

Making clinical data accessible to people with Intellectual Disability

Michelle Moloney

A dissertation submitted to the University of Dublin,
in partial fulfilment of the requirements for the degree of
Master of Science in Health Informatics.

2007

Declaration

I declare that the work described in this dissertation is, except where otherwise stated, entirely my own work, and has not been submitted as an exercise for a degree at this or any other university.

Signed: _____

Michelle Moloney
11th September 2007

Permission to lend and/or copy

I agree that the Trinity College Library may lend or copy this dissertation upon request.

Signed: _____

Michelle Moloney
11th September 2007

Acknowledgements

A sincere thank you to Lucy Hederman, my supervisor, who patiently got me there in the end. To family and friends who listened and encouraged throughout I owe a great deal. To my proof readers, Hoss and Eamon, I am grateful and relieved that you were both with me throughout the completion. Mostly though this is for Larry. A man who never had the educational opportunities presented to me and an uncle who sadly did not get the second chance he so craved.

TABLE OF CONTENTS

LIST OF FIGURES	VII
LIST OF TABLES	VIII
LIST OF ABBREVIATIONS	IX
CHAPTER 1: INTRODUCTION	1
1.1 INTRODUCTION	1
1.2 UNDERSTANDING INTELLECTUAL DISABILITY	2
1.3 MOTIVATION	4
1.4 METHODOLOGY	5
1.5 OVERVIEW	6
CHAPTER 2: ACCESSING CLINICAL DATA	7
2.1 ABOUT CLINICAL DATA	7
2.2 LEGISLATION AND CAPACITY	9
2.3 METHODS OF ACCESSING CLINICAL DATA	10
2.4 FOR PEOPLE WITH INTELLECTUAL DISABILITY	11
CHAPTER 3: ACCESSING NON CLINICAL DATA WITH ID	13
3.1 BACKGROUND	13
3.2 CURRENT PRACTICE IN ACCESSING NON CLINICAL DATA FOR PEOPLE WITH ID	15
3.3 DATA ACCESSIBILITY CONSTRAINTS FOR PEOPLE WITH ID	16
3.3.1 <i>ICT Skills</i>	16
3.3.2 <i>Assistive Technology Requirements</i>	17
3.3.3 <i>Website Accessibility</i>	22
3.3.4 <i>Mapping</i>	25
3.3.5 <i>Filtering</i>	26
3.3.6 <i>Access Control</i>	26
3.3.7 <i>Cognitive Capability</i>	27
CHAPTER 4: SMH CASE STUDY USING IP PROTOTYPE	30
4.1 ST. MICHAELS HOUSE (SMH)	30
4.2 PURPOSE	31
4.3 MY HEALTH DATA	31
4.4 METHOD	32
4.4.1 <i>Prototype</i>	35
4.4.2 <i>Interface design</i>	35
4.4.3 <i>System development</i>	38

4.4.4	<i>The participants</i>	38
4.4.5	<i>Scenarios</i>	38
4.4.6	<i>Usability evaluation</i>	39
4.4.7	<i>Exclusions</i>	40
4.4.8	<i>Limitations</i>	40
4.5	FINDINGS	40
CHAPTER 5: DISCUSSION		42
5.1	DO PATIENTS WANT ACCESS TO THEIR MEDICAL RECORDS?	42
5.2	POTENTIAL BENEFIT OF LETTING PEOPLE HAVE ACCESS TO DATA.....	43
5.3	POTENTIAL CONCERNS OF LETTING PEOPLE HAVE ACCESS TO DATA	45
5.4	IT SPEND IN MENTAL HEALTH	45
5.5	HUMAN RIGHTS	46
5.6	FUTURE INTERACTIONS.....	46
CHAPTER 6: CONCLUSION.....		48
6.1	CONCLUSION.....	48
6.2	FUTURE WORK	50
REFERENCES		52
APPENDICES		61

LIST OF FIGURES

FIGURE 3.1 AN ATD ON-SCREEN KEYBOARD	18
FIGURE 3.2 A SELECTION OF ATD TRACKBALLS	19
FIGURE 3.3 ICF FRAMEWORK FOR MODELLING OUTCOMES OF ATD	20
FIGURE 3.4 A TYPICAL ATD SELECTION FRAMEWORK	21
FIGURE 3.5 SPECIALISED BROWSER DISPLAYING FAVOURITE WEB SITES	25
FIGURE 3.6 INTERNET ACCESS CONTROLS	27
FIGURE 3.7 INTELLIGENT MODEL FOR RATING COGNITIVE CAPABILITY	29
FIGURE 4.1 AN IP FORM EXAMPLE	34
FIGURE 4.2 USER INTERFACE – I HAVE THE BEST POSSIBLE HEALTH.....	36
FIGURE 4.3 USER INTERFACE – I WANT TO WATCH MY WEIGHT.....	37
FIGURE 4.4 USER INTERFACE – I DRINK LOTS OF WATER	37
FIGURE 5.1 CURRENT WEB SITE FUNCTIONS	44

LIST OF TABLES

TABLE 1.1 IQ RANGE PER ID LEVEL.....	3
TABLE 1.2 DEGREE AND PREVALENCE OF ID	3
TABLE 2.1 IT USE AMONG PRIMARY CARE PHYSICIANS IN 7 COUNTRIES	8
TABLE 3.1 PRIORITY ACCESS FOR WEB ACCESSIBILITY	23
TABLE 5.1 PATIENT ACCESS TO MEDICAL RECORD SURVEY RESULTS.....	42

LIST OF ABBREVIATIONS

ATG	Assistive Technology Group
AT	Assistive Technology
CIS	Client Information System
EASTIN	European Assistive Technology Information Network
EHR	Electronic Health Record
EMR	Electronic Medical Record
EU	European Union
GPS	Global Positioning System
ICF	International Classification of Functioning
ICT	Information and Communication Technology
ID	Intellectual Disability
IP	Individual Plan
IQ	Intelligence Quotient
ISO	International Standards Organisation
IT	Information Technology
MAPS	Memory Aided Prompting System
NHS	National Health Service
NIDD	National Intellectual Disability Database
PCASSO	Patient Centered Access to Secure Systems Online
POM	Personal Outcome Measures
SCR	Summary Care Record
SMH	St. Michaels House
SOAP	Subjective Objective Assessment Plan
UK	United Kingdom
US	United States
W3C	World Wide Web Consortium
WAI	Web Accessibility Initiative
WCAG	Web Content Accessibility Guidelines
WHO	World Health Organisation

CHAPTER 1: INTRODUCTION

1.1

INTRODUCTION

Healthcare and the people involved in healthcare are moving away from the old paper based systems. There is a shift towards an integrated Information Technology (IT) strategy that will reduce workload, increase efficiency, have capacity for growth and augment system interoperability. This integration has occurred slower than expected but it is evident that IT will play a progressively vital role within health care (Renold et al, 2005). Coupled with this, technology advances are encouraging healthcare “consumers” or “patients” to become more actively involved in their healthcare by facilitating communication through different mediums with the healthcare provider.

The internet has emerged as an effective vehicle for relaying clinical data as it is a popular and easy to use tool (Masys & Baker, 1997) and because of this health data is becoming more frequently available online. The National Health Service (NHS) in England are in the process of rolling out their Summary Care Record (SCR). This will amalgamate all health information held on a patient and allow patients to view data held on them via the internet. The NHS have projected that by 2008 all citizens in England will have an SCR (Honeyman et al, 2005).

Individuals with Intellectual Disability (ID) have more health interactions during their lifetime than the general population yet they encounter considerable health inequalities. A well documented barrier surrounds the training needs of staff who deal with the intellectually disabled (Melville et al, 2006). There is some apprehension that the internet is forming a new health disparity as it can leave behind those who are already unequal, such as those with ID. Blair contends that this health disparity which exists in real life should not be intensified in the virtual world (Blair, 2004).

Some efforts are being made to ensure this group is not left behind in the digital divide. The European Union (EU) launched various initiatives to encourage eInclusion and eAccessibility which expressly targeted vulnerable groups in our society such as those with ID. It began with ‘eEurope 2002 – an Information Society for All’ in 2000 which had the eventual objective of bringing every citizen

online. In 2002 the EU launched the 'eEurope Action Plan 2005' which focused on the strategy of eAccessibility. They then dedicated 2003 as the 'European Year of People with Disabilities' and at an EU conference that year titled 'Accessibility For All', the closing statement was:

"We should aim for all citizens to be able to use electronic communications, whether they have less digital skills, are living in remote regions, have less income, or have special physical or mental needs. Everyone should share the benefits of the information society in terms of access to services and of greater choice, lower prices and higher quality" (Von Niman & Nordby, 2004).

1.2

UNDERSTANDING INTELLECTUAL DISABILITY

ID (favoured in Japan) can also be referred to as intellectual handicap, mental handicap, mental retardation (favoured in the US), learning disability (favoured in the UK and Australia), cognitive disability, developmental disability or learning difficulty. As the term ID is commonly recognised and is not considered offensive, the term is being adopted by the international community (Panek & Smith, 2005). For the course of this dissertation this impairment will be referred to as ID. The WHO define it as:

"a condition of arrested or incomplete development of the mind characterized by impairment of skills and overall intelligence in areas such as cognition, language, and motor and social abilities" (WHO, 2001).

ID may also involve other physical or sensory impairments. Table 1.1 displays the four levels of ID and the Intelligence Quotient (IQ) range that the level infers. A recent study (Standen et al, 2002) states that in practice people may be assigned to an ID level based on the level of support they need rather than relying solely on the IQ score. ID is thought to occur among 1% and 3% of the population (WHO, 2001).

ID LEVEL	IQ RANGE
Mild	IQ between 50-69
Moderate	IQ between 35-49
Severe	IQ between 20-34
Profound	IQ below 20

Table 1.1 IQ Range per ID Level. (WHO, 2001)

In the Republic of Ireland as of April 2006, 25,518 people were listed on the National Intellectual Disability Database (NIDD). This represents a prevalence rate of 6.5% per thousand. This can be viewed in greater detail in Table 1.2 below. The NIDD is used to aid decisions with respect to service planning, service management and service funding and is not used as a medical or epidemiological tool.

	People with ID	%	rate per 1,000*
Mild	8,529	33.4	2.8
Moderate	9,636	37.8	2.46
Severe	3,986	5.6	.02
Profound	046	4.	0.27
Not verified	232	9.	0.59
All levels	25,518	100.0	6.51
*Prevalence rates per thousand population are based on Census of Population 2002 figures (Central Statistics office, 2003)			

Table 1.2 Degree and Prevalence of ID. (National Intellectual Disability Database, Ireland 2006)

A report detailed that the lifespan of those with ID has increased partly due to improved health care but also because of the move toward community based living. Therefore the ID population in Ireland is an ageing population. They state that 77.3% of those with mild ID live at home with 5.2% living in a residential service. For those with a moderate, severe or a profound level of ID 52.3% live at home with 45.8% living in a residential service (Barron & Kelly, 2006).

The level of ID as with any disability can vary from person to person. Those who have ID commonly have difficulty with memory and reasoning, have a short attention span particularly for topics of little interest to them, find it problematical to learn compound skills, have poor motor control and have trouble with language and emotions. They often have limited reading and writing skills.

In designing computer software the 'Design for All' and 'Universal Access' concepts should be applied. Text size, colour contrast and sound should be modifiable by the user. As mentioned individuals with ID generally have a weak attention span so movement through the software should follow a similar format.

1.3

MOTIVATION

Working in the area of ID for a number of years motivated the research topic for this dissertation, with an added incentive being that 2007 is designated the European Year of Equal Opportunities, where the issue of accessible information is a very prominent focus. Another factor was the low participation rate of computer access by those with ID, particularly the lack of encouragement and promotion in using a computer where potential access was possible. Insufficient training in basic Information and Communication Technology (ICT) skills remain commonly unaddressed and support the low entrance rates. As studies have shown that ICT skills can be learnt by those with ID, this is an area that no longer deserves to be overlooked.

As technology is enabling healthcare data to become available at a persons own convenience day or night, patients are taking a more active role in their health management. Individuals with ID require many health inputs and encouraging them to partake in their own health care has many advantages, particularly with regard to self management of routine conditions such as diabetes (view Appendix A for a sample diabetes symbol resource). In the UK, The Mental Capacity Act 2005, asserts that if an individual with ID has the capacity to self-medicate, that they have the right to do so. Within this context it would appear that those with ID, certainly those with the capacity to make their own health decisions, should be able to access a relevant subset of their health data.

1.4

METHODOLOGY

The focus of this study was to determine if it is feasible for individuals with ID to have access to clinical data. To assess the potential for this I developed a prototype which mapped filtered health data in an iconic format. This was then viewed in units where assistive technology was supported and accessed by 6 participants who had mild to moderate ID. The aim of the prototype was to evaluate if individuals could access it, could they then understand the mapped data and did they derive any benefit from it. This experiment took the form of a qualitative study.

To begin with, a number of informal interviews took place. One was held with a former member of the organisations defunct Assistive Technology Group (ATG) to discuss the impact assistive technology has had on promoting computer access. Other informal interviews were held with nursing staff and speech and language therapists within St. Michaels House (SMH) discussing health data sets and symbol mapping. Interviews were conducted with a member of the Delivering Outcomes to People Project, funded by POBAL, in relation to the individual personal plans. A semi structured interview was held with the deputy CEO of SMH to determine current guidelines regarding giving clients access to their clinical data.

A research proposal was submitted to the research board of SMH detailing various aspects of the proposed research. This board meet once a month and after asking for clarification on a few points, namely how much staff time this would take up, how the data would be mapped and the perceived benefits, the approval was given to proceed with the research.

The electronic research began with a comprehensive review of the literature pertaining to those with ID and topics regarding computer access, universal design and health record datasets. The literature on technology related articles for those with ID is quite limited. One factor is that this area had really only begun to advance quite recently and secondly, the majority of articles are from a clinical viewpoint. Another aspect that impeded research is the numerous terms by which ID is also known as. The consequence of this entailed numerous varied searches taking place while essentially looking for the same data results. Accessing clinical data, legislation and benefits were reviewed for both ID and non-ID individuals. Searches with a selection of keywords, a list of which can be

found in Appendix B, were entered on electronic databases and online journals. Articles were reviewed in order to design the prototype in an accessible format for the participants selected for the study.

