	He clicked on the menu 'List all pages' and found the page. Then he clicked on the title to go to the page.
Do a search for the word 'test' and go to one page that has the word on it.	He thought a little bit then typed the word 'test' into the appropriate search text box at the top of the screen and then clicked on the 'click to search' button. When the search results appeared he read the instructions at top of screen and then clicked on the title of one of the pages to go to the page.
Go back to the 'home page'	Was done by immediately clicking on the appropriate menu command.
Please try to 'log in' using the following, User-name: *admin* Password: *admin*	With no delay he clicked on the correct link in order to present the log in page. Then he typed in the correct text boxes the user-name and the password and clicked the appropriate button.
Please try to change the following page 'test page 1.' • Please try to add and delete some text. Add *'This page was made in order to test the system.'* • Try to create a link to the site www.nhs.uk	Found the page by clicking on the menu 'List all pages,' clicked on the title to go to the page and then clicked on the appropriate button to put it in edit mode. He added the text and then he deleted it. Creating a link: Roy immediately said, "I think I am going to use the Help for this one." He clicked the appropriate video link on the right margin of the page. While watching the video he paused it twice but then started it again and saw the whole video clip. I asked him why he paused the video and he said that he wanted to remember what to do and also take a better look at which button to press. He then went to back to the page and pressed the proper button for creating a link. He typed the Web address at the proper place and hit OK.
Please try to make a new page with the title 'Living healthy lives' • Write the following on it: *'One way to keep healthy is by exercising.'*	He took time to read the screen first. Then he clicked on the appropriate menu command which showed the new page creation form. He read the information at the top of the form then he typed the title into the proper place

• Try to add an image	and after some thinking pressed the button to create the new page. After the page was created he typed the text on it. Adding an image: Immediately reported that he is going to use the Help for this as well. He clicked the proper link to view the Help video on image insertion. While watching the video he paused it two times concentrating on the screen, (in the previous task of creating a link he also paused the video and when I asked him about it he said that he wanted to remember what to do and also take a better look at which button to press so I did not ask him a second time) then he hit the continue button and watched the whole video. At the end of the video he mentioned, "it is still too much to remember." After watching the Help video he went to the editor and clicked the correct button for image insertion. He stared at the dialogue box that opened for some time, then he clicked the correct button. At the new dialogue that appeared he chose a picture. He stared at the new dialogue for some time again, then clicked the OK button and the picture was inserted successfully.
Please try to delete the page 'test page 1.'	Mentioned, "I have to find the page first." Clicked on 'list all pages,' found the page, clicked on its title, went to the page. There he stared at the screen for fifteen-twenty seconds, and then he clicked on the appropriate button for deletion. At the confirmation page that appeared he read the screen and then confirmed deletion.
Now please try to undelete 'test page 1.'	He spent some time thinking, and then he mentioned the Trash Bin. He clicked around trying to find the Trash Bin. He clicked several menu commands reading the screens that appeared. When he found the Trash Bin under the Administration menu he clicked on it. He read the instructions on the Trash Bin page, found 'test page 1' and

	clicked the Restore button next to it.
Please try to register a new user. User-name: *Mary* Password: *Mary* e-mail: *mary@server.com* Security question: *What is your favourite colour?* Security answer: *red*	Clicked on the Administration menu, then clicked on appropriate command, filled in the form appropriately and created the user at his own pace with no difficulties.

Appendix 5 - Literature Supported System Requirements

The table below lists the system requirements demanded by the Health Trainers and how they are supported in the literature by principles of design for people with learning difficulties.

Friedman and Bryen (2007) compiled two lists of top Web access design recommendations for users with 'cognitive disabilities' based on the frequency cited by the existing Web design guidelines and on guidelines that had achieved a high degree of agreement. The first Friedman and Bryen list (denoted with the letter 'A' in the below table) contains twenty two existing Web design guidelines which are cited by Web accessibility experts, government and advocacy organizations with a frequency of more than 15%. According to the authors these were identified in an extensive literature review. Friedman and Bryen also compiled a second list (denoted with the letter 'B' in the table) of additional Web design recommendations for people with learning difficulties. The recommendations of this second list are cited by less than 15% of the guidelines in the literature.

The first column in the below table presents the requirements asked by the Health Trainers while the second column lists principles of design from the literature which support it. Most supportive design principles come from Friedman and Bryen's (2007) two lists described above.

In the second column of the table within parentheses the letter 'A' represents the first Friedman and Bryen list while 'B' represents the second list. The digit following the letter represents the guideline number. For example (B-11) denotes guideline number eleven in the second Friedman and Bryen list.