1.5

OVERVIEW

Chapter 1 expresses the objectives, methodology and motivation for this study. Chapter 2 explains what clinical data is, and depicts an individual's right to view this data in terms of legislation and capacity. It outlines the various mediums through which this data can be accessed, highlighting the emergence of patient access via web portals. Chapter 3 discusses how the use of assistive technology devices can balance or relieve physical or cognitive impairments and how the proposed Web Content Accessibility Guidelines (WCAG) 2.0 place increased focus on designing for those who have cognitive disabilities. It details barriers to access faced by those with ID, while also mentioning the benefits that this group can garner from this access. Chapter 4 describes the environment, design and evaluation of the prototype. Chapter 5 details potential benefits and public interest in accessing clinical data. It discusses the possibility of those with ID performing a self-management role regarding their healthcare. Chapter 6 offers conclusions and outlines future developments.

CHAPTER 2: ACCESSING CLINICAL DATA

2.1

ABOUT CLINICAL DATA

Clinical data which can also be referred to as health data and medical data, is regarded as sensitive information. Therefore when an individual wishes to view their clinical data certain statutory guidelines apply. Depending on your health the clinical data recorded on you can be succinct or alternatively run for hundreds of pages. Also depending on an individuals rationale for viewing their record they may wish to see only a specific portion of it. The data has historically been captured in paper format but has increasingly been acquired in electronic format.

How the records are organised is up to your medical team but a common approach used to organise the clinical data record is a format called S.O.A.P (Subjective Objective Assessment Plan). The “S” for “Subjective” identifies the patient and the reason they have visited the doctor. This data will include details such as previous medical history, social history and family history. The “O” for “Objective” records the information gathered during the visit and will retain details such as the physical exam and any blood tests or procedures performed. The “A” for “Assessment” is what the doctor determines is wrong with the patient based on the information available. The “P” for “Plan” outlines the treatment plan advised (Samuels & Wolfe, 1994).

The 9th Commonwealth Fund International Health Policy Survey of Primary Care Physicians undertaken in 2006 involves doctors from Australia, Canada, Germany, the Netherlands, New Zealand, the UK and the United States. The survey findings suggest that a high percentage of doctors in the Netherlands, Australia, New Zealand and the UK use Electronic Medical Records (EMRs) and observes that these countries have been well supported by strong national investment in IT. German doctors poll mid way whilst Canadian and US doctors fall well behind. However, Germany and Canada are in the process of delivering upon national plans that for the former will utilise e-health smart cards and for the latter will involve a national system called The Health Infoway. The US remains without a national plan to address IT capacity in healthcare. More pertinent is the finding displayed in Table 2.1 below, which states that doctors from Australia,

New Zealand and the UK reported that their EMR allowed patients have access to clinical data retained on them (Schoen et al, 2006).

	AUS (%)	CAN (%)	GER (%)	NET (%)	NZ (%)	UK (%)	US (%)
Electronic medical record (EMR) system							
Do you currently use EMRs in your practice?							
Yes	79 ^{b,c,d,e,f,g}	23 ^{c,d,e,f,g}	42 ^{d,e,f,g}	98 ^{e,f,g}	92 ^g	89 ^g	28
No, but plan to implement in the next year	6 ^{b,c,d,e,f,g}	18 ^{c,d,e,f,g}	9 ^{d,e,f,g}	1 ^{f,g}	3 ^g	4 ^g	31
Does your EMR system allow you to (base: all doctors; percent yes)							
Share records electronically with clinicians outside your practice							
	10 ^{b,d,e,f}	6 ^{c,d,e,f,g}	9 ^{d,e,f,g}	45 ^{e,f,g}	17 ^g	15	12
Access medical records when you are outside the office							
	19 ^{b,d,e}	11 ^{c,d,e,f,g}	16 ^{d,e,f,g}	32 ^{e,f,g}	36 ^{f,g}	22	22
Provide patients with easy access to their medical records							
	36 ^{b,c,d,f,g}	6 ^{c,e,f,g}	15 ^{d,e,f,g}	8 ^{e,f}	32 ^{f,g}	50 ^g	10
Do you currently use any of the following technologies in your practice? (base: all doctors)							
Electronic ordering of tests							
Yes, routinely	65 ^{b,c,d,f,g}	8 ^{c,d,e,f,g}	27 ^{d,e,f,g}	5 ^{e,f,g}	62 ^{f,g}	20	22
Yes, occasionally	6 ^{c,f,g}	4 ^{c,f,g}	18 ^{d,e,f,g}	8 ^f	6 ^{f,g}	10	9
Electronic prescribing of medication							
Yes, routinely	81 ^{b,c,f,g}	11 ^{c,d,e,f,g}	59 ^{d,e,f,g}	85 ^{e,f,g}	78 ^{f,g}	55 ^g	20
Yes, occasionally	3 ^{c,g}	4 ^g	5 ^g	4 ^g	3 ^g	4 ^g	8
Electronic access to patients' test results							
Yes, routinely	76 ^{b,c,e,f,g}	27 ^{c,d,e,f,g}	34 ^{d,e,f,g}	78 ^{e,f,g}	90 ^{f,g}	84 ^g	48
Yes, occasionally	7 ^{b,c,e,g}	17 ^{c,d,e,f}	24 ^{d,e,f,g}	8 ^{e,g}	2 ^{f,g}	7 ^g	19
Electronic access to patients' hospital records							
Yes, routinely	12 ^{c,e,f,g}	15 ^{c,d,e,g}	7 ^{d,e,f,g}	11 ^{e,f,g}	44	19 ^g	40
Yes, occasionally	7 ^{d,e,g}	10 ^{e,f,g}	7 ^{d,e,g}	11 ^{e,f,g}	17 ^f	5 ^g	18
Yes, routinely to first 3	61 ^{b,c,d,f,g}	4 ^{c,e,f,g}	15 ^{d,e,g}	4 ^{f,g}	60 ^{f,g}	15 ^g	13
Yes, routinely to all 4	10 ^{b,c,d,e,f}	2 ^{e,f,g}	4 ^{d,e,g}	1 ^{e,f,g}	33 ^{f,g}	5 ^g	10
Unweighted N	1,003	578	1,006	931	503	1,063	1,004

SOURCE: Commonwealth Fund International Health Policy Survey of Primary Care Physicians, 2006.

NOTES: Reading from left to right starting with Australia (AUS), the letter indicates significant differences with the country or countries to the right, as indicated ($p < .05$).

^b Different from Canada.

^c Different from Germany.

^d Different from the Netherlands.

^e Different from New Zealand.

^f Different from the United Kingdom.

^g Different from the United States.

Table 2.1 IT Use Among Primary Care Physicians In Seven Countries, 2006. (The 9th Commonwealth Fund International Health Policy Survey of Primary Care Physicians, 2006).

2.2

LEGISLATION AND CAPACITY

Initial legislation dealt with an individual's right to request access to paper based clinical data held on them but progressed to cover clinical data that was captured electronically. All the legislation stipulates that a request for access should not be facilitated if felt that receiving the information may cause an individual harm or undue distress. Presently great effort is being placed on delivering a legal framework that will facilitate the assessment of an individual with ID and their capacity to make independent health care decisions.

In the United Kingdom (UK) The Data Protection Act of 1984 has given patients the right to view their health records for quite a while (Honeyman et al, 2005). This legislation was followed by The Access to Health Records Act 1990 which governed access to manual health records while the updated Data Protection Act of 1998 governed access to electronic records held on an individual. The Freedom of Information Act 2000 gave an individual the right to request access to any information held on them by public bodies such as hospitals, doctors surgeries, dentists, pharmacists and opticians.

The Data Protection Agency in Ireland advise individuals of their entitlement to access their medical record whether electronic or paper based through section 4 of The Data Protection Act, 1988 and the Data Protection (Amendment) Act 2003. Section 30 of The Disability Act 2005 instigated the National Disability Authority to provide clear guidelines concerning how public bodies offer accessible information resources and services (Law Reform Commission, 2006).

Nationally the "Vulnerable Adults and the Law" Report was published by the Law Reform Commission in December 2006 and contains two main elements. Firstly it deals with the concept of capacity in making decisions and secondly it outlines the structures required to support vulnerable people when it comes to making those decisions. The report discusses how some people with ID have the ability to form significant decisions on their own, sometimes with a little external help, whilst others have limited room to exercise autonomy in their day to day lives.

Within a healthcare context it mentions that well established practices such as having a consent form signed by a guardian have no standing in law and that theoretically some routine treatments such as going to the dentist could be looked upon as assaults. The Commission notes that the current framework for

assessing capacity in relation to health related decisions is uncertain at best and has advised the Minister for Health and Children to appoint a working group to develop guidelines to address this (Law Reform Commission, 2006).

2.3

METHODS OF ACCESSING CLINICAL DATA

Informally individuals can call their health care provider and request access to their medical data over the phone. They also have the option of faxing or emailing a request in. Alternatively an individual may ask to view their medical record while attending a doctor or while on a hospital visit. However in each of these cases the health care provider can reject the request and ask the individual to submit the request formally in writing before they act upon it which is in line with the legislation previously discussed. The health care provider then has 40 days to respond to the request. If an access fee is charged the individual is liable.

The statutory rights of the individual will determine the amount of data that they can see. These rights will also affect the manner in which the data can be viewed. For example can a copy of the data be taken home for analysis or must the data be viewed while your GP is in the room allowing the individual to ask any questions that come up.

An emerging trend allows individuals to access their medical records online via secure web based patient portals. These portals allow the patient / consumer to authenticate onto the health provider site and view a summary of their record. Towards the late nineties large healthcare companies started to add Internet technology to their healthcare information network packages, as part of a strategy to gain customers, make money and promote efficiency (Cooper,1999). For the patient this technology can facilitate secure access to portions of their clinical data online as well as allowing them to renew medications, make appointments and obtain lab test results (Romano, 2003).

Some web portals that relate health data are national affairs such as the Australian effort entitled HealthConnect, whereas others are specific to partner hospitals or determined by health practices working together within an agreed radius. The Patient Centered Access to Secure Systems Online (PCASSO) funded by the National Library of Medicine in the US was explicitly created to facilitate secure access to health data via the internet. It captures mental health

and genetic data which if revealed could cause comprehensive damage to a person (Masys & Baker, 1997).

In the UK the NHS began trialing its national SCR system on 16/03/2007. Initially a few sites were selected to upload restricted clinical data such as existing medications, recognised allergies and adverse reactions. An individual can remove some or all of the data uploaded; an individual can retain the data uploaded but make the SCR invisible; an individual can choose not to display certain data until their consent has been given. An audit trail can be requested to alleviate an individuals concerns regarding who has been accessing their medical data. As the SCR develops it is envisaged that all encounters within the NHS will be captured so that an overview of an individuals interactions within the healthcare system can be attained. These sites will be subject to independent evaluation and will serve as a learning tool before new sites are added. A similar project run by NHS Scotland has been in operation for some time (ICO, 2007).

HealthConnect is a national effort by Australia which aims to connect electronically all key healthcare providers by 2008. Key developments such as e-prescriptions, e-referrals and electronic hospital discharge summaries are at various stages of implementation. The Australian government has provided financial support and incentives since 1996 to encourage early adoption of IT by healthcare providers in order to establish a national healthcare information system. HealthConnect will permit an individual to access their clinical data online (Schoen et al, 2006).

2.4

FOR PEOPLE WITH INTELLECTUAL DISABILITY

Legislation gives those with ID or their parent/guardian the right to request access to the clinical information that is being retained on them. There are stipulations within legislation in numerous countries that a request can be rejected if it is likely to cause harm to the individual. At a national level whether this data is provided is subject to The Data Protection (Access Modification) (Health) Regulations, 1989 (S.I. No. 82 of 1989). This determines that:

“Health data relating to an individual should not be made available to the individual, in response to an access request, if that would be likely to cause serious harm to the physical or mental health of the data subject” (Data Protection Agency).

The Disability Act 2005, demands that all government agencies produce data that is where possible compatible with assistive technology before 2015. General practice within this community involves health personnel speaking to the individual and explaining any queries they have. Conventionally this data is not available in accessible format.

Within a health context it is important to get individuals with ID involved in their own health care. Down Syndrome Scotland developed a booklet called 'Keeping Well' which advises those with ID on how to look after their health and to keep healthy as they grow older (Down Syndrome). The Elfrida Society publishes documents by those who have ID for ID. They have a project called 'Access to Health' which offers explanations in a story format using pictures. Going for a blood test would be an example of this (Elfrida) . Getting access to this data requires that the individual with ID has computer access, has use of assistive technology devices if required and finds the web site accessible. As those with ID do not have a high incidence rate of using computers, if they wanted access to this data they would need to request it from someone else.

CHAPTER 3: ACCESSING NON CLINICAL DATA WITH ID

3.1

BACKGROUND

Traditionally individuals with ID have been underserved by IT, sometimes finding themselves excluded from the information society, even though they stand to gain significantly from technological advances (Standen et al, 2006). Limited research has been carried out to explore how those with ID use technology. A study carried out by (Carey et al, 2005) comprised 83 participants with ID and revealed that 41% of their study group used a computer, 25% used the Internet and 11% used electronic organisers. They derived that barriers included cost, insufficient training, lack of support and access issues but noted that participants evoked an interest in using these technologies. Technology offers many opportunities for individuals with ID but accessibility is central.

The use of computers are thought to bring many benefits to those with ID. It can improve the self esteem of an individual and give them a feeling of accomplishment if they successfully utilise a computer. They can function as training tools and encourage autonomy by assisting people in their day to day lives through the use of prompting devices and video based training resources. The use of multimedia can promote self determination in those with ID as it can support individuals who perform habitual tasks and therefore reduce their reliance on others. They can be used as a means to educate by promoting interaction and word recognition as well as enabling communication for those who have no voice. For fun computer games and access to the internet through specific web browser software can be facilitated (The Arc, 2005; Davies et al, 2001).

In 1996 the World Wide Web Consortium (W3C) established the Web Accessibility Initiative (WAI) who in turn in 1998 developed the Web Content Accessibility Guidelines (WCAG) with the aim of helping designers implement accessible websites. W3C promote:

“The power of the Web is in its universality. Access by everyone regardless of disability is an essential aspect”.

With WCAG 2.0 more importance has been placed on web accessibility guidelines for those with cognitive disability.

'Design for all' is a move towards developing products in a manner that makes them usable to the widest audience possible. Sometimes this approach is not practically attainable and the use of Assistive Technology (AT) may be implemented to achieve access (Von Niman & Nordby, 2004). The 'Universal Design' theory concedes that technology interfaces should be designed anticipating the requirements of the mainstream thus reducing further solutions being applied for those users having difficulty (Hoppestad, 2007). The 'User Interfaces for All' framework calls for software applications to be usable by virtually all (Savidis et al, 2006).

Accessibility can prove to be a far greater test for those with ID than other disabilities. Partly this is because it is the least understood of the disabilities. Also the diverse range of cognitive disabilities creates a very complex situation. The International Standards Organisation (ISO) defines usability and accessibility with regard to IT in the following manner.

Usability is termed: 'the effectiveness, efficiency and satisfaction with which specified users achieve specified goals in particular environments' (ISO, 1998).

Accessibility is classified as: 'the usability of a product, service, environment or facility by people with the widest range of capabilities' (ISO, 2003).

This offers direction for those developing IT for those with ID and should be used in accompaniment with design for all principles.

As ICT becomes more affordable, as can be seen with mobile devices falling in price, it becomes easier to acquire (Bertini & Kimani, 2003). Coupled with that it is more obtainable and user friendly which breaks down some access barriers. Those with ID have a diverse range of requirements for technology. ICT can be used effectively as an educational tool, a task management and skill development tool. Largely the software obtained for use in the ID community involves the use of drill and practice which concentrates on straightforward skill

acquisition (Trehin, 2004). ICT can also increase social involvement and improve a persons quality of life (Li-Tsang et al, 2004).

An individual with ID may not be able to access a computer at all unless they avail of Assistive Technology (AT). As there has been a huge growth in the AT industry this has resulted in a selection of ATDs available for those with physical, sensory or cognitive impairments. Factors such as cost, configuration and training need to be considered when procuring an ATD.

For the most part technology developed for those with ID has been of a pedagogical nature. For example a prompting system, comprised of verbal and visual components, can be used to enable cognitively impaired individuals to perform day to day tasks. Each task is broken down into a list of steps which in turn form a prompting script. Conventional prompting systems utilised pre defined scripts and were not in tune with changing user needs and dynamic situations. A recent study by (Carmien, 2003) discusses a prompting system calls MAPS (Memory Aided Prompting System) which targets individuals with a cognitive impairment. For the individual it provides a PDA prompter which interfaces with a GPS (Global Positioning System) server thus allowing the user to interact with real time events, for example, prompting the user to wait for a delayed bus. For the caregiver it allows creation, modification, viewing and sharing of scripts.

3.2

CURRENT PRACTICE IN ACCESSING NON CLINICAL DATA FOR PEOPLE WITH ID

In a recent study it was determined that how the family, support personnel and staff approach IT with an individual with ID is a key feature in establishing successful IT involvement. Even though many households were equipped with a computer, using it was not encouraged as they felt a user with ID could not comprehend how to use such a difficult system and they were afraid that the user would damage it. The study reported that it was common place for those with ID to not have computer access while at home (Li-Tsang et al, 2005).

Many of those with ID have difficulties with reading and writing. Therefore any data that they wish to read must be in accessible format. Finding data that meets those needs can be hard when even government agencies do not facilitate this level of access (Paris, 2005).

Individuals with ID have used ICT to enhance communication. Children with ID have used email to talk to other schools and discuss items with teachers. Adults have successfully completed their grocery shop online. In a study carried out by (Mechling et al, 2003) a multimedia program using still photographs and video instruction was used to teach individuals with ID how to use a debit card and automatic teller machine. The results of the study indicated that it was an effective teaching strategy.

Using the internet permits those with ID to become knowledgeable consumers and gives them improved access to information. To achieve this, access to a computer, provision of assistive software and basic ICT skills such as utilising the mouse and keyboard are crucial. Tim Berners-Lee wrote that the principles of universal access were:

'Irrespective of hardware or software platform, network infrastructure, language, culture, geographical location, or physical or mental impairment' (Berners-Lee,1998).

Access to the internet is not without its pitfalls for this group. It can be addictive, promote social exclusion and cause potential harm as vulnerable individuals may be exploited. There are software solutions available that allow controlled access to the internet. In addition specialised web browsers such as Webwide allow users to view websites using text or symbols (Blair, 2006).

3.3 DATA ACCESSIBILITY CONSTRAINTS FOR PEOPLE WITH ID

3.3.1 ICT SKILLS

Basic ICT skills are needed to facilitate access to a PC. Using the mouse a user can learn how to click and drag. Using a keyboard a user can learn how to press keys and be taught the value of important keys such as enter and the arrow keys. Lastly a user can be taught how to browse the internet. Studies have shown that it is possible for those with ID to be taught the above skills (Li-Tsang et al, 2004). Key aspects on delivering this training to persons with ID is to retain a low trainer to trainee ratio and to break down the skills into easy steps to suit the level of ID of the individual. Limited software exists that explicitly targets IT training skills of this group. A further study depicted that IT training prospects for those with ID were quite bleak. Regular training was not a feature common to ID service

providers. The prerequisites to access a computer can not be arrived at unless training is received for those individuals (Li-Tsang et al, 2005).

3.3.2 ASSISTIVE TECHNOLOGY REQUIREMENTS

For those with ID, Assistive Technology Devices (ATD) are often required to enable access to computers as individuals may have other impairments that are linked to their condition such as physical or sensory disabilities as well as poor motor control. The view of (Hoppestad, 2006) indicates that cognitive, social, emotional and physical factors need to be factored in before procuring a device. (Standen et al, 2006) remarks that as those with ID have cognitive impairment devices should be simple to use because a device with numerous functions may prove difficult to remember especially where multiple devices are used. For an individual with ID the use of an ATD can reduce dependency and assist that person in becoming involved in the community, partaking in education and becoming a valued member of the workforce.

In 2003 the International Alliance of AT was founded by seven organisations based throughout Europe and the United States who have been developing and maintaining national databases containing information on AT for some years. They agreed to work together and share their experiences, in order to enhance the service provided to users by providing more complete information on AT whilst also extending their user base. EASTIN (European Assistive Technology Information Network) was the first project to emerge from the Alliance. The project facilitates access to six national systems through its website allowing the user access to a wealth of AT information (Andrich et al, 2006).

The devices for computer access can be broken down into three main groups namely input devices, output devices and software. A diverse range of input devices have emerged due to the growth in the AT industry according to (Prazak et al, 2004). A case in point is the assorted adaptations of keyboards and the computer mouse that are obtainable. (McCoy, 1998) remarked that the determining factor in choosing an apt physical interface is dependent on the user's level of physical disability. Therefore if no physical disability exists a conventional keyboard or a modified keyboard with enlarged keys may be used. For those with muscular control difficulties electronic word boards facilitate selection based on iconic representations. Access via a switch may be required

for those with severe disabilities. The user hits the switch when the cursor arrives at the desired item.

A choice of pointing devices like mouse, trackball (see Figure 3.2 below), touchpad and switches are available (Prazak et al, 2004). The trackball for instance is suitable for those with motor impairment, dexterity issues and restricted motion range as it requires little strength and the wrist or forearm does not need to be raised during use. To reduce the number of devices required trackball can be used with an on-screen keyboard (see Figure 3.1 below), where users hover over the on-screen keys, to assist text entry (Wobbrock & Myers, 2007).



Figure 3.1 An ATD on-screen keyboard. (Wobbrock & Myers, 2007)



Figure 3.2 A selection of ATD trackballs. (Wobbrock & Myers, 2007)

For those unable to speak Boston College developed two technologies, EagleEye and Camera Mouse (Gips et al, 2004). These technologies facilitate access to a computer and cursor control through movement of a person's eyes or head. For individuals with extremely limited motor control BlinkLink and EyebrowClicker, systems designed to interpret an individual's blink or eyebrow motion, can be used to enable computer access (Grauman et al, 2003). The Whistling User Interface was designed to permit users control the on-screen cursor through whistling, humming or hissing (Sporka et al, 2006).

In the realm of output devices many advances have been made. Within the Voice Output Technology arena text and keystrokes entered on a computer can be read aloud to the user via speech synthesis. Screen magnifiers and screen readers can be used to enlarge or invert text as well as change background colours to aid the visually impaired.

Software programs available include word prediction programs which use features such as spell-check and list commonly used words to help predict what an individual is typing. Other programs exist that encourage task planning (Hoppestad, 2006).

Sparks contends that any assessment tool used for computer access would include an assessment of physical aptitudes, cognitive functioning, environmental factors and support structures (Sparks, 2000). He highlights that an integrated approach is crucial for any AT assessment. The WHO have an International Classification of Functioning, Disability and Health that is referred to as the ICF.

The ICF developed a framework for modelling the outcomes of ATD which is displayed in Figure 3.3 below. Once an ATD is purchased it follows the factors and outcomes that affect the likelihood of continued use through introductory, short-term and long-term stages. Social attitudes, background and structures as well as age, education and experience are all culminating factors in the overall outcome.

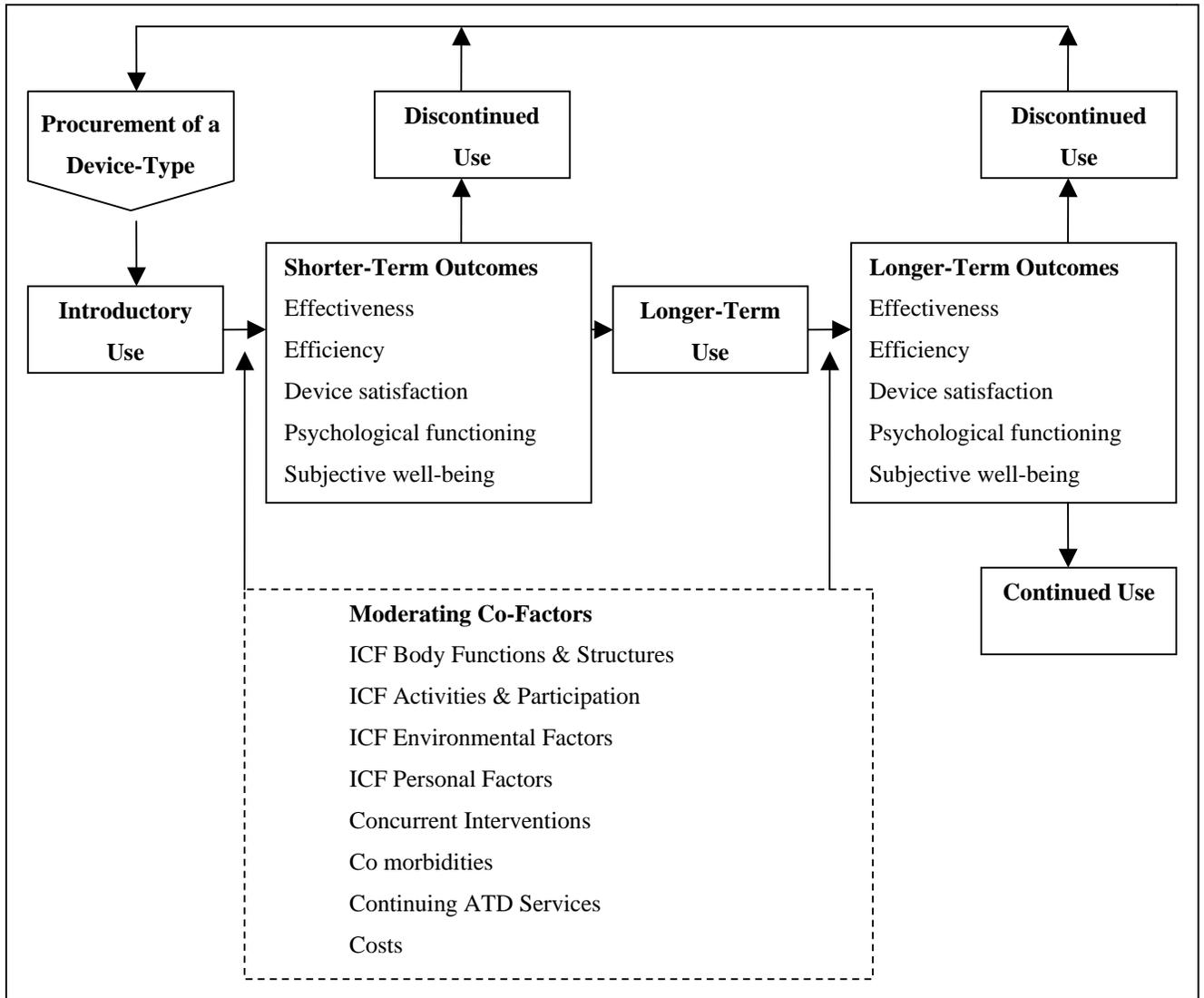


Figure 3.3 ICF Framework for Modelling Outcomes of ATD (Scherer et al, 2007)

A second framework, depicted in Figure 3.4 below, analyses the selection process for an ATD. The priorities, product partiality and expectations of both parties, the user and provider, are examined during the decision making process

and will impact on the ATD assessment in an objective and subjective manner. Scherer et al explains how varying personal and social factors can be measured during the decision making process, from a user and provider perspective, thus highlighting at an early stage a potential mismatch of technology and user, which would lead to an unsuccessful outcome. Successful implementation of an ATD can result in the pursuit of employment, education and community involvement. They also suggest that the selection framework must have the capacity for change depending on the ATD under deliberation as the influences will not be the same (Scherer et al ,2007).