Health Trainers' user requirements	Literature support for each requirement
There must be video Help for new visitors	(B-37) Use video to supplement text.

explaining what the website is about and how they can use it.	
Dynamically hide 'click here to see this page as it was before' (found at the bottom of each page) from guest/visitors because they do not to use it. Only Registered Users and the Health Trainers (after they log-in) must be able to view this command because they are the only ones that use it.	(B-54) Layer functionality; hide less frequently used functions. (A-7) Uncluttered, simple screen layout.
Dynamically hide the page creation menu command 'Add a New Page' from guests/ visitors because they do not to use it. Only Health Trainers and Registered Users (after they log-in) must be able to see this menu because they are the only ones that use it.	(B-54) Layer functionality; hide less frequently used functions. (A7) Uncluttered, simple screen layout.
Dynamically hide the command 'Administration' from guests/visitors because they do not to use it. Only Health Trainers and Registered Users (after they log-in) must be able see this menu command because they are the only ones that use it.	(B-54) Layer functionality; hide less frequently used functions. (A-7) Uncluttered, simple screen layout.
Guests/visitors who do not have to log-in must only see four menus 'go to home page,' 'list all pages,' 'websites' and 'your ideas.' The rest of the menus must become visible only when a user logs in because only logged in users use them.	(B-54) Layer functionality; hide less frequently used functions. (A-7) Uncluttered, simple screen layout.
Dynamically hide the 'View Changes' menu from the visitors because they do not use it. Only Registered Users and the Health Trainers must be able to see it after they log-in.	(B-54) Layer functionality; hide less frequently used functions. (A-7) Uncluttered, simple screen layout
The editor size must be the same size as an A4 page so that the Health Trainers can fit the same amount of text on the screen as they would fit on an A4 piece of paper. This way what they see on the screen will print similarly on a hard copy page.	(B-26) Text prints out easily.
In the FCKeditor, Format drop down list, H1 must become 'Heading 1,' H2 'Heading 2' etc.	(B-51) Provide definitions of terms and lingo. (A-2) Use clear and simple text.
The Health Trainers must be able to upload sound files for voice captioning of text, voiceover.	(A-19) Provide audio/voice captions (audio files) for text. (B-2) Use voice to read the text without screen readers.

The visitors/clients must be able to listen to the sound files uploaded (for voice captioning of text, voiceover).	(B-2) Use voice to read the text without screen readers. (A-19) Provide audio/voice captions (audio files) for text.
The buttons for editing a page in the FCKeditor which will not be used by the Health Trainers must be removed. According to the Health Trainers the following buttons must be removed: 'Source', 'DocProps', 'Save', 'NewPage', 'Preview', 'Templates', 'PasteWord', 'SpellCheck', 'Find', 'Replace', 'SelectAll', 'RemoveFormat', 'Form','Checkbox', 'Radio', 'TextField', 'Textarea', 'Select', 'Button', 'ImageButton', 'HiddenField', 'StrikeThrough', 'Subscript', 'Superscript', 'Outdent', 'Indent', 'Blockquote', 'JustifyFull', 'Anchor', 'Flash', 'SpecialChar', 'PageBreak', 'Style', 'FitWindow', 'ShowBlocks'.	(A-7) Uncluttered, simple screen layout (B-54) Layer functionality; hide less frequently used functions.
The editor of the wiki must be WYSIWYG (What You See Is What You Get) No text editing tags.	(A-7) Uncluttered, simple screen layout
Simplify the User Accounts system.	As supported by the literature in Section 6.3.2.1
The Web address must change from www.bit.uwe.ac.uk/???? to something simpler/shorter and easier to remember.	As supported by the literature in Section 6.3.2.1
The video of the Help system must be in the form of short tutorials.	(B-42) Reduce short-term memory load.
The video tutorials of the Help system must be broken to smaller chunks.	(B-42) Reduce short-term memory load.
The text of the Help system must be short, simple and to the point, not long and boring.	(B-19) Use a maximum of 2 sentences per Web page. (B-23) Maximum number of lines 60-70 characters per Web page. (B-42) Reduce short-term memory load.
Conspicuous Print Button for guests/visitors. Although users can print a page using the Web browser's print command, when they do it through the browser all the menus,	(B-26) Text prints out easily.

buttons and other interface controls show in the printout. The dedicated 'print' button must only print the content of a page without the interface controls showing in the printout.	
There should be Help videos on the topics of 'How to make a link' and 'How to add a picture.'	(B-59) Structure tasks, cue sequences and provide step-by-step instructions.
The rectangle that logically encloses the wiki must move down and the margin left between the top of that rectangle and the Web browser buttons must become wider in order to make the separation between the wiki and the browser window more apparent.	(A-8) Maintain white space: Use wide margins (B-18) Use of borders can clearly delineate sections of text and graphics. (B-25) Use boxes to highlight information.
There must be Help in the right column of each page.	(B-59) Structure tasks, cue sequences and provide step-by-step instructions.
System must allow and facilitate the content creators to use large fonts.	(A-6) Use larger fonts, fonts in minimum 12pt or 14pt.
The text on the wiki interface and the Help system must be at least 14 points or bigger.	(A-6) Use larger fonts, fonts in minimum 12pt or 14pt.
The caption of the print button must be 'click here to print this page.'	(B-1) Use descriptive hyperlinks
The tooltip of the 'click here to print this page' button must say, 'click here to open a new window from which you can print this page'	(B-1) Use descriptive hyperlinks
The caption of the delete button must become 'click here to DELETE this page.'	(B-1) Use descriptive hyperlinks
The command used to upload an image from the Administration page must have the following caption, 'click here to upload a picture.'	(B-1) Use descriptive hyperlinks
Menu: The 'create page' menu must become 'add a new page.'	(A-2) Use clear and simple text. (B-1) Use descriptive hyperlinks
The caption of the 'edit page' button must become 'click here to change this page.'	(B-1) Use descriptive hyperlinks (A-2) Use clear and simple text. (B-51) Provide definitions of terms and lingo. Some words have multiple meanings.