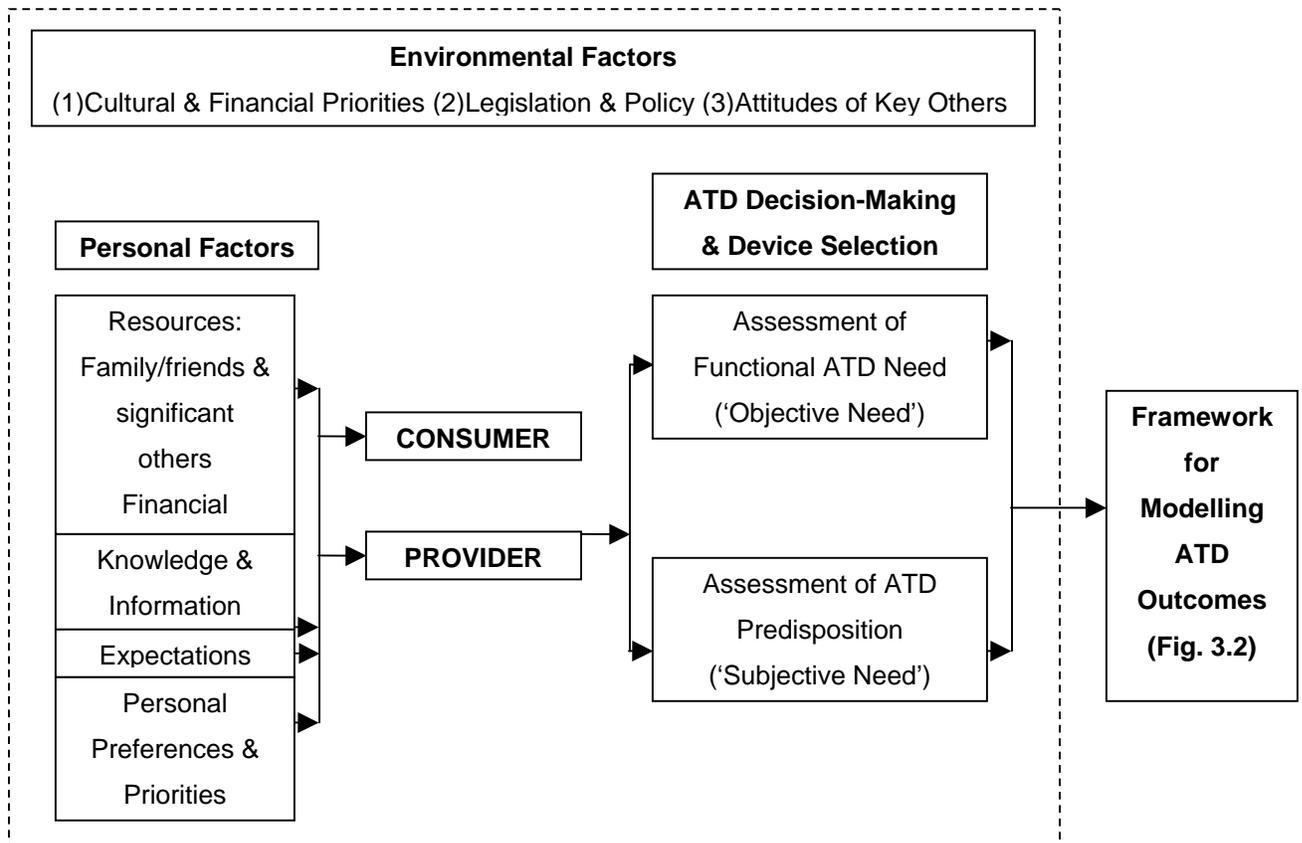


Figure 3.4 A Typical ATD Selection Framework. (Scherer et al, 2007)

Cost, training and configuration are all factors to be considered with AT. Hoppestad explained that in order for an ATD to be used successfully it must serve a purpose, create benefits and the user must feel motivated to use it (Hoppestad, 2006). Sparks maintains that the only feasible manner to measure the success of AT involvement is to determine how successfully the user can function in real world situations (Sparks, 2000).

However, it is estimated that 75% of all AT systems and devices are abandoned (Reimer-Reiss, 2000). A contributing factor to this abandonment is the lack of training people receive to ensure proficient operation and understanding of the technology (De Jonge & Rodger, 2006). Similarly, current practice involves customisation of commercial devices to suit a users need and De Jonge & Rodger mention that this task needs to be performed accurately to prevent non use of the ATD. A study analysing the under usage of AT in people with severe ID was carried out by (Wehmeyer, 1988). It determined that insufficient funding, limited training, difficulty of the device and a lack of knowledge about AT as the capital reasons for non use. Hoppestad agreed with the previous study while adding insufficient assessments, inadequate follow up and a shortage of research corroborating ATD usage as obstacles for a successful ATD intervention (Hoppestad, 2007).

3.3.3

WEBSITE ACCESSIBILITY

Web accessibility legislation has been created by many governments to allow all users equal opportunity to partake in the IT revolution if they so wish. However for the most part it has had limited scope as it only applies to certain organisations such as government web sites, and the level of compliance as well as the level of enforcement varies greatly between countries (Anderson et al, 2004). Anderson asserts that making government web content accessible is a basic human right for those with disabilities. A review of government web site accessibility in Northern Ireland, concluded that 85% of all government internet homepages were unsuccessful in meeting minimum accessibility standards. It goes on to state that although numerous UK sites fall below the required standards set out by the WAI no cases have been taken to the UK courts on this matter (Paris, 2005).

Guidelines re website accessibility have been formulated by the W3C and the US Federal Government. The W3C guidelines called WCAG, which were created with the primary goal of promoting accessibility, have three priority levels which are used to rate a websites accessibility. Priority 1 represents a minimum level of accessibility with priority 2 being more accessible and priority 3 being completely accessible. The criterion for each priority are listed below in Table 3.1.

Conformance of these guidelines comprises of three levels A, AA and AAA. There is not much evidence apparent on the web that these guidelines are being

adhered to, particularly with reference to continuous text, with the suggestion that this is due to the guidelines not being well known (Nordbrock et al, 2004).

Priority	Description	Criterion
Priority 1	A Web content developer must satisfy this criterion. Otherwise, one or more groups will find it impossible to access information in the document. Satisfying this criterion is a basic requirement for some groups to be able to use Web documents.	<ul style="list-style-type: none"> - Provide alternative text for all images. - Provide alternative text for all image hot spots. - Give each frame a title. - Provide alternative text for each APPLET. - Provide alternative text for all image-type buttons in forms.
Priority 2	A Web content developer should satisfy this criterion. Otherwise, one or more groups will find it difficult to access information in the document. Satisfying this criterion will remove significant barriers to accessing Web documents.	<ul style="list-style-type: none"> - Use relative sizing and positioning (% values) rather than absolute (pixels). - Use a public text identifier in a DOCTYPE statement. - Make sure event handlers do not require use of a mouse. - Do not use the same link phrase more than once when the links point to different URLs - Explicitly associate form controls & their labels with the LABEL element - Create link phrases that make sense when read out of context - Include a document title - Do not cause a page to refresh automatically - Nest headings properly - Provide a NOFRAMES section when using FRAMES - Avoid scrolling text created with the MARQUEE element
Priority 3	A Web content developer may address this criterion. Otherwise, one or more groups will find it somewhat difficult to access information in the document. Satisfying this criterion will improve access to Web documents.	<ul style="list-style-type: none"> - Identify the language of the text - Provide a summary for tables. - Separate adjacent links with more whitespace - Include default, place-holding characters in edit boxes and text areas. - Client-side image map contains a link not presented elsewhere on this page - Included a document TITLE - Use a public text identifier in a DOCTYPE statement.

Table 3.1 Priority Access for Web Accessibility. (W3C (1999) Web Content Accessibility Guidelines 1.0, <http://www.w3.org/TR/WCAG10/>)

The new version of the guidelines still in draft mode, WCAG 2.0, will focus more on usability and (Anderson et al, 2004) suggests that users with ID are likely to benefit most from this change. The authors suggest that this is a significant move forward as a chief criticisms of WCAG 1.0 has been the limited guidelines that have expressly benefited those with ID and that those guidelines that were explicit were consigned a conformance level of AAA. There is also the need to

ensure existing web sites are accessible and tools such as the eAccessibilityEngine introduce automatic accessibility enhancements (Alexandraki et al, 2004). This tool allows the users select a disability profile which can be later amended by the user.

Sites that have gained AAA status and are geared at being accessible to those with ID have some or all of these features; simple and well organised sites, intuitive features such as enlarge text and high contrast, minimal text per page, visual cues such as the use of icons and colours, anchor links, recorded information, downloadable documents written in easy English, untagged PDFs, a text-only version and video clips (Anderson et al, 2004). These features aid navigation and increase understanding for those with ID.

For individuals with ID browsing the web and making use of the information found can present a few problems, for instance the hearing impaired may require audio captioning. Those with ID have difficulty comprehending continuous text as they find it hard to extrapolate the information they are looking for (Nordbrock et al, 2004). Readability guides suggest using language that is simple, easy to understand, uses everyday common terms and short sentences to reduce complexity and avoid ambiguity. Tools such as the DeLite System, have been developed to highlight difficult sections of text as well as evaluate the web pages readability rating per the WCAG respective guideline (Jenge et al, 2006). It can still be a challenge as (Loiacono & McCoy, 2006) assert that screen readers cannot decipher images, therefore an image will not be read to a user if there is no text attached to it, signifying that the visually impaired will not have access to the data.

Web browsers presently used to access the internet are not manageable for the majority of individuals with ID. WebTrek is a browser developed explicitly to facilitate access to the internet for this group. This specialised browser offers audio prompting, minimised screen clutter, use of pictures which help surmount reading and writing problems and the option to personalise the interface (Davies et al, 2001). Poulson & Nicolle developed an adopted web browser for those with ID which can be viewed in Figure 3.5 below. During this they identified three guidelines that would improve web accessibility for all. Firstly they stated that a picture placed on the home page should clearly indicate what the site is about. Secondly they recommend the provision of easy page descriptions as meta tags

as this may potentially be useful when site content needs to be translated into symbols. Finally they suggest that simple language is used throughout (Poulson & Nicolle, 2004).

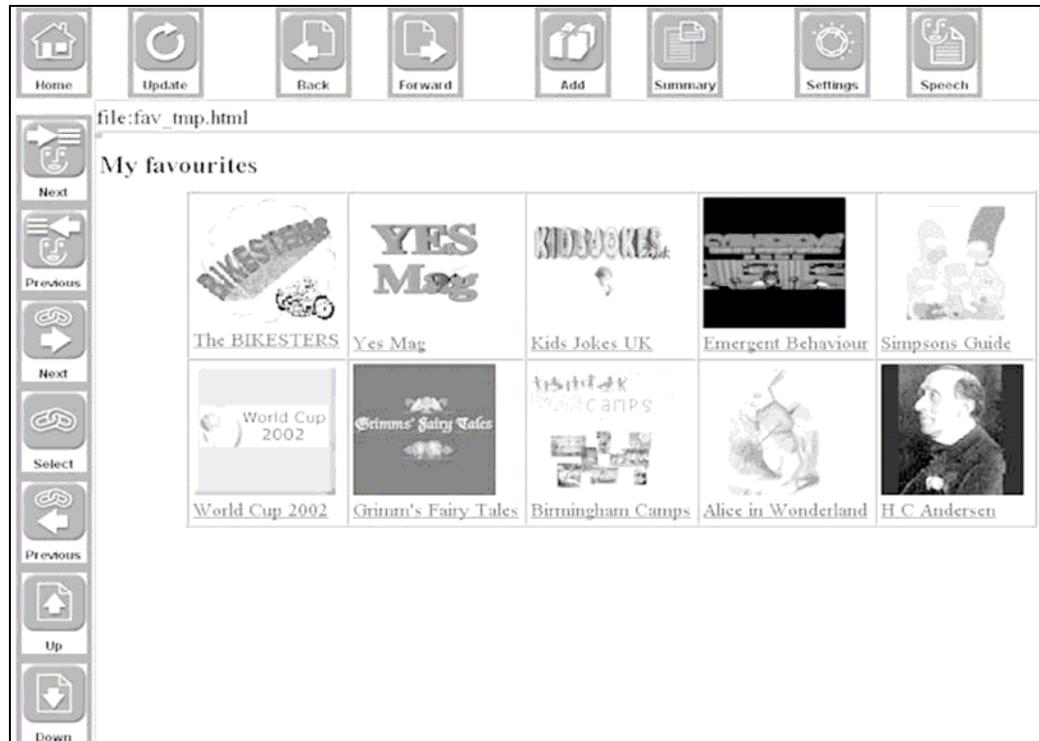


Figure 3.5 Specialised browser displaying favourite web sites (Poulson & Nicolle, 2004).

A study carried out by an EU project group called IRIS discovered that a web site was more likely to be considered accessible and usable if the user could determine their personal style of how information should be displayed. A website that is designed following the WCAG 1.0 will allow users to choose their own style sheets. A study by Grappa identifies online help and the search function as key areas in supporting the user whilst using a web site. It highlights the importance of assisting the user particularly when their search or use of online help has been unsuccessful (Gappa et al, 2004).

3.3.4

MAPPING

Regardless of the assistive technology used, the language set must be reasonable to the user. Generally the language set takes one of two forms, that is, text (letter, words, phrases) or symbols (icons, pictures). A language set

comprised of words and phrases might be quicker to process on the computer but could take the user longer to create as the hierarchy of words could cause cognitive load as users struggle to retain the order in which they accessed the words and phrases.

It is noted by McCoy, that the use of iconic language sets have proved valuable in assisting communication with those who have ID. With this an icon or icon sequence is automatically translated into an equivalent word or phrase. The test for the ID community is to formulate an icon set that is simple to use thus enabling the user to recollect the required icon sequence so that they achieve the preferred output (McCoy, 1998). Research has shown that those with ID show a higher aptitude on memory tasks when visual imagery strategies are used compared to verbal strategies (Roskos-Ewoldsen et al, 2006).

3.3.5 FILTERING

How a dataset is filtered depends on the dataset in question and from that determining what is relevant for exposure, who it should be made available to and how useful it is to the users. For individuals with ID data can be filtered based on the level of ID, age, capacity, language ability, ICT skills, consent, additional physical and sensory impairments.

As those with ID can have any combination of impairments it is difficult to develop software that will facilitate all, albeit (Parsons et al, 2006) reported that mainstream software was used more than products explicitly designed for those with ID. Much of what is developed serves an educational purpose and is filtered on cognition level and is age appropriate. Sensory software is also available that allows the users interact using sounds and graphics.

When browsing the internet specialised browsers can be used that will filter what the individual with ID can potentially see, much in line with the restrictions that can be placed on children accessing the internet. However the data is filtered, it is imperative that the individual is not harmed or distressed by the data revealed and that the correct level of content is utilised.

3.3.6 ACCESS CONTROL

A recent study of ICT use by those with ID showed that computers were used to aid internal communication rather than facilitate external communication (Parsons

et al, 2006). In this context users were able to locally authenticate onto the PC to access interactive games and email. Many users require the help of their key worker to help them access the computer. A common approach is a dual log on whereby the key worker logs onto the computer first followed by the individual with ID. This ensures an audit log of software interactions can be retained. If personal data on the ID individual is held on the PC authentication means that only authorised users for authorised purposes can gain access to a system. This authentication also determines what the ID user can do on the computer, for example internet access may be blocked.

It would not be common practice without the ID community for those with ID to have independent access to the internet. All not all material available on the web is appropriate for those with ID, software can be used to block certain material such as violent images. The basic concept being that content selection software can block or allow what online data a user can see as can be viewed in Figure 3.6 below.