The tooltip of the 'edit page' button must become 'click here to add or delete information on this page.'	(B-1) Use descriptive hyperlinks (A-2) Use clear and simple text. (B-51) Provide definitions of terms and lingo. Some words have multiple meanings.
Menu: The 'Index' menu must become 'list all pages.'	(B-1) Use descriptive hyperlinks (A-2) Use clear and simple text.
Menu: The tooltip of 'list all pages' menu must say 'click here to see a list of all pages.'	(B-1) Use descriptive hyperlinks
Menu: The 'Home' menu must become 'Go to home page.'	(B-1) Use descriptive hyperlinks
Menu: The tooltip of 'go to home page' must say 'click here to go to the homepage of the site.'	(B-1) Use descriptive hyperlinks
The tooltip for the 'websites' menu command must say 'click here to see important websites for people with learning difficulties.'	(B-1) Use descriptive hyperlinks
Menu: The tooltip of the 'your ideas' menu must say 'click here to e-mail us your ideas about this website.'	(B-1) Use descriptive hyperlinks
The log-in command (at top right of site) must become, 'To add or change pages you must be a Registered User or a Health Trainer. First Click here to login.'	(B-1) Use descriptive hyperlinks
The 'log-in' button caption must become 'click here to log in'	(B-1) Use descriptive hyperlinks
The command 'Click here to view previous versions of this page' must become 'Click here to see this page as it was before.'	(B-1) Use descriptive hyperlinks (A-2) Use clear and simple text.
Menu: The tooltip of the 'create page' command must say 'click here to add a new page to this site.'	(B-1) Use descriptive hyperlinks (A-2) Use clear and simple text. (B-51) Provide definitions of terms and lingo. Some words have multiple meanings.
The caption of the 'save' button must change to 'save this page on the Web.'	(B-1) Use descriptive hyperlinks
The terms 'internal' and 'external link' in the Help system are technical and they must be	(B-51) Provide definitions of terms and lingo. Some words have multiple

replaced by the simpler terms 'link to another page' and 'link to another website'	meanings. (A-2) Use clear and simple text.
The wiki must always present the Home Page when started.	(A-3) Consistent navigation and design on every page.
Specific subjects of the Help system (especially long subjects) must be offered as video rather than as text.	(B-37) Use video to supplement text. (B-19) Use a maximum of 2 sentences per Web page.

Appendix 6 - Abbreviations

(AAC) Augmentative and alternative communication

(AAIDD) American Association on Intellectual and Developmental Disabilities

(AAMR) American Association on Mental Retardation

(API) Application Programmer Interface

(ATAG) Authoring Tool Accessibility Guidelines

(BIA) United States Bureau of Indian Affairs

(CeDR) Centre for Disability Research of Lancaster University

(CPSR) Computer Professionals for Social Responsibility

(DH) Department of Health

(EAT) Electronic Assistive Technology

(ESF) European Social Fund

(GPs) General Practitioners

(GUI) Graphical User Interface

(HCI) Human-computer interaction

(HEFCE) Higher Education Funding Council for England

(ICT) Communication Technologies

(IIS) Internet Information Server

(IQ) Intelligence Quotient

(IT) Information Technology

(LDA) Learning Disabilities Association of America

(MIT) Massachusetts Institute of Technology

(MP3) Digital music format which can be played on appropriate digital music players usually called MP3 players.

(NHS) National Health Service

(OAF) Open Accessibility Framework

(O/S) Computer Operating System

(OSI) The Open Source Initiative

(PD) Participatory Design

(PR) Participatory Research

(PAR) Participatory Action Research

(PCT) Primary Care Trust

(PDA) Personal Digital Assistant

(PWLD) People with learning difficulties

(SEN) Special Educational Need

(SLD) Severe Learning Disabilities

(SRS) Simple Random Sampling

(SRS) Software Requirements Specification

(TBI) Traumatic Brain Injuries

(UAAG) User Agent Accessibility Guidelines

(UK) United Kingdom

(UCD) User-Centred Design

(UWE) University of the West of England

(VLE) Virtual Learning Environment

(W3C) World Wide Web Consortium

(WAI) Web Accessibility Initiative

(WCAG) Web Content Accessibility Guidelines

(WHO) World Health Organization

(WYSIWYG) What You See Is What You Get. The term is used in computing to describe a system in which content displayed during editing appears very similar to the final output.

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