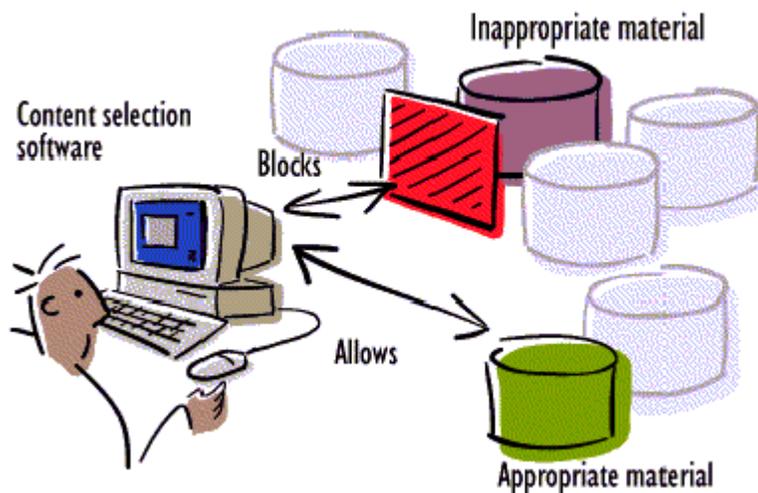


Figure 3.6 Internet Access Controls. (W3C (1996) PICS: Internet Access Controls without Censorship, <http://www.w3.org/PICS/iacwcv2.htm>)

3.3.7

COGNITIVE CAPABILITY

Adams maintains that modern day living is rooted in a progressively more cognitive way of life and that this cognitive function is more essential than ever in

this IT society. (Adams, 2007). In order to assist those with ID a successful computer access strategy needs to be identified. A method to appraise computer access can involve the following steps:

- (1) Monitor the individuals environment
- (2) Gauge the skill level of the individual
- (3) Propose and personalise the computer access system
- (4) Provide sufficient training for the individual
- (5) Implement the system
- (6) Supply support and follow up if required.

How competent an individual with ID is in accessing a computer can be difficult to calculate exactly. It has been said by (Pushchak & Sasi, 2004) that an assessment of a persons ability should be used to determine the most suitable mix of user interface. Using the WAIS-III IQ test model they propose rating the cognitive ability of an individual with ID with relation to computer access. WAIS-III is the most commonly used test for rating cognitive ability. Fuzzy logic techniques are used to overcome the vagueness is quantifying how exact the hardware or software chosen is in meeting the needs of the individual. An example of the fuzzy rules applied to evaluate verbal comprehension is displayed directly below:

“ IF Vocabulary is High AND Similarities is High AND Information is High THEN
Verbal Comprehension Index is High
IF Arithmetic is Medium AND Digit Span is Medium AND Letter-Number
Sequencing is Medium THEN
Working Memory Index is Medium “ (Pushchak & Sasi, 2004)

The cognitive rating arrived at is based on the verbal IQ and performance IQ which can be viewed in Figure 3.7 below.

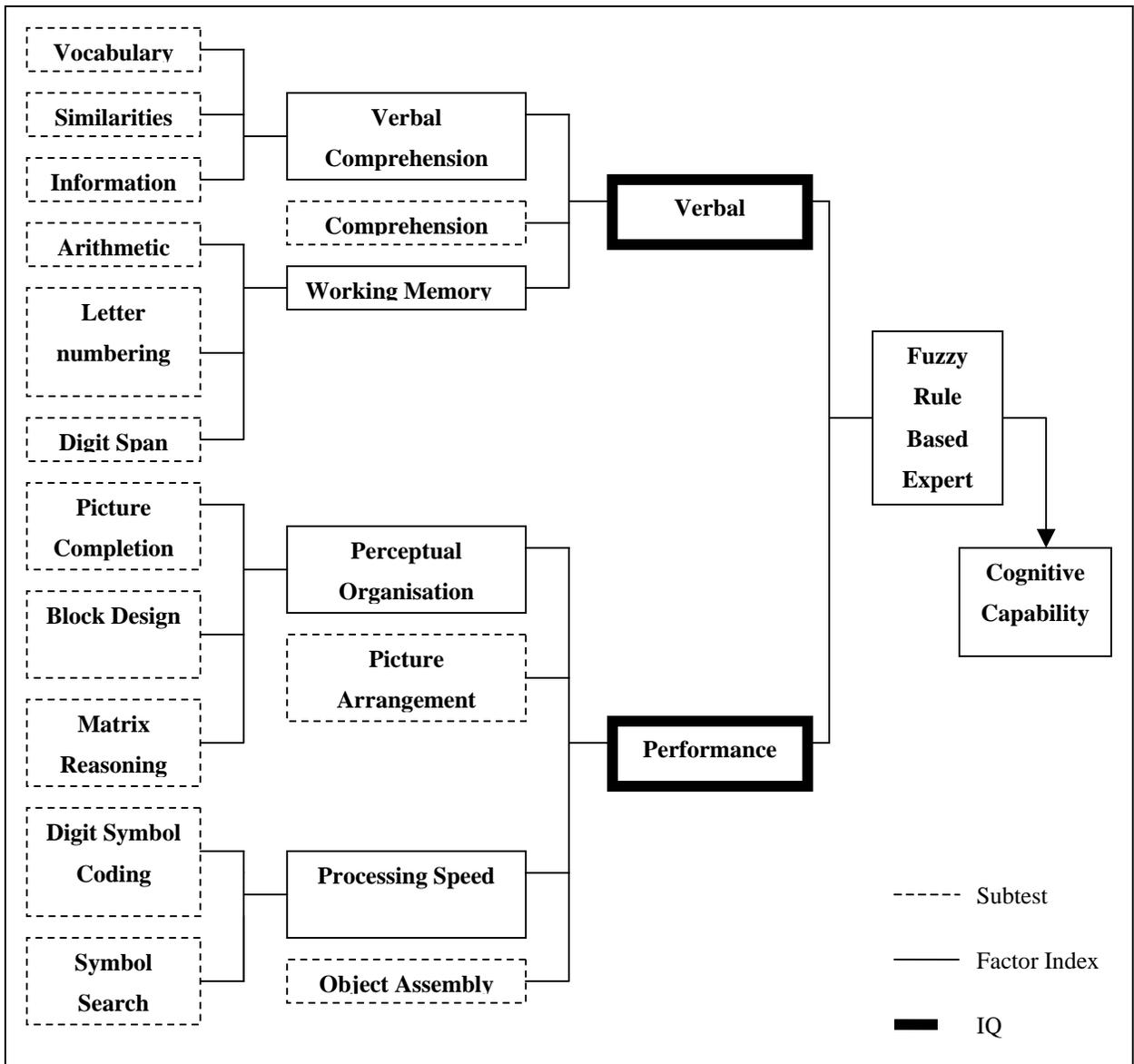


Figure 3.7 Intelligent Model for Rating Cognitive Capability (Pushchak & Sasi, 2004)

It is proposed that this model will deal with the varied definitions applied in determining how capable a person with ID is in accessing a computer, and that it will advocate a fitting blend of hardware and software user interfaces.

CHAPTER 4: SMH CASE STUDY USING IP PROTOTYPE

4.1

ST. MICHAELS HOUSE (SMH)

SMH is a voluntary organisation founded by parents in 1955 which provides services to over 1500 people with ID in over 160 locations throughout Dublin. Nearly 1200 clients have mild to moderate ID with those having severe and profound ID accounting for the remainder. SMH is required to maintain the national dataset of the NIDD for each person attending its service. This data is then exported on a nightly basis. In addition to this required dataset SMH capture further information on the Client Information System (CIS). This system is available to staff only and retains information on the skill levels of the individual - for example eating, mobility, sight and hearing, the medication that an individual is on, the immunisations received, the clinical team involved with the individual, the respite breaks taken, the accidents and challenging behaviour incidents involving the individual, the clinical inputs for children attending mainstream schools, the individual program plan and an individuals appointments record.

An Assistive Technology Group (ATG) was set up in SMH in 2004. This group was involved in procuring computers, wireless routers, motorised desks, access devices & software titles for 17 units. Of the monitors that were provided 8 of them were touch screen. ATG decided to buy 5 or 6 software programs that met the most needs (IT Mouseskills, Switch It Jigsaw, Switch It At Home, Makin' Sense with Letters). It had been agreed that a post would be created for a support person who would facilitate the support and promotion required in using computers and software for clients and staff. However this post was never filled. Due to this and other issues the ATG finished up.

Presently any requests to access clinical data are performed on a case-by-case basis whereby the client is then given selected data out of their file for review. Clinical data can be withheld if it might cause the client harm. The data is generally explained to the client by medical staff or a social worker as data is not in accessible format and therefore needs to be simplified.

4.2

PURPOSE

Increased emphasis has been placed on the accessibility of information for people with ID. The purpose of this qualitative experiment is to evaluate the potential for those with ID to access clinical data. A prototype was developed with a view to evaluate this and accessed using 6 participants.

4.3

MY HEALTH DATA

The nurse managers in conjunction with the speech and language department have been working on an accessible health booklet for each individual called 'My Health' which is still at a draft stage. Simple language and images are used throughout the booklet. This is linked with the Individual Plan (IP) outcome priority 'I have the best possible health'. The IP is described in detail in the Method section in 4.4 below.

'My Health' is divided into the following nine sections:

- (1) Introduction and information
- (2) Communication
- (3) General health
- (4) A check up
- (5) Male / female health
- (6) Lifestyle
- (7) People who help me stay healthy
- (8) My health plan and goals
- (9) My healthcare appointments

The introduction and information section explains that the booklet is about an individual's health and encourages the individual to set goals regarding their healthcare. An about me area contains details such as name, date of birth, next of kin and medical card number. A part of this section revolves around consent. Does the individual give it, who would they like to help them fill out the record and who would they like to be able to see it.

The communication section documents how a person can communicate for example by speech or using eye contact and asks if the individual has a communication passport or book. It asks whether an individual can read or write or requires the use of symbols.

The general health features an area where weight should be recorded as well as asking questions such as whether an individual is hepatitis immune, if they suffer from diabetes or epilepsy or have breathing difficulties. It keeps a record of the individuals pulse, temperature and blood pressure as well as list the current medications that the individual is on. The check up section monitors the eyes, ears, heart, teeth, skin, eating and drinking, mobility, feet, using the toilet, pain sensations, sleep patterns and the feelings of an individual. It also gives more precise information on epilepsy, diabetes and breathing difficulties if the individual has any of these complaints.

The section Female / Male health covers topics such as periods, breast checks and checking private areas. The lifestyle section records if the individual drinks or smokes and if they exercise. The people who help me stay healthy section asks the individual to tick off who keeps them healthy. Some of the choices to choose from are family, dentist and therapist.

My health plan and goals are considered the most significant stage of the process and warrant much thought. Having reviewed the health plan for the individual certain areas should be identifiable as requiring follow up. Therefore the health problem, the goal chosen, what needs to be done and who will help all need to be recorded. Actions need to be taken to ensure the priorities are seen to. Finally my healthcare appointments is a list of all the appointments the individual has.

It is hoped that when the finalised version of 'My Health' is available that processes can be put in place to have it electronically available to individuals and their key workers.

4.4

METHOD

Using ideas garnered from research, plus the clinical data that SMH holds, build a prototype displaying clinical data. As clients in SMH cannot access their clinical records at present in electronic format the use of IP data has been approved for this procedure and will be used to demonstrate how clinical data could be filtered, mapped & access controlled. The focus group for the evaluation of the prototype will be adult clients who have mild to moderate ID.

An IP is completed on a yearly basis for each client by his or her key worker. From 25 outcome measure options, which are displayed in Figure 4.1 below, the client and key worker work together to determine three goals that they wish to work on for the next year. For example if the outcome priority is 'I have friends', the goal attached to that might be invite John to dinner once a month. Two options are of particular interest , 'I exercise my rights' and 'I have the best possible health' as it is here that clients can express a wish to read the files held on them and express a desire to have more involvement in their health status. From the data that has been collated we have seen an increased number of clients who are requesting these options.

The IP data is captured in a SQL database and a profile of each clients data in relation to 'I have the best possible health' was extracted. This data was analysed and four scenarios created to reflect the health goals of the participants. Scenario one wanted to do more exercise specifically yoga and walking. Scenario two wanted an oral hygiene program to be put in place. Scenario three concerned weight management and proper eating plans. Scenario four involved getting their eyesight checked. As the IPs have been captured electronically for three years in SMH for two of the participants it was possible to show them last years health goal as well as this years. This data was considered appropriate for the participants to view as they had worked on their IP with their key worker previously and were therefore already aware of the goal and working towards it.

2. Outcome Measures	Outcome Present?			Support Present?	Is Outcome A Priority?
	Not Present	Almost Present	Is Present		
I realise my goals	<input type="checkbox"/>				
I choose my daily routine	<input type="checkbox"/>				
I have time, space and opportunity for privacy	<input type="checkbox"/>				
I decide when to share personal information	<input type="checkbox"/>				
I use my environment	<input type="checkbox"/>				
I live in an integrated environment	<input type="checkbox"/>				
I participate in my community	<input type="checkbox"/>				
I interact with others in the community	<input type="checkbox"/>				
I have different social roles	<input type="checkbox"/>				
I have friends	<input type="checkbox"/>				
I am respected	<input type="checkbox"/>				
I choose services	<input type="checkbox"/>				
I am connected to my natural supports	<input type="checkbox"/>				
I am safe	<input type="checkbox"/>				
I exercise my rights	<input type="checkbox"/>				
I am treated fairly	<input type="checkbox"/>				
I have the best possible health	<input type="checkbox"/>				
I am free from abuse and neglect	<input type="checkbox"/>				
I experience continuity and security	<input type="checkbox"/>				
I choose where I live and with whom I live	<input type="checkbox"/>				
I choose where I work	<input type="checkbox"/>				
I have intimate relationships	<input type="checkbox"/>				
I am satisfied with services	<input type="checkbox"/>				
I am satisfied with my personal life situation	<input type="checkbox"/>				
I choose my personal Goals	<input type="checkbox"/>				
Totals	0	0	0	0	0

Figure 4.1 An IP form example (SMH).

The following steps were taken prior to testing the prototype:

- (1) The participants and key workers were contacted to confirm availability to test the prototype. An estimated time frame of one hour was given.
- (2) Dates were scheduled for the testing to take place, grouped where possible by the unit the participants were attached to.
- (3) As the number of participants in this study was small the author was able to talk to each key worker in advance of the study taking place outlining what was going to happen during the study. The key worker was asked to have a copy of the participants IP on hand during the study and to explain to the participant the study process.
- (4) The author visited the unit that each participant attends prior to the agreed test time to ensure the prototype was working accurately with the associated users ATD.

On the day of testing the following procedure was followed:

- (1) Verbal instructions were given to the participant and the key worker outlining the procedure and any questions the participant posed were answered.
- (2) The key worker authenticated onto the computer.
- (3) The participant using the mouse or keyboard launched the prototype by clicking on a link on the Intranet page.
- (4) The participant then started to view their personalised health related IP goal, using a single click to move through the screens.
- (5) Throughout this process the participant was evaluated and prompted on what to do and how to do it where required.
- (6) The test was deemed over when the participant had viewed all their health data. To indicate this a screen citing well done is displayed which can be viewed in Appendix C.
- (7) On completion the participant had the option of repeating the process again.
- (8) To conclude participants were asked what they liked and did not like about the system and if they liked using a computer. Each interaction with the system was logged.

4.4.1 PROTOTYPE

The objectives were to evaluate if individuals could access the prototype and to track if they had any problems using it or understanding the mapped data. Lastly, determine if there are any benefits to the participants being able to access this information. Current guidelines that are applicable to clients who request access to data held on files will be adhered to. Only the essential elements of the prototype were implemented in order to carry out the experiment.

4.4.2 INTERFACE DESIGN

The universal design approach was followed with the principles of simplicity, consistency and accessibility adhered to (Story, 1998). The user interface would deliver minimal functionality. It was determined that symbol representations would be used where possible in addition to the use of nominal text. It was important that the symbols used in the interface were consistent where possible with what the participants use in their daily life as a main function of this prototype is that it was understood. Therefore it was necessary to liaise with the speech

and language department, the nurse managers and those working on the IPs to ensure correct symbols were used.

For each of the 25 goals viewable in Figure 4.1 symbols have been agreed at a national level and used with the permission of Mayer-Johnson LLC. The 25 symbols were developed in Boardmaker which is one of their products. Consequently all other symbols used in this work were from the 'My Health' draft version which is still in development.

As the text usage in the prototype was minimal and the participants were language literate there was no requirement for audio feedback. The language level used was considered suitable for the users. The user performed their selection by clicking on or near the active area. For example if they felt they had the best possible health they would click the yellow smile icon as this symbolised YES, and if they felt they did not they would click the red cross icon which symbolised NO. This action required a single click of the input device.



Figure 4.2 User Interface – I have the best possible health (SMH).

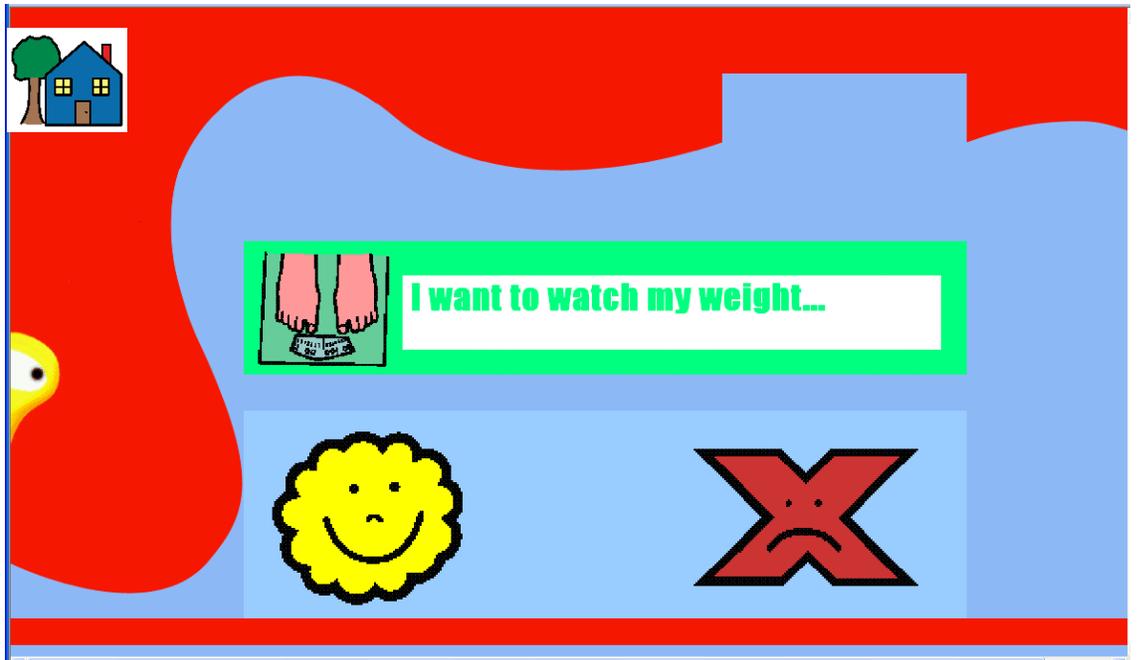


Figure 4.3 User Interface – I want to watch my weight (SMH).



Figure 4.4 User Interface – I drink lots of water (SMH).

The icons used were consistent and standardised throughout the prototype which can be viewed in Figure 4.2 – Figure 4.4. Once the participant moved away from the first page, that is Figure 4.2, a home icon was displayed in the top left hand

corner of all subsequent screens. Visual feedback was integrated into the prototype an example of which can be viewed in Appendix C.

4.4.3 SYSTEM DEVELOPMENT

The prototype has been developed in ASP.NET using the Microsoft Visual Studio 2005 development environment and was developed with the participants level of ID in mind. The graphical icons used were in gif format. All IP related information is stored on a SQL 2000 relational database. The health related IP data for the 6 participants was extracted from a table and imported into another table where the IP data was condensed and only keywords remained. This data was then mapped to the suggested symbols. A link for this prototype was placed on the Intranet and was available to only the nurse managers, the key workers of the participants and the participants themselves.

4.4.4 THE PARTICIPANTS

A sum of 6 clients with ID took part in the study, this number reflecting the timeframe of the study and the availability of clients. The user group were adult clients who have mild to moderate ID. Three participants of each ID level were involved. The mean age of the 6 clients was 32 with 4 male and 2 female. All participants involved in this study did not have a vision impairment. Each participant was assigned their scenario based on what their health priority was in their IP.

4.4.5 SCENARIOS

Listed are the four scenarios used in this prototype. All scenarios start with the 'I have the best possible health' option depicted in Figure 4.2 so the scenarios below do not include that as the first screen. For each screen the participant selects a YES or NO option. These scenarios were developed by the nurse managers.

Scenario One:

Screen 1: Getting around

Screen 2: I walk on my own

Screen 3: I use a wheelchair, stick or frame

Screen 4: I exercise.

Screen 5: I exercise 3 or more times a week.

Screen 6: Ideas for exercise.

Screen 7: I get tired when I exercise.

Scenario Two:

Screen 1: My teeth

Screen 1: I have bad breath.

Screen 2: I have pain in my mouth.

Screen 3: I wear dentures. They are clean and fit well.

Screen 4: I visit the dentist.

Screen 5: My toothbrush is changed every 3 months.

Scenario Three:

Screen 1: Eating and drinking.

Screen 2: I want to watch my weight.

Screen 3: My weight.

Screen 4: I eat a healthy diet.

Screen 5: I have a special diet.

Screen 6: I eat 5 pieces of fruit / veg a day.

Screen 7: I drink lots of water.

Screen 8: My drinks check list

Scenario Four:

Screen 1: My eyes

Screen 2: I find it hard to see.

Screen 3: I have eye check ups.

Screen 4: I want a check up for my eyes.

Screen 5: I wear glasses.

Screen 6: My glasses are clean and fit well.

4.4.6

USABILITY EVALUATION

The language level and symbols used were evaluated by those in the speech and language department and the nurse managers. The prototype was then intensively tested to ensure the multiple scenarios were working sufficiently. Prior to the test date the prototype was assessed in the participants unit to ensure it operated in a correct format where a participant used an ATD.

4.4.7

EXCLUSIONS

The initial sample comprised of only those participants who had entered a priority regarding 'I have the best possible health'. This list was then limited to the units that had assistive technology devices in place. From this only adult clients that had a mild or moderate level of ID remained. Individuals who had vision impairments and required the use of a Braille reader were excluded. From the sample remaining, participants who had used the accessible computer in the unit or had shown an interest in using the computer, in line with those who had basic ICT skills were favoured.

4.4.8

LIMITATIONS

As the prototype was using participants with differing levels of ID the prototype was developed with those suffering from moderate ID primarily in mind, as this user group would require more support in utilising the prototype. The poor level of basic IT skills acquired by the participants had to be taken into consideration. Also more specific information needs to be gathered on the reading and writing skills of the participants as the information provided was generic and not always indicative of the correct level.

The participants do not have their own active directory accounts and therefore the key worker needs to authenticate onto the computer before the participant can use it. Therefore this prototype can not be used independently by the participant. A further limitation was the small amount of computers that were considered to be accessible. The study was approved to use an individuals IP data only so there was a restricted amount of data to work with.

4.5

FINDINGS

Firstly the participants showed interest in using the computer albeit four of them had some difficulty in launching the prototype from the Intranet. However with some prompting from the key worker this issue was overcome. Once the prototype was open access was no longer an issue as the participants were able to flow from screen to screen using a single click. As the prototype was developed in a simple and consistent manner all 6 participants could understand the majority of what was being displayed. Queries did arise such as 'what is a denture'. For those with mild ID it was perhaps too simple, so alternative work would need to be completed in order to maximise the ability of this group.

As there is no regular IT training in SMH for those with ID and no dedicated trainer to facilitate those with an interest in acquiring the computer skills, the skill set of the 6 participants was quite low. Four of the participants had some difficulty using the mouse and the keyboard. As where possible the interaction required from the participant was a single click the issues were not insurmountable. However in order for these individuals to gain further benefits when accessing a computer, routine IT training should be given to ensure the basic skills are acquired. One of the participant had access to a computer in their home environment.

The participants appreciated that the prototype had lots of images. They also felt it was developed just for them as it depicted the scenario they had outlined regarding a health priority in their IP. They felt it was useful to see this information in pictorial format. For the screens that were laden with images such as the ideas for exercise interface, which displayed images of different types of exercise, the page background was white to reduce the amount of clutter on the screen. Some participants also expressed a desire to view their other IP priorities while using the prototype.

The key workers found it helpful and thought it could be used as a support tool when explaining to the participants the goals they had decided on to achieve the health priority. It was felt that this would be a useful aid at the planning stage as it would be more interactive for the participant. For example, the participant has selected health as a priority. Then they select the items they feel they need to work on to improve their health.

These results would encourage future development. The participants and their key workers found it useful to be able to view the goals set for the year in iconic format. However more time would need to be spent in assessing generic user interfaces specific to the level of ID. This would ensure the layout and language level used are available at the most appropriate level for the individual using the system. Future developments for this prototype would need to increase perception for other impairments such as audio should be added for the hearing impaired. Further testing would need to be carried out to ensure ATDs such as speech recognition software are compatible and sustainable.

CHAPTER 5: DISCUSSION

5.1

DO PATIENTS WANT ACCESS TO THEIR MEDICAL RECORDS?

A study carried out by (Michael & Bordley, 1982) in 1980 using 200 sample patients showed that almost 80% of the participants thought they should be able to see their medical record, 67% felt it would help them understand their illness better, 54% felt it would have a positive impact on their care and 52% felt a personal copy should be supplied if requested. A further breakdown of these results can be viewed in Table 5.1 below.

QUESTION		Response (%)	
		Female	Male
1. Should you see your record?	Yes	74	84
	No	23	12
	No Opinion	3	4
2. Would reading it help you understand your illness?	Yes	65	72
	No	30	16
	No Opinion	5	12
3. Would reading it improve your quality of care?	Yes	54	53
	No	41	36
	No Opinion	5	11
4. Should you have a personal copy?	Yes	52	48
	No	44	45
	No Opinion	4	7

Table 5.1 Patient Access to Medical Record Survey Results. Source: (Michael & Bordley, 1982).

The study highlighted that drawbacks such as improved note taking on the doctors behalf and at times limited understanding of what was recorded on the record by patients were offset by benefits such as an improved relationships between the physician and patient as well as patient satisfaction at reviewing the information held.

A more recent study carried out in the summer of 2003 by (Honeyman et al, 2005) took place in a clinical practice where patients were routinely handed their paper record while they waited and had access to view their record in electronic format in a booth accessed via fingerprint technology. Using 0 as not interested and 10 as very interested the patient sample returned an average score of 7.64

when asked if they were interested in seeing their medical record. This mean score increased to 8.05 when asked if they were interested in viewing the record in electronic format. A primary reason given for this increase was the fact an individual could just sit at the computer and access the data without having to ask anyone to do anything for them thus they were not taking up anyone else's time.

These studies would indicate that in general patients would like access to their health data. Despite this there has been a low uptake in patients requesting access. Reasons for this include not knowing that they have the legal right to do so, a fear that the information listed will be too complicated and therefore hard to understand and a general disinterest (Pyper et al, 2002). With the advent of new technologies facilitating online access to health data such as the SCR it will be worth watching if patients exercise their legal right more.

5.2

POTENTIAL BENEFIT OF LETTING PEOPLE HAVE ACCESS TO DATA

Samuels & Wolfe ascertain that viewing your record makes an individual more informed as well as encourages them to become more actively involved and assiduous towards their health care. As an audit trail can be produced to document who has accessed their health data, this can empower individuals to own the data and allow them to have more control over who views it. The individual gets an opportunity to scrutinise the data retained on them and amend data that they feel is incorrect (Samuels & Wolfe, 1994).

The option to view your health data online offers other benefits. A core advantage is the ability to directly access the data from virtually anywhere. If the system is available nationally, the continuity of care experienced as an individual moves between health providers is a huge gain. It is a time saving and convenient way of interacting with the healthcare system and can present a self management component. For instance this could involve a user recording their weight, blood pressure and temperature. The individual would then submit these outcomes on the healthcare provider portal, where the relevant doctor could review the results (Cooper, 1999).

Offering access to medication lists, booking appointments online and viewing test results are said to improve patient quality (Adler, 2007). In a study by Honeyman individuals felt that accessing their record would help break down barriers and give them more confidence when dealing with their doctor (Honeyman et al,

2005). Jensen suggests that this could potentially expand to take the form of virtual office visits (Jensen, 2005).

From a health provider point of view, it can be a source of revenue whilst also reduce costs, as can be viewed with the health service providers in the US who are involved in an aggressive marketing strategy that is now targeting the consumer directly. This can be viewed in Figure 5.1, which details statistics from a US organization called Healthcare Information and Management Systems Society. They promote health understanding by focusing on the best use of IT in healthcare. A high percentage is allocated to the role of marketing and promotion as a function of a web site. The health providers realise that by offering additional services online such as the facility to book doctor appointments and renew drug prescriptions that they may secure the custom of the consumer. Additionally they will also offer the consumer the opportunity to pay their medical bill online which along with other self service mechanisms will reduce the hospitals operational costs.

We are looking at how to help our customers schedule appointments online, request prescription refills online, or any other functions that don't involve seeing direct patient care. As a result of providing self-service mechanisms on the Web, we hope to reduce operational costs associated with these services.

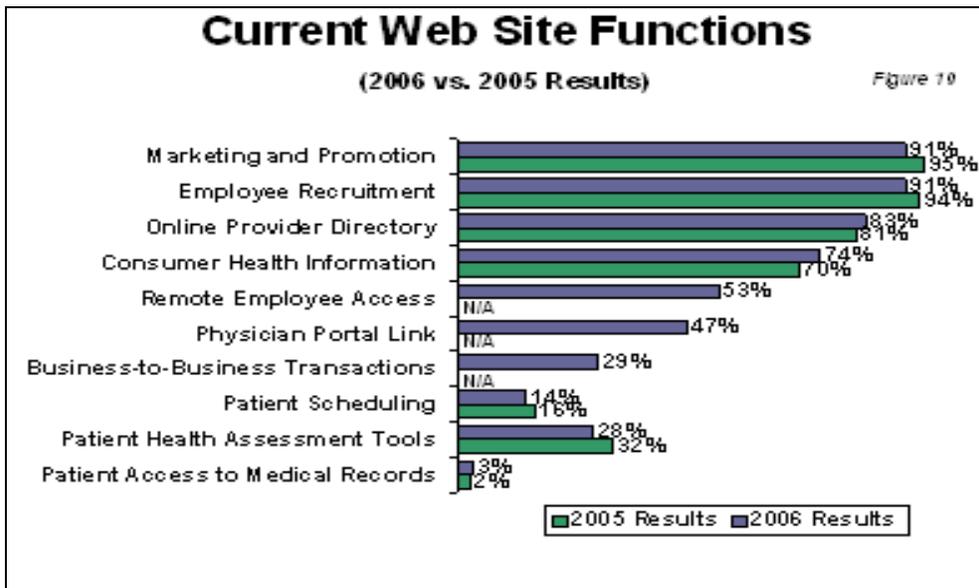


Figure 5.1 Current Web Site Functions. Source:(Healthcare Information and Management Systems Society, 2006 www.himss.org/2006survey/docs/Healthcare_CIO_key_trends.doc).

For clinicians themselves access to this data aids decision support and facilitates more resourceful use of their time.

5.3 POTENTIAL CONCERNS OF LETTING PEOPLE HAVE ACCESS TO DATA

Research has shown that clinicians have concerns regarding the possible negative effects a patient might experience after accessing their health record. Instances noted regard patients misinterpreting the data held on them which may lead to self esteem issues. It may also draw attention to the shortcomings of the doctor (Honeyman et al, 2005).

A concern for those trying to access their electronic record is security. Comments such as 'there is always the ability of others to get into the system' and 'it depends on trust of people here, all systems are fallible' were recorded in a recent study (Honeyman et al, 2005). In the same study when asked about accessing their medical data over the internet security issues were again raised. Comments from those worried ranged from 'don't think it should happen at all' to 'there could be too much tampering'.

5.4 IT SPEND IN MENTAL HEALTH

The WHO estimate that most countries apply less than one percent of their total health budget towards the mental health budget (WHO, 2001). Barron & Kelly report that "historical under-funding of intellectual disability services" is evident (Barron & Kelly, 2006). Within the literature the budget percentage allocated to IT was not apparent.

WHO believe that the internet will change how we access treatment. This will vary from straightforward questions to video consultations or telemedicine. WHO believe one of the chief tests for the future will be how IT is used to benefit those with mental health (WHO, 2001).

Within the ID community ensuring that all individuals have access to IT is not a foremost concern. However various initiatives such as eAccessibility and eInclusion are slowly changing that. Thirty four European countries adopted e-Inclusion in June 2006. This program places an emphasis on individuals with disabilities. In November 2006, the Irish government donated €37,000 to the

Brother of Charity Services in Clare. This operates as a service provider to those with ID and was agreed as part of the Access Skills and Content Initiative to tackle e-Inclusion. The donation was explicitly for the procurement of specific hardware and software that would enhance access to IT for individuals with ID (Government, 2006).

5.5

HUMAN RIGHTS

It has been documented that individuals with ID have often been denied the prospect of living their life in a manner that suits their own distinct interests and predilections. It has been argued that they are often used as a conduit for other peoples interests and preferences even though habitually the intent is good. This is partly due to the fact that it is assumed they do not have the capacity to make their own decisions. In a report referred to earlier in chapter 2 titled Vulnerable Adults and the Law, it is said that:

“The decision making capacity of adults with intellectual disability may depend in part on factors such as their experience of making decisions and the opportunities available to them to make, or participate in the making of, decisions relevant to their life” (Law Reform Commission, 2006).

To allow an individual with ID to retain their dignity, self determination should be endorsed. As mentioned previously those with ID have repeatedly suffered form health inequalities. An example of this is detailed in a 2006 report by MENCAP called Death by Indifference, which acknowledged that six individuals with ID had passed away as a consequence of derisory healthcare (Stewart & Ward, 2007).

5.6

FUTURE INTERACTIONS

IT is quickly and immeasurably altering the way in which healthcare providers correspond with their patients. For instance the process of emailing your health care provider for private exchanges is still in its youth. Fears that it will be too time consuming and concerns regarding reimbursement are reasons for the slow uptake by doctors (Romano, 2003). In spite of this a recent survey conducted using 1200 doctors cites the provision of online patient – doctor exchanges as the top trend for the future (DeShazo et al, 2005).

For those with reduced cognitive impairment software has been developed that enables users to manage their health care at home. It can send prompts to take your medication, supervise activity and offer instructions through the mediums of text, video and audio (AbleLink). Where those with ID have the relevant capacity this will encourage self monitoring, independence and self empowerment especially with regard to routine conditions such as diabetes. Perhaps a more cost effective method would be the installation of two way cameras as outlined by (QHFHL, 2000). This would offer the possibility of 'electronic house calls' where a nurse can liaise with an individual over a video link. As a high percentage of those with mild ID live at home, for instance in Ireland this accounts for 73% of the ID population, this may be a future way of caring for these individuals whilst also encouraging them to get more involved in managing their own health care.

Studies have encouraged the possibility that virtual reality can offer a role in developing life skills and encourage independent living for those with ID (Standen et al, 2006; Standen & Brown, 2006). Blair gives the example of a virtual dentist which prepares an individual for a visit to the dentist, with a belief that this could lead to more informed choices (Blair, 2004).

On another level access to online medical data could be given to parents or guardians of these individuals to permit them view medications or glucose levels for example. This may offer huge benefits to the caregiver as it could potentially free up time that was otherwise spent visiting the doctor in order to renew prescriptions.

CHAPTER 6: CONCLUSION

6.1

CONCLUSION

Traditionally individuals with ID have been underserved in the realm of ICT. This exclusion can diminish a persons choice, reduce opportunities and result in needless complications in work and social settings. Some efforts are being made to address this issue. For instance initiatives such as eEurope, eAccessibility and eInclusion all place a focus on ensuring vulnerable groups in society, such as those with ID, are not left behind in the digital revolution.

Individuals with ID require more medical inputs from healthcare providers during their lifetime than a member of the general public. At a national level 73% of all those with mild ID (Barron & Kelly, 2006) reside at home so policy should be focused on assisting these people handle their care in this environment (Schoen et al, 2006) with particular reference to self management of routine conditions such as diabetes. Individuals who have the capacity should be encouraged to self medicate as well as monitor temperature, weight and cholesterol. Software solutions exist which provide alerts and prompts as a reminder to take your medication which can facilitate independent living. These alerts can occur in audible, vibrate and visible (flashing light) mode and attached messages can be viewed in text, audio or iconic format (Bertini & Kimani, 2003).

There is a growing trend that permits individuals to gain access to their medical data online. National electronic health records have been implemented or are in the process of being implemented in Australia, Canada and the UK. Innovative examples in the literature showcase the viability of using web based portals to access clinical data as can be seen with HealthConnect and the SCR. There is some anxiety that the internet is forming a new health disparity as it can leave behind those who are already unequal, such as those individuals with ID. It is fair to say that those with ID have a complex learning pattern, as well as numerous impairment permutations, and that accessing data via the internet may not be the choice method for some of these individuals to acquire information about their health (Jensen, 2005). Web Content Accessibility Guidelines have been developed that suggest best practice to enable designers present information in an appropriate fashion for those with ID (Nordbrock et al, 2004).

However all the guidelines in the world will not ensure computer access unless those with ID have the opportunity to participate in ICT. Literature on IT adoption within the ID community is very limited and Hoppestad stated that further research into computer

access for this population is necessary as after conducting extensive research only a few relevant articles on this topic were retrieved (Hoppestad, 2007). Studies have shown that individuals with ID have limited access to computers. Family members that have computers in their home are slow to encourage access, as they feel that the computer is too complex or that the individual might somehow damage it (Li-Tsang, 2005). Basic IT training is essential in order for those with ID to access technology (Breen, 1993). It has been established in a previous study that those with ID can learn ICT skills once the adequate support is in place (Li-Tsang et al, 2004). If those with ID could avail of such training it would reduce the digital divide this group experiences.

The research presented in this study indicates that although many barriers to computer access exist and are experienced by this group the majority of them can be overcome with careful planning and support. Individual selection assessments when choosing ATDs are required to ensure that the device is not abandoned, which can lead to further frustration and a lack of motivation for the individual. Universal design is key to web accessibility. This plus adhering to the guidelines set out by the WCAG facilitate independent access to web sites through the use of specialised web browsers for those with ID.

Nationally the NIDD has determined a minimum dataset for those with ID which each agency must provide. However this is not used as a medical or epidemiological tool, on the contrary it is used purely for service planning. The only health related data the NIDD captures is the level of ID and whether a person has a physical or sensory disability. As many agencies do not have their own ICT systems in place this is their only electronic recording of those attending their service and is relied on to run reports. Therefore questions like how many individuals have diabetes, how many can read and write and how do the individuals communicate cannot be quickly answered, if answered at all. It is clear that details such as these should be captured and that the NIDD could facilitate this.

Following on from that much of the health data captured on an individual remains in paper format. Generally this is not accessible as the records can be messy, the files may include information on other family members and minimal data may be recorded. Bridget Meaney, the editor of *Medicine on the Net* has said “ The crux of it is this: We’re going to eventually see a time when health information is available only via computer. When that will come down the line – five years, 10 years , we don’t know – but it’s going to happen” (Romano, 2003). This is an issue that needs to be addressed by the ID community as a whole.

The prototype developed examined three key issues. Firstly could the data be accessed, secondly could the participants understand it and thirdly were there any perceived benefits to having access to this data. As some of the participants had basic ICT skills they had difficulty initially using a mouse or keyboard and opening the link to the prototype on the Intranet. However, with prompting from the key worker these issues were overcome and it was felt that if the participants accessed their computers on a more regular basis, and with the proper supports in place, these issues could be alleviated altogether.

Participants enjoyed the fact that the data displayed was personalised and received pleasure from seeing the health goals they had set out for the year displayed in iconic format. It was felt that this would be a useful aid and support tool at the goal planning stage as it would be more interactive for the participant. For example, the participant has selected health as a priority. Then they select the items they feel they need to work on to improve their health. As the availability of data that could be used during the study was minimal it is felt that with access to a further dataset, such as the 'My Health' proposal, the benefits for participants would be greatly increased. Facilitating access to a relevant health dataset for those with ID promotes self determination, self empowerment and autonomy and will encourage those who have the capacity to make decisions about their own healthcare which is a basic human right.

6.2

FUTURE WORK

The findings revealed during the prototype study encourage further development. However, the development would be based on making the 'My Health' dataset available to individuals with ID, their key workers and other relevant personnel. Audits would need to be carried out to determine the reading and writing skills of individuals, the basic ICT skill levels for both the individual with ID and their key worker, those that require an ATD to facilitate access and to determine which individuals currently have access to a computer whether at home or within the service. Assessment procedures regarding ATD selection and ICT skills would need to be designed.

Users would need to be included in the design stage to ensure data is displayed in the most appropriate manner. The design for all and universal design concepts should be utilised. Satisfaction levels, competence, productivity, empowerment, independence, social belonging and community integration would all need to be considered for the individual. Analysis of user impairments and the level of impairment would need to be undertaken. This increased perception would ensure that audio was included for the hearing impaired and that perhaps familiar voices were used in speech synthesis quality as Savidis et al suggest that this is the best option for those that have cognitive impairment (Savidis et al, 2006).

Usability analysis would need to be completed and should involve rigorous testing with manifold real life scenarios. Further testing would need to be carried out to ensure ATDs used by the individuals are compatible and sustainable.

This project would involve a broad spectrum of departments working together to enable it to operate in a manner where the individual receives the most benefit. It offers huge challenges but as Nelson Mandela said:

“What challenges us is to ensure that none should enjoy lesser rights; and none tormented because they are born different...”.

REFERENCES

- AbleLink **AbleLink**
Homelife software solution
<http://www.com/desktop/homelife.asp.ablelinktech> (accessed 08 August 2007)
- Adams, 2007 **Adams R** (2007).
Decision and stress: cognition and e-accessibility in the information workplace
Universal Access in the Information Society, **5**(4): 363:379
- Adler, 2007 **Adler K** (2007).
Why It's Time to Purchase an Electronic Health Record System
Leading Edge, **4**(2): 43-46
- Alexandraki et al, 2004 **Alexandraki C, Paramythis A, Maou N, Stephanidis C** (2004).
Web Accessibility through Adaptation
In: K. Miesenberger et al. (Eds.): ICCHP 2004, LNCS 3118, 302-309
- Anderson et al, 2004 **Anderson S, Bohman P, Burmeister O, Sampson-Wild G** (2004)
User Needs and e-Government Accessibility The Future Impact of WCAG 2.0
In: Proceedings of the 8th Workshop on User Interfaces for All, June 28-29, Vienna, Austria (Springer), 289-304
- Andrich et al, 2006 **Andrich R, Da Dalt R, Giust R, Agnoletto A** (2006).
EASTIN: A Trans-national Information Network on Assistive Technologies
In: Proceedings of the 10th International Conference on Computers Helping People with Special Needs 2006, July 11-13, Linz, Austria (Springer).
- Barron & Kelly, 2006 **Barron S, Kelly C** (2006).
National Intellectual Disability Database Committee. Annual Report 2006. Dublin: Health Research Board.

- Berners-Lee, 1998 **Berners-Lee, T** (1998).
Web Architecture from 50,000 feet.
<http://www.w3.org/DesignIssues/Architecture.html> (accessed 07 July 2007).
- Bertini & Kimani, 2003 **Bertini E, Kimani S** (2003).
Mobile Devices Opportunities for Users with Special Needs
In: Proceedings of the 5th International Symposium, Mobile HCI 2003,
September 8-11, Udine, Italy (Springer)
- Blair, 2004 **Blair, J** (2004).
Assessing the value of the internet in health improvement
http://www.intellectualdisability.info/values/internet_ib.html (accessed
18 August 2007).
- Blair, 2006 **Blair, J** (2006).
A computer and internet future: enabling inclusion?
Learning Disability Practice, **9**(9): 32-37
- Breen, 1993 **Breen, S** (1993).
Access for people with intellectual impairment: Results from the ACT-IT
project
*In: Proceedings of the IEE Colloquium on Information Access for
People with Disability 1993*, May 5: 3/1–3/2
- Carey et al, 2005 **Carey A, Friedman M, Bryen D** (2005)
Use of electronic technologies by people with intellectual disabilities
Mental Retardation, **43**(5): 322-333
- Carmien, 2003 **Carmien, S** (2003)
MAPS: Dynamic Scaffolding for Independence for Persons with
Cognitive Impairments
*In: Proceedings of the 9th International Conference on User Modeling
2003*, June 22-26, Johnstown, PA, USA (Springer).
- Cooper, 1999 **Cooper D** (1999).
Providers Influencing Advancement of E-mail, Internet Applications
Clinical Data Management, **6**(3): 7
- Data Protection Agency **The Data Protection Agency**
<http://www.dataprotection.ie/> (accessed 12 November 2006).

- Davies et al, 2001 Davies D, Stock S, Wehmeyer M (2001).
Enhancing Independent Internet Access for Individuals with Mental
Retardation through Use of a Specialized Web Browser: A Pilot Study
*Education and Training in Mental Retardation and Developmental
Disabilities*, **36**(1): 107-113
- DeShazo et al, 2005 **DeShazo C, Fessenden R, Schock P** (2005).
Realizing IT's Potential
Physician Executive, **31**(4): 26-29
- De Jonge & Rodger, 2006 **De Jonge D, Rodger S** (2006).
Consumer-identified barriers and strategies for optimizing
technology use in the workplace
Disability and Rehabilitation: Assistive Technology, **1**(1): 79-88
- Down Syndrome **Down Syndrome Scotland**
Keeping Well Health Plans
<http://www.dsscotland.org.uk/publications/learning-disability/keeping-well.pdf>
(accessed 07 July 2007).
- Elfrida **The Elfrida Society**
Access to health
<http://www.elfrida.com/publications.htm> (accessed 07 July 2007).
- Gappa et al, 2004 **Gappa H, Nordbrock G, Mohamad Y, Velasco C** (2004).
Preferences of People with Disabilities to Improve Information
Presentation and Information Retrieval Inside Internet Services –
Results of a User Study.
*In: K. Miesenberger et al (Eds.): ICCHP 2004, LNCS 3118, 296-
301*
- Gips et al, 2004 **Gips A, DiMattia P, Gips J** (2004).
The Effect of Assistive Technology on Educational Costs Two Case
Studies.
In: K. Miesenberger et al (Eds.): ICCHP 2004, LNCS 3118: 206-213

- Government, 2006 Department of the Taoiseach (2006)
Minister Kitt announces funding of €1.45 million for community groups
in Information Society Initiative
<http://www.taoiseach.gov.ie/index.asp?locID=199&docID=2974>
(accessed 02 April 2007).
- Grauman et al, 2003 **Grauman K, Betke M, Lombardi J, Gips J, Bradski G** (2003).
Communication via eye blinks and eyebrow raises video-based
human-computer interfaces
Universal Access in the Information Society, **2**(4): 359-373
- Honeyman et al, 2005 **Honeyman A, Cox B, Fisher B** (2005).
Potential impacts of patient access to their electronic care records
Informatics in Primary Care, **13**(1): 55-60
- Hoppestad, 2006 **Hoppestad B** (2006).
Essential elements for assessment of persons with severe neurological
impairments for computer access utilizing assistive technology devices:
A Delphi study
Disability and Rehabilitation: Assistive Technology, **1**(1-2): 3-16
- Hoppestad, 2007 **Hoppestad B** (2007).
Inadequacies in computer access using assistive technology devices in
profoundly disabled individuals: An overview of the current literature
Disability and Rehabilitation: Assistive Technology, 1-11, iFirst article.
- ICO, 2007 **Information Commissioner's Office** (2007).
The Information Commissioner's view of the NHS Electronic Care
Records.
http://www.ico.gov.uk/upload/documents/library/data_protection/detailed_specialist_guides/information_commissioners_view_of_nhs_electronic_care_reco%E2%80%A6.pdf (accessed 09 May 2007).
- ISO, 1998 **International Standards Organisation** (1998).
ISO 9241-11: Guidance on Usability
- ISO, 2003 **International Standards Organisation** (2003).
ISO/TS 16071: Ergonomics of human-system interaction – Guidance on
accessibility for human-computer interfaces

- Jenge et al, 2006 **Jenge C, Hartrumpf S, Helbig H, Osswald R** (2006).
Automatic Control of Simple Language in Web Pages
In: K. Miesenberger et al (Eds.): ICCHP 2006, LNCS 4061, 207-214
- Jensen, 2005 **Jensen, J** (2005).
Open for Business
Marketing Health Services, 25(2): 38-42
- Law Reform Commission, 2006 **The Law Reform Commission** (2006).
Report: Vulnerable Adults and the Law (LRC 83 – 2006). Dublin: The Law Reform Commission.
- Li-Tsang et al, 2004 **Li-Tsang C, Chan C, Lam C, Hui-Chan C, Yeung S** (2004).
Evaluations of an Information and Communication Technology (ICT) Training Programme for Persons with Intellectual Disabilities
In: K. Miesenberger et al. (Eds.): ICCHP 2004, LNCS 3118, 1032-1038
- Li-Tsang et al, 2005 **Li-Tsang C, Yeung S, Chan C, Hui-Chan C,** (2005).
Factors affecting people with intellectual disability in learning to use computer technology
International Journal of Rehabilitation Research, 28(2): 127-133
- Loiacono & McCoy, 2006 **Loiacono E, McCoy S** (2006).
Website accessibility: a cross-sector comparison
Universal Access in the Information Society, 4(4): 393-399
- Masys & Baker, 1997 **Masys DR, Baker DB** (1997).
Patient-Centered Access to Secure Systems Online (PCASSO): A Secure Approach to Clinical Data Access Via the World Wide Web
In: Proceedings of 1997 AMIA Annual Fall Symposium, American Medical Informatics Association, 340-343, Nashville, TN.
- McCoy, 1998 **McCoy K** (1998).
Interface and Language Issues in Intelligent Systems for People With Disabilities
In: V.O. Mittal et al. (Eds.): Assistive Technology and AI, LNCS 1458, 1-11

- Mechling et al, 2003 **Mechling L, Gast D, Barthold S** (2003).
Multimedia Computer-Based Instruction to Teach Students With
Moderate Intellectual Disabilities to Use a Debit Card to Make
Purchases
Exceptionality, **11**(4): 239-254
- Melville et al, 2006 **Melville C, Cooper S, Morrison J, Finlayson J, Allan L, Robinson N,
Burns E, Martin G** (2006).
The outcomes of an intervention study to reduce the barriers
experienced by people with intellectual disabilities accessing primary
health care services
Journal of Intellectual Disability Research, **50**(1): 11-17
- Michael & Bordley, 1982 **Michael M, Bordley C** (1982).
Do Patients Want Access to Their Medical Records?
Medical Care, **20**(4): 432-435
- Nordbrock et al, 2004 **Nordbrock G, Gappa H, Mohamad Y, Velasco C** (2004)
Automatic Modification of Text for People with Learning Disabilities
Using Internet Services
In: K. Miesenberger et al (Eds.): ICCHP 2004, LNCS 3118: 995-998
- Panek & Smith, 2005 **Panek P, Smith J** (2005)
Assessment of terms to describe mental retardation
Research in Developmental Disabilities, **26**: 565-576
- Paris, 2005 **Paris M** (2005).
Website accessibility: a survey of local e-government websites and
legislation in Northern Ireland
Universal Access in the Information Society, **4**(4): 292-299
- Parsons et al, 2006 **Parsons S, Daniels H, Potter J, Robertson C** (2006).
The use of ICT by adults with learning disabilities in day and residential
services.
British Journal of Educational Technology, **37**(1): 31-44
- Poulson & Nicolle, 2004 **Poulson, D & Nicolle, C** (2004).
Making the Internet accessible for people with cognitive and
communication Impairments
Universal Access in the Information Society, **3**(1): 48:56

- Prazak et al, 2004 **Prazak B, Mina S, Kronreif G** (2004).
Accessibility through Standard Low Cost Pointing Devices
In: K. Miesenberger et al (Eds.): ICCHP 2004, LNCS 3118: 782-787
- Pushchak & Sasi, 2004 Pushchak T, Sasi S (2004).
Intelligent Model for Rating Cognitive Capability for Computer Access of
People with Disabilities
In: K. Miesenberger et al (Eds.): ICCHP 2004, LNCS 3118: 991-994
- Pyper et al, 2002 **Pyper C, Amery J, Watson M, Crook C, Thomas B** (2002).
Patients' access to their online electronic health records.
Journal of Telemedicine and Telecare, 8(2): 103-106
- QHFHL, 2000 **Quality Letter for Healthcare Leaders** (2000).
Online Patient Access to Medical Records
Quality Letter for Healthcare Leaders, 12(5): 7
- Reimer-Reiss, 2000 **Reimer-Reiss, M** (2000).
Assistive Technology Discontinuance
Technology and Persons with Disabilities Conference, Los Angeles CA.
- Renold et al, 2005 **Renold C, Meronk C, Kelly C** (2005).
Technology in Community-Based organizations that serve older
people: High Tech Meets High Touch
Educational Gerontology, 31(3): 235-245
- Romano, 2003 **Romano, M** (2003).
Not just a web site
Modern Healthcare, 33(21): 22
- Roskos-Ewoldsen et al, 2006 **Roskos-Ewoldsen B, Connors F, Atwell J** (2006).
Visual Imagery Scanning in Young Adults with Intellectual Disability
American Journal of Mental Retardation, 111(1): 35-47
- Samuels & Wolfe, 1994 **Samuels B, Wolfe S** (1994).
How to obtain your medical records
Consumers' Research Magazine, 77(5): 18

- Savidis et al, 2006 **Savidis A, Grammenos D, Stephanidis C** (2006).
Developing inclusive e-learning systems
Universal Access in the Information Society, **5**(1): 51-72
- Scherer et al, 2007 **Scherer M, Jutai J, Fuhrer M, Demers L, Deruyter F** (2007).
A framework for modeling the selection of assistive technology devices
(ATDs)
Disability and Rehabilitation Assistive Technology, **2**(1): 1-8
- Schoen et al, 2006 **Schoen C, Osborn R, Huynh P, Doty M, Peugh J, Zapert K** (2006).
On The Front Lines Of Care: Primary Care Doctors Office Systems,
Experiences, And Views in Seven Countries
Health Affairs, **25**: 555-571
- Sparks, 2000 **Sparks, N** (2000).
Assistive Technology Assessment Criteria
In: *Proceedings of the International Special Education Congress 2000*,
July 24-28, Manchester, England.
http://www.isec2000.org.uk/abstracts/papers_s/sparks_1.htm.
(accessed 06 June 2007).
- Sporka et al, 2006 **Sporka A, Kurniawan S, Slavik P** (2006).
Acoustic control of mouse pointer
Universal Access in the Information Society, **4**(3): 237-245
- Standen & Brown, 2006 **Standen P, Brown D** (2006).
Virtual reality and its role in removing the barriers that turn cognitive
impairments into intellectual disability
Virtual Reality, **10**: 241-252
- Standen et al, 2002 **Standen P, Battersby S, Lannen T** (2002).
Control of Virtual Environments for People with Intellectual Disabilities
In: *K. Miesenberger, J. Klaus, W. Zagler (Eds.): ICCHP 2002, LNCS*
2398: 147-149
- Standen et al, 2006 **Standen P, Brown D, Anderton N, Battersby S** (2006).
Systematic Evaluation of Current Control Devices Used by people with
ID in non immersive virtual environments
CyberPsychology & Behavior, **9**(5): 608-613

- Stewart & Ward, 2007 **Stewart C, Ward T** (2007).
Human Rights and Intellectual Disability
Journal of Developmental and Physical Disabilities, iFirst article.
- Story, 1998 **Story, M** (1998).
Maximising usability: The principles of universal design
Assistive Technology Journal, **10**:4-12
- The Arc, 2005 **The Arc** (2005).
Technology for people with Intellectual Disabilities
<http://www.thearc.org/NetCommunity/Page.aspx?&pid=1433&srcid=183>
(accessed 15 April 2007).
- Trehin, 2004 **Trehin, P** (2004).
Computer User for People with Learning Difficulties: Basic Needs
In: K.Miesenberger et al.(Eds.): ICCHP 2004, LNCS 3118, 961-968.
- Von Niman & Nordby, 2004 **Von Niman B, Nordby K** (2004).
ESTI's human factors contribution to eEurope
Universal Access in the Information Society, **3**(1): 107-110
- W3C W3C
<http://www.w3.org/WAI/> (accessed 13 May 2007).
- Wehmeyer, 1988 **Wehmeyer, M** (1988).
National survey of the use of assistive technology by adults with mental
retardation
Mental Retardation, **36**(1): 44-51
- WHO, 2001 **World Health Organization** (2001).
The World Health Report 2001- Mental Health: New Understanding,
New Hope. Geneva, World Health Organization.
- Wobbrock & Myers, 2007 **Wobbrock J, Myers B** (2007).
Enabling devices, empowering people: The design and evaluation of
Trackball EdgeWrite.
Disability and Rehabilitation: Assistive Technology, 1-22, iFirst article.

APPENDICES

APPENDIX A

SAMPLE DIABETES SYMBOL RESOURCE PACK

COPYRIGHT WIDGET SOFTWARE



APPENDIX B

LIST OF THE SEARCH TERMS USED

This is not an exhaustive list.

access control	medical policy
access methods	medical records
access portal	medical records -- access control
access to a patients data	medical records -- law and legislation
access to medical records	mental health policy
adaptive technology	mental retardation
alert prompt technology intellectual disability	nidd annual report
assistive technology	patient accessible
canada health infoway inc	patient record
canada institute of health informatics	people with mental disabilities
capacity	personal health record
clinical data record	security control measure
cognition	summary care record
cognitive impairment	synapses
computer access	user security access
consumer health record	user sensitive inclusive design
design for all	vulnerable people capacity
developmental disabilities	WHO mental health
e-accessible	
e-health	
EHR EMR PHR	
e-inclusion	
health data	
health plans intellectual disability	
ict training	
inclusion	
intellectual disabilities	
intellectual disabled people	
internet	
iSoft	
learning disabilities	
medical data	

APPENDIX C

ADDITIONAL SCREEN SHOTS FROM PROTOTYPE